

Promoting psychological wellbeing for people with dementia and their carers: An enhanced practice resource



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Introduction and Overview

Welcome

Welcome to Promoting psychological wellbeing for people with dementia and their carers: An enhanced practice resource. This resource is designed to enhance your understanding of dementia from a psychological perspective, and to enable you to apply this learning to supporting people with dementia and their families and carers.

This resource aims to build on the learning in [▶ Dementia Skilled - improving practice resource](#). If you are not already familiar with this resource we suggest you read it prior to commencing this resource. It can be downloaded by clicking on the title above.

Who is this resource for?

This learning resource is for people who are working with people with dementia, their families and carers at the Enhanced Dementia Practice Level as identified within:

▶ **Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families and carers.**

This level is defined as ‘...the knowledge and skills required by health and social services staff that have more regular and intense contact with people with dementia, provide specific interventions, and/or direct /manage care and services’.

How is this resource structured?

The knowledge and skills developed through each section of this resource are designed to build incrementally upon each other. We therefore recommend that the first time you view this resource you should complete the sections in sequential order.

The learning resource sections are shown below:

Section 1: What makes us who we are?

Section 2: Understanding dementia from a psychological perspective

Section 3: Assessment of dementia; Introduction to the most common dementias

Section 4: Communication – People with dementia and caregivers

Section 5: Evidence-based psychological interventions in dementia care

Section 6: Psychological approaches to distressed behaviour

Section 7: Other resources

Throughout the resource we use learning activities to help you reflect on how you can use this information to inform your practice.

How should this resource be used?

This resource can be used in the way that best suits you, your team or your organisation. The activities that appear throughout the sections are designed to allow you time to reflect on the topic discussed. This resource can be used for individual learning, group based learning or to stimulate discussion in learning events.

Introduction and Overview

For individual use you can type into the activity sections throughout and save a copy of this resource (with your own answers) onto your computer. You can also, of course print sections out as you wish. For easy navigation the menu guide for this resource is available at any time by selecting the tabs at the bottom of the screen.

We would recommend that you complete all of the learning activities throughout this resource.

Related links

The following links will lead you to key resources to help you further understand the background to this resource.

If you are not already familiar with these we strongly recommend that you familiarise yourself with the following:

- [Scotland's National Dementia Strategy: One year on report](#)
- [Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families and carers](#)
- [Standards of care for dementia in Scotland](#)



Resource Summary

A number of promising psychosocial approaches have been developed and there is room for further development in this area, based on a psychological understanding of dementia and its effects. Although there is no cure for dementia, there is every reason to be hopeful when working in the field of dementia care. Each member of staff can make a real difference to the people with dementia, their families and carers that they come into contact with and this can be a positive difference. We need to focus on the here and now in looking at outcomes – achieving a good contact with a person with dementia today is worthwhile, even if tomorrow it is forgotten or the person has developed new difficulties. People with dementia live in the moment; the challenge for us is to live in that moment alongside them.

Ways of understanding and approaching people with dementia described throughout this learning resource, as well as the psychosocial approaches outlined earlier in this section, can improve quality of life and pre-empt problems such as distressed behaviour. However, once distressed behaviour presents real problems, standardised approaches do not work consistently or at all, whether they are pharmacological or psychosocial. Every person with dementia who is distressed is different and it would be bad practice to apply a standard therapy, without first investigating a range of contributing bio-psychosocial causes. As the case-specific approach demonstrates, a bagful of questions rather than a bagful of answers is required.



Section 1

What makes us who we are?

Cognitive Capacity
Personality / character
Emotions
Thoughts
Motivations
Behaviour

Our biological / genetic inheritance
Our life experiences
Our health
Our lifestyle, environment and relationships

Getting older - physical changes
Getting older - psychological changes
Changes we should be concerned about

Section 1

What makes us who we are?

Learning Objectives

By the end of this section you will be able to:

1. Explain the interacting capacities or domains which collectively contribute to defining who we are.
2. Explore the potential influences on psychological capacity which make us who we are.
3. Demonstrate an understanding of the potential influences of the ageing process on psychological capacity.

The person with dementia is first and foremost an individual and many problems in dementia care arise because of failure to treat the individual in a person-centred way. In addition, dementia involves a (usually) slow, gradual loss of multiple human capacities which enable us to make sufficient sense of the *world or environment*¹ and to operate reasonably efficiently and safely within it. For these two reasons, before we consider the effects of dementia we must first outline:

- the interacting capacities or domains which, collectively, contribute to defining who we are as individuals;
- the influences which shape those capacities and;
- a sense of the changes which routinely occur as we age, in the absence of dementia.



¹ Throughout this document, we use the term *world or environment* to denote the whole physical and social environment: everything you encounter as you pass through life.

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What are the psychological capacities which make us who we are?

There is an important caveat to this section. In order to try and understand human behaviour, psychologists tend to try to simplify and categorise aspects of human existence into component parts. We emphasise:

- Firstly, that the capacities listed here do not comprise an exhaustive list.
- Secondly, it is impossible in any case to identify every capacity which goes into making us the individual we are but, even if it were possible, every individual is greater and more complex than the sum of his or her component parts.
- Thirdly, there is infinite variability between individuals because everybody has a unique, interacting combination of capabilities and relative strengths, which have been shaped by a unique mix of factors that shaped them.
- Finally, there is a great deal of overlap such that many of the capacities listed could be categorised differently or merged.

The following categories should therefore be seen merely as a means to help understand what makes us who we are and then, later in this document, what happens when these capacities are compromised by a dementia.



Cognitive capacity

Cognitive capacity refers to how efficiently we are able to use our brains. We tend to break it up into different domains for ease of reference but also because many domains are associated with distinct areas in the brain. This makes them, to some extent, both conceptually and physiologically distinct, but it is important to remember that there is considerable overlap and many parts of the brain contribute to each domain. The efficient working of any one domain is likely to require the involvement of a network of brain areas and may also rely on other domains to be working effectively. For example, memory for words will require memory and language domains to work together.

- *Memory* refers to our capacity to learn, integrate and remember information when required, sometimes many years later. This includes memory for facts and experiences, as well as how to perform tasks and motor actions.
- *Attention* refers to our ability to concentrate, at any one instant, on what is important and selectively shut out the other information which is constantly being provided by our senses and thoughts.
- *Language* refers to our ability both to communicate to others using sounds, symbols and movements and also, our ability to understand what others are communicating.
- *Perception* is primarily the capacity we have to interpret or make sense of the information provided by our vision, hearing, touch, smell and taste. It can also refer to making sense of information coming from within us – both bodily sensations and thoughts.

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- *Praxis/psychomotor capacity* is the way we are able to put thoughts into action – from the motor skills and memory required to build a car, to picking up a pencil.
- *Executive functions* are regarded as belonging to higher cognitive domains. Many capacities are engaged automatically, most of the time. The executive functions enable us to consciously direct what we do or stop doing, regulate behaviour, make choices or judgements, solve problems and engage in abstract thought.

Personality/character

In everyday terms, personality or character really encompasses who we are or what makes us a unique individual and therefore combines all the capacities described in this section. However, for psychological purposes it is more narrowly defined as our characteristic and generally stable way of responding, across a range of different situations. Part of personality is attachment style - the way we respond to feelings of

abandonment and our need to be close to others.

Emotions

All animals experience emotions such as fear or anger but humans appear to experience a much greater and more complex range. The term refers mainly to what we feel in response to an internal event² (e.g. a thought) or an external event (e.g. a loud bang). They can therefore be short-lived in nature or intensity but some emotions can become lasting states, such as a general sense of wellbeing or, conversely, anxiety or low mood. If these latter states are severe and impinge on daily life, a mental health problem may develop. Emotions are inextricably linked with thoughts, motivations and behaviour.

² *Throughout this document, when we use the word event, it means anything that happens to you. Note that it also includes internal events (e.g. a thought, memory, emotion, a bodily sensation or an illness), as well as external ones.*

Thoughts

Basically, a thought is a mental activity where some aspect of life comes into consciousness. For example, this could be an internal event (e.g. a memory suddenly becoming salient) or a response to an external event (e.g. consciously identifying someone coming towards you). Thoughts are therefore linked to attention. We are thinking all the time and are able to consciously manipulate information in a logical way, sometimes for long periods, to solve problems or make plans.

Motivations

Motivations are the processes that drive behaviour, including thinking, that make us do what we do, when we do it. They range from basic drives, such as the desire to eat or drink, to the motivations that lead you to improve the lives of the people with dementia that you work with. Emotions, thoughts and executive functions are heavily involved in motivation.

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Behaviour

Clearly, engaging in complex thought is behaviour but, for the purpose of this resource, we define behaviour as anything we do or say; anything involving observable motor movement. The extent to which we are able to control our behaviour is important. This includes initiating behaviour, such as getting started on an activity, as well as inhibiting behaviour e.g. stopping ourselves from doing something dangerous or inappropriate. How we regulate our behaviour is influenced strongly by our emotions, motivations, thoughts and executive functions.

What has influenced our psychological capacities to make us who we are?

There are a number of influences which affect the nature and strength of the capacities that interact to make each of us a unique individual. Our genetic inheritance is fixed and relatively strong. Other influences can continue to be relatively stable from early adulthood until late in life, but they are subject to change in certain circumstances, meaning that our capacities may also change, sometimes dramatically.

Our biological/genetic inheritance

It is obvious that we inherit all the basic characteristics which make us human, just as other animals such as dogs, inherit their characteristic ways of being. However, there is massive variability in what we inherit from previous generations and, ultimately, from our parents' genes at conception. We inherit a unique combination of characteristics, strengths and weaknesses including:

- physical characteristics such as height,

body shape, hair and eye colour

- our susceptibility to different medical and mental conditions
- our susceptibility to many psychological factors such as personality traits
- demographic factors such as longevity and a host of others

We cannot change our individual genetic inheritance but this is clearly not the only factor which makes us a unique individual. Through our executive functions we are uniquely self-determining, flexible beings, who experience and learn from many influences throughout our life. Similarly, many environmental events affect our bodies, including our genes.

Our life experiences

It has long been clear that life experiences and the environment have a profound effect on making us who we are. Even events

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before we are born, in our mother's womb, have an effect – most obviously, factors such as poor diet or toxic exposure, but also psychological factors such as high stress in the mother. The most obvious and rapid changes take place as we move through the development phases from birth, through childhood and adolescence to early adulthood. This is natural maturation interacting with the multitude of environmental influences and events which make up everyday life. Thus, we learn that we do not need to become distressed when our mother is out of our sight. We learn how to socialise with others when we go to school, or even before that. We learn to harness our cognitive and motor skills to undertake highly complex tasks, such as welding or controlling a netball. Later, we learn from experience in relationships, including close and/or sexual relationships, how to attain a feeling of belonging and not being alone.

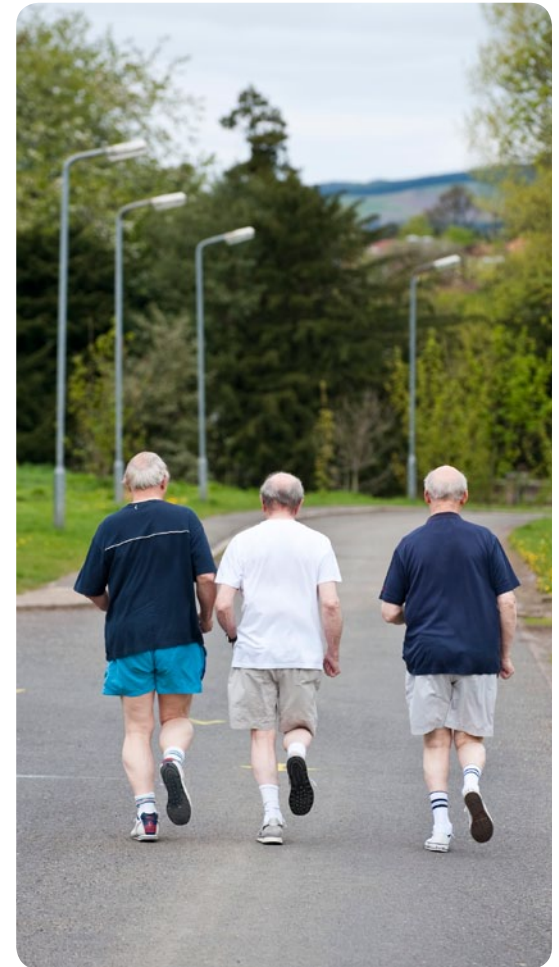
It is important to note that life experience and environmental events continue to shape

us throughout life, even in extreme old age. A little appreciated fact is that many major life events take place in later life, including multiple losses in relationships, capabilities, options and health.

Our health

Health psychology examines the relationship between biological, environmental/ experiential and psychological variables. The relationship is highly complex.

At an obvious level, health has a profound effect on our psychological characteristics, over and above the social effects of disease such as being unable to work or go out. For example, a delirium severely affects memory, concentration, perception and other thought processes. Pain or tiredness affects at least concentration. Many medical conditions increase the risk of mental health difficulties, especially depression. Depression affects memory, concentration and motivation.



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Similarly, the lifestyles we choose affect health and there has been a concerted effort over many years to induce people to change lifestyles to improve health, for example by not smoking, taking exercise and eating healthy food.

However, there is another less obvious relationship. Psychological state affects health. For example, older people who are depressed are at greater risk of disability or even death, than older people who are not depressed. It is known that depression affects the immune system. Less obviously still, there is evidence that psychological variables such as social status, level of education, degree of social support and loneliness influence the extent to which people are healthy or unhealthy.

Our lifestyle, environment and relationships

The word *lifestyle* has attained vogue status in recent years with an implicit meaning of a healthy way of living; it sometimes even means home-furnishing!

In psychology it retains a much broader meaning. It is the way a person lives and the environment in which this takes place, including relationships. The term describes how we deal more or less efficiently and safely with the many complexities of the everyday world. It is therefore an important component of identity, our sense of who we are as individuals and also our place within a community. Therefore it can encompass where and how we live, how we pass our time, what kind of food we eat, what habits we have and the kinds of relationships we have within and beyond the home. A specific lifestyle can be individual, family, or at community/society level, but there are always individual differences, however slight, within a family, or between families in a community.

There is an element of choice, but the degree of choice is variable. In general, the more favourable your circumstances (e.g. sufficient income, education, health) the more lifestyle choices you have. If it is a struggle to get enough to eat, to accomplish physical tasks, to care for one's children,

or motivate yourself because of illness, the number of lifestyle options you have is much more limited. These are also more limited if people have minimal experience of other possibilities and/or are innately conservative. This is even more so in communities or societies which frown on or are even actively hostile to lifestyles different from their view of the norm.

Lifestyle is an interactive process. We live in a given way partly because of our psychological make-up, including our experiences and the way we live largely determines the nature of what we experience and what we view as normal. When changes to lifestyle and the environment in which we live are forced on us by circumstances, certainties about who we are and our place in society diminish, making it difficult, and sometimes impossible, to adapt. Later life is commonly such a time, when enforced changes may be experienced.

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Activity 1a /1b:

What makes us who we are?

Consider the influences that have made you who you are. To what extent has your *genetic inheritance* affected the way you look, your personality, the way you think, the way you behave, the way you express emotion? Describe some of these influences in the space below.



Reflection

- What about your life experience, your health, your lifestyle? How have these helped shape who you are?
- How does who you are influence your lifestyle?

What changes can we expect as we age? What changes should we be concerned about?

Getting older – physical changes

The main feature of ageing is the loss of physical rather than psychological capacity. This can include a range of changes:

- The skin thins and loses elasticity so that it wrinkles and sweats less, making it take longer for tears and cuts to heal.
- Muscles shrink and bone mass diminishes, causing strength and endurance to decline.
- It therefore becomes harder to sustain or sometimes even undertake strenuous effort, an effect exacerbated by the fact that reflexes slow, and often, joints become more painful.
- Changes in circadian rhythms affect sleep patterns, another reason for lowered energy.
- Sexual capacity declines (although, contrary to popular belief, many older

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- people continue to enjoy sexual relationships).
- All the senses can deteriorate. For example, you may be unable to taste flavours or detect scents as well as before, or be unable to hear higher frequency sounds or judge depth. Decline in hearing and sight tend to have the most profound consequences for communication. The combination of decline in reflexes and the senses can have major effects, for example making driving difficult or impossible, or affecting communication.
 - The efficiency of all organs declines. For example, the heart and lungs do not function as well as before and this can have effects such as raised blood pressure or more difficulty extracting oxygen from the blood. Equally, it takes longer for your kidneys to eliminate waste products and in fact, the whole process of metabolism slows. One major effect of this is that older people have increased susceptibility to the effects of prescription drugs and alcohol.

It is important to note that it is possible to minimise many of the effects of the ageing process by a healthy lifestyle including a balanced diet, minimising recreational intake of toxins (alcohol or nicotine) and regular exercise. This applies both when such practices have been adopted earlier in life, but improvements also occur when healthy habits begin in old age. It is never too late. Many older people are fitter than the average younger person, as is evidenced by the now commonplace observation of older people successfully completing marathons and other sporting achievements. There is, again, an interactive link between health and psychological factors, in that adopting a healthy lifestyle has effects on psychological capacity. For example, even mild exercise has an effect not just on health, but also psychological wellbeing. It appears to be as effective as antidepressants in improving symptoms of mild to moderate depression. Similarly, maintaining social engagement appears to affect not only psychological wellbeing, but also general health.

Getting older – psychological changes

With regard to psychological capacities, the ageing process usually does not lead to significant changes. Contrary to popular belief, memory itself does not decline greatly. The most consistent finding has been a slowing of the ability to process, learn and act on new information. For some years this led to a belief that intelligence declines later in life, but it was eventually realised that all intelligence tests contain items where the person involved has to perform against the clock. When older people are given time, they perform nearly as well as younger people. That is, the ability to learn and remember new information remains intact as we get older; it just takes longer. Slowness in processing can affect other domains, such as attention and lifestyle. For example, even without hearing problems, older people may start to avoid larger social gatherings because they have difficulty keeping up with multiple conversations, or screening out competing stimuli. Even in one to one situations, for example when a waitress asks an older person which of 15 coffee options

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they want, it may take longer for them to understand and respond to what she is saying.

Psychomotor slowing means that thinking processes may slow but, for most older people, thinking remains logical, personality remains intact and emotions are experienced as intensely as before. Overall, while there can be some problems such as occasional difficulty recalling names or the odd memory lapse, the critical point is that usually, our cognitive capacity and all the components that make up the individual person we are, remain largely intact.

It follows that many older people retain the same motivation to continue to grow, to enjoy and make sense of life and their relationships with others. Thanks to advances in health care and nutrition, they may now have many more years in which to do this during what is often called the Third Age – the years post-work when the person may pursue interests and preferred activities. The University of the Third Age, started in 1973, is perhaps the

best known structured example, but there are countless examples of people well into their 80s undertaking activities like learning (or teaching) a new language, learning to make furniture, taking up a musical instrument or learning to maintain cars.



Activity 1c: *Getting Older*

Think about older people you have been involved with who do not have dementia. Have you ever talked to them as though they are qualitatively different from you or seen others do this? For example, have you observed someone raise their voice when they address an older person— automatically assuming that they are deaf or slow at information processing? Do people make assumptions that people are inferior or less intelligent just because of their age? How often does this happen in front of your eyes?

This is called ageism and we all fall into it

sometimes – even the authors. Think about some of the birthday cards we have all seen in shops, that draw attention to stereotypical beliefs regarding getting older and becoming an older person.

The only cure is to remember and keep remembering, that this person was once as young as you and is still an intelligent person with thoughts and feelings that should be acknowledged. The only difference is that this person was born before you and, probably, their body doesn't work as well as it used to and their thought processes may be slightly slower.

Changes we should be concerned about

It follows that many changes which are often considered to be the inevitable effects of ageing are in fact the result of processes which are not part of the usual ageing process. These changes are not unavoidable results of becoming older; they are consequences of events which are more common later in life, but are not exclusive to later life. Many of these are

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preventable, treatable or, at a minimum, they can be ameliorated or their effects lessened. Unfortunately, because of a lack of understanding about the usual effects of ageing, a lack of resources or less priority being given to the needs of older people at times, treatable aspects of an older person's presentation can remain unaddressed. We sometimes use the term excess disability to describe the results because, without intervention, the people concerned are more disabled by these factors than they need be.

Given that the main changes associated with the ageing process are physical, it is no surprise that ill-health contributes a great deal to the excess disability which older people can often experience. Almost all older people have chronic medical and physical co-morbidities and these tend to multiply, the older people get. However, the fact that someone is older does not mean that these changes are inevitable or won't respond to treatment. For example, incontinence – a common cause of depression, as well as a problem in its own right - is not an inevitable

part of ageing. The risk for incontinence increases with age because of changes in the bladder, but it can be treated or ameliorated. It may seem strange to include health in a document on psychological approaches, but no medical or allied health professional can work effectively with older people unless they understand the blurring of boundaries between physical and psychological health which is one of the defining features of ageing.

The best known example of this blurring is the way that infections, pain, dehydration, constipation or certain prescription drugs or combinations of drugs, can cause delirium, whereby to the untrained eye the older person appears to have many of the symptoms of dementia. They may also experience hallucinations or become delusional. Failure to identify delirium and treat its causes can be problematic, either because the cause is dangerous or because misdiagnosis leads to inappropriate treatment. Delirium can occur earlier in life, but older people are much more susceptible.

Another example of the blurring of physical and psychological boundaries in later life is the fact that chronic illness also greatly increases the risk of developing depression. In addition, many other psychosocial losses such as loss of mobility and independence, loss of status, death of close family members and friends, loss of financial security and loss of the home can cause both health and psychological problems. Many older people appear able to deal with these losses, but some lose confidence and can become depressed or anxious. As with physical health, the effects can be greater than with younger people. In particular, the cognitive effects of depression can mimic dementia. However, the main point is that only a minority of older people develop affective or anxiety disorders as a result of these medical and social losses. Being old is not intrinsically depressing. A depressed or anxious older person is just as likely to benefit from treatment as a younger person, with the rider that a medical work up by a medical practitioner who is knowledgeable regarding ageing is important, to identify any

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physical health problems (or medications) that are contributing to the symptoms being experienced.

In summary, many of the things we regard as part of normal ageing such as memory loss or incontinence are in fact abnormal ageing. They are the consequence of the multiple physical and psychological events which can occur throughout life, but which are most commonly associated with old age. Many can be treated or at least ameliorated; without this input people are more impaired than they need be – they have excess disability.



Activity 1d:

Changes out with the ageing process

Think back to older people you have worked with who have been diagnosed as having dementia or other mental health problem.

Do you know whether this person was screened for factors which complicate accurate diagnosis such as: infections, constipation, pain, depression and the effects of multiple medicines (polypharmacy)?

Perhaps you could make a list of the investigations which were performed, using the space opposite?

A large, empty rounded rectangular box with a thin purple border, intended for taking notes during the activity.

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Is it usual practice in your team or the service you work in, to routinely undertake such screens in order to control for the blurring of boundaries between mental health, physical health and cognition which so frequently occurs in old age?

If not, what screening do you think should be introduced or at least considered within your team? Use the space below to list the types of investigations which may be helpful in certain circumstances and what you can do

Summary

In this section we have looked at the psychological capacities which make us human and the combination of genetic and environmental factors which influence these from before birth and throughout life, to make each of us unique. Section 2 describes what happens to these capacities when they are compromised by dementia, a condition which is not something we can all expect to develop as we age. It also describes how the same environmental factors that influence us throughout life, have a powerful effect on the way the dementia is experienced and how they can lead to behaviour which is stressful for both the person with dementia and those who provide their care.



Section 2

Understanding dementia from a psychological perspective

Memory
Attention
Language
Perception
Praxis / psychomotor skills
Executive function

Attachment style

Emotion, behaviour and mental health

Genetic inheritance
Health
Life experiences
Lifestyle, relationships and environment

Section 2

Understanding dementia from a psychological perspective

Learning objectives

By the end of this section you will be able to:

1. Demonstrate an understanding of dementia from a psychological perspective.
2. Analyse the potential influence of other health and lifestyle choices on psychological function.
3. Recognise how changes in psychological function can impact on the lived experience of the person with dementia.

Psychological aspects of dementia

Dementia is an umbrella term for the effects of a large range of conditions which progressively and (usually) slowly destroy the cells (neurons) which transmit information in the brain and other parts of the central nervous system. This has a devastating effect because, unlike some other cells, dead neurons are not replaced. Production of important chemicals (neurotransmitters) which neurons use to communicate, are also severely impaired. Dementia is a disorder which is not associated with the usual effects of ageing, because even in the over 85s the highest estimated prevalence is 25%-30% of the population in European countries. This means that, even very late in life, a minimum of 70% of the population do not develop dementia.

In this section, we first look at the effects dementia can have on the psychological capacities introduced in Section 1. In Section 2b we look at the way diverse influences such as lifestyle and health, which have

shaped those capacities from before birth and throughout life to make us who we are, continue to have a strong influence on how the person with dementia experiences the condition and its effects. Finally, in Section 2c, we describe characteristic behaviours which occur in dementia which are commonly called challenging behaviour but for which here the term distressed behaviour is preferred.

Psychological aspects of dementia

Because brain cells are progressively destroyed regardless of dementia type, the most dramatic consequences are in the observable effects of brain impairment – the psychological functions. In this sense, though the cause is organic disease, psychological aspects are significantly affected. Attention in the popular literature, as well as amongst health professionals, tends to be focussed almost entirely on only one domain – memory. This is unfortunate because all psychological functions are

Section 2

Understanding dementia from a psychological perspective

ultimately affected, often profoundly if the dementia runs its full course. This section looks in more detail at what can happen to the psychological processes briefly outlined in Section 1. It is important information for those who want to care adequately for people with dementia, because it helps explain a lot of behaviour which it is difficult to comprehend - and often stressful - for those who think only memory is affected. Further resources available from NHS Education for Scotland (NES) include Cognitive Rehabilitation in Dementia Resources designed for staff, individuals with dementia and their carers, to facilitate the use of proven techniques to improve coping and functioning with the cognitive difficulties associated with dementia.

Cognitive capacity

Memory

Memory is profoundly affected in all dementias and is usually the first sign that something is wrong. Technically, the term memory includes not only memories

themselves, but the process by which we learn and remember information. A detailed description of memory can be found in our NES Cognitive Rehabilitation in Dementia Resources.

To develop a better understanding of the effects of memory impairment, try the following exercises:



Activity 2a I: Memory

A) Close your eyes and take a few minutes to think back to this morning, or last evening. Try and remember what you did over a set period of time, for example, from the time you arrived home until you went to bed. You will usually be able to remember not only a large number of things you did, but also a large amount of detail such as what your emotions were, what events looked like or sounded like. Once you are engaged in the exercise, one memory will cue another, as in

reminiscence therapy discussed in section 5 of this resource. In addition, you will usually be able to remember the order in which things occurred.

B) Now consider what it is like for someone with moderate dementia. They will be able to do very little of this, perhaps none, even from events over the last hour. They might have impressions or vague memories of episodes and how things sounded, looked or felt. They will probably not know when they occurred, such as whether it was an hour ago or last year, nor in what order. Imagine what it would be like not to have access to what has recently happened, access to the day to day progression of life and things you must learn to keep safe. It can be a profoundly disorienting, frustrating and even frightening situation, which becomes progressively worse throughout the disease.

C) Next time you are with a person with dementia and you find yourself asking a direct question about the recent past (anything from more than 10 minutes ago),

Section 2

Understanding dementia from a psychological perspective

make a note for yourself. If the person looks uneasy or otherwise distressed, or makes something up (confabulates), be aware that you have just unwittingly made life difficult by setting them a test that they cannot pass. It's easy to do, because many conversations start with questions and we think nothing of it, because we can easily retrieve recent information. This is not the case for someone with memory impairment.

D) Start planning and practising (even with friends) methods of having a conversation without asking questions involving the past. See if you can then hone your skills with people who have dementia, such that you rarely put them on the spot again. It is an acquired skill, not something that comes naturally to most people, but likely to avoid inadvertently causing distress.

Attention

Attention is part of the executive functions but it merits description in its own right because it is essential for achieving desired goals, for learning and also for safety. A

detailed description of attention can be found in our NES Cognitive Rehabilitation in Dementia Resources.

To gain insight into having control over your capacity to attend, try the tasks in activity 2a: Attention. If you do these activities note how, though your attention may drift, you can voluntarily bring it back on task. Then consider those with dementia and what it would be like not to have the same level of control, or to have lost it entirely.



Activity 2a II: Attention

A) If you engage in activities such as yoga, meditation, progressive muscular relaxation or any mindfulness activity, you will be used to attending intensely to specific body sensations, for example the column of air entering your lungs as you breathe in. You will also be used to the frustration of your mind wandering and how you can force your

attention back when you want. Most of us take our ability to do this for granted. Next time this happens, consider the plight of the person with dementia, whose attention will constantly be wandering and who may no longer have the capacity to bring attention back to the desired stimulus.

B) Go into a garden or some other place where there are multiple stimuli and concentrate for a minute or so first on what you can smell, then what you can see, then what you can hear. Notice how you are able to do this and also how your attention may wander, but you are able to voluntarily bring it back. Consider the person with dementia who cannot do this effectively, or at all.



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C) Consider the famous picture below.



You may be able to see an old woman or a young woman. You will find that you can only see one at a time, even though you might be able to switch very rapidly. Every time you switch, you are redirecting your attention. Notice the way you can do this. People with anything other than mild dementia often cannot switch in this way.

D) If you have ever had an injury where you were required to take high strength medication and you can remember the side effects this had, note how your capacity to attend to what is important was affected. This is a minor demonstration of what it is often like for people with dementia all the time.

E) Take time to notice when people with moderate to severe dementia have difficulty with their attention:

- Where they appear to be heading somewhere with a definite goal, then seem to lose track of that goal because something else captures their attention.

- Where a person maintains attention on the same goal for more than an hour. Examples include asking the same question repeatedly, or frequently making for the same location, because he/she is unable to switch off this train of thought and cannot be diverted from it.
- Where a person keeps changing what they are attending to, as they are only able to focus on something for a short period.
- People with dementia in a group setting, such as a care home or a day care centre, who become distressed in situations where there is a lot of noise and activity going on. If you think the environment is too stimulating, you might try taking them to somewhere quieter. Consider whether that environment could be changed, to make it less toxic to someone with impaired attention.

These are examples of impaired attention, or impaired control of attention. Consider the danger and discomfort inherent in not being able to focus attention or switch off attention

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when you want or need to. Think of changes which you could make to your practice or to the environment to avoid potential distress for people with impaired attention.

Language

Though memory is clearly implicated in language, for example learning and remembering a large vocabulary, psychologists tend to treat it as a distinct entity because it can be affected, even if memory is relatively intact. A detailed description of language can be found in our NES Cognitive Rehabilitation in Dementia Resources.

To develop some understanding of the effects of just one aspect of language disturbance in dementia – naming difficulties, try the exercise that follows:



Activity 2a III: Language

A) Read the next paragraph out loud, but assume that you have forgotten every word in italics and every word with a similar root. (Thus, for the first italicised word – memory – you are not allowed to use remember, memory or memories). Try and substitute another word or phrase, while keeping the flow going. For example, the first line might become, “Though that place in your brain where you store stuff you don’t want to forget is clearly implicated in ability to talk, for example getting lots of words into your brain and then getting them out again....”

Though *memory* is clearly implicated in *language*, for example learning and remembering a large *vocabulary*, psychologists tend to treat it as a *distinct entity* because it can be affected even if *memory* is *relatively intact*. Any *human language* consists of an almost *infinite* number of *unique combinations* of *sounds* and *symbols* which acquire *specific meanings*. In both *written and spoken form*, *language* is an essential tool for accurate communication of ideas and concepts. *Humans* have a vast *array* of ways of using *language*. For example we are able to *play* with it to make others *laugh* and use *subtle nuances* such as *irony* and *sarcasm* to make the *meaning* the *opposite* of the *face value* of the *words* used, or *puns* to convey multiple *meanings*.

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B) This is an academic exercise but you should get some idea of how difficult it is to make sense when you cannot think of words, how frustrating it is and how, when you substitute other words or phrases, it subtly changes the meaning. Try this again, with other more simple passages.

C) Consider what would happen if, in addition to not being able to remember words, like many people with dementia, you frequently said the wrong word (e.g. lion for dog). Try this with the passage above and see what an impact that would have on communication with others.

D) Now listen carefully to people with dementia who appear not to make sense, or whose sentence construction makes them difficult to understand. They are talking to try and communicate and it may be that, if you bear in mind what has happened to their language functions, they are making sense after all. You may be able to understand some of it.

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E) Another useful exercise is to be with people who speak another language that you do not understand. Get them to alternately ignore you, then to talk to you quite loudly. Continue in this situation and monitor your emotions until you become annoyed or switch off. Then consider what it would be like to have receptive aphasia (difficulty understanding what is said to you) all the time and be unable to switch off.

How might you adapt your interactions with people with language problems, to make these more rewarding for them? Use the space below to list some changes you feel you could make:

Perception

Perception is the process whereby the brain interprets (makes sense of) information received by the five senses: touch, smell, vision, hearing, taste. It is mostly unconscious (in jargon, implicit) and often occurs in a kind of gestalt whereby multiple senses integrate and combine what is coming in. However, we can choose to make it explicit. For example, when multiple stimuli are confusing us, or when we want to experience a particular sense (e.g. enjoy the smell of cut grass), we can use our ability to focus attention on just one sense.

A detailed description of perception can be found in our NES Cognitive Rehabilitation in Dementia Resources.

To develop some understanding of the effects of impairment in perception in dementia, try the exercises that follow:



Activity 2a IV: *Perception*

A) For visual perception, look at the picture used in the attention exercises, which shows both an old woman and a young woman in a hat. The ability to recognise one or the other but not both simultaneously is not only a demonstration of attention; it is also a demonstration of your ability to manipulate perception. Examine how you manage to make the switch from one image to another and how much of an effort that can be.

B) Test various other senses to look at how perception works. For example, for tactile perception, ask someone to put some common objects in a bag and try and identify what they are by touch, or ask someone else to do so. Somehow, by using memory, in combination with your sense of touch – and sometimes what you expect to be there, you will normally be able to name most items

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and visualise these in your mind. This is a remarkable skill, combining information from a number of senses to understand the world. This often challenges the capacity of many people with dementia.



Consider what it would be like to progressively lose the ability to recognise objects or people you know well, how would this affect you?

Imagine what it is like for relatives who become unrecognisable to the person with dementia...

Try to reflect on how you might feel if these changes were happening to you.

C) At home, at day care, or in a care home, be aware of how difficult it can be for people with dementia to use their senses to work out what is going on. If there is an area the person avoids, or where he or she becomes distressed or hesitant, try walking slowly through as if you had dementia, seeing what they are seeing, or hearing what they are hearing. You may find that there are too many confusing stimuli for someone with impaired perception, for example a mirror – so it looks as if a person is coming straight towards them, or a dark area of carpet that they perceive as a hole they may fall into, or a highly polished floor that looks as if it is wet and slippery. Consider whether you are able to suggest changes to this environment to make it less intimidating to the person with dementia.

Praxis/psychomotor skills

Praxis is best described as putting thoughts or knowledge into action – the link between thinking and doing. Obviously it has links to procedural memory which is the memory of how to do certain things or carry out tasks. For psychological purposes, praxis or psychomotor capacity refers to the ability to perform tasks involving fine motor skills and hand-eye coordination.

A detailed description of praxis/psychomotor skills can be found in our NES Cognitive Rehabilitation in Dementia Resources.

To demonstrate how complex tasks can be for people with praxis difficulties, try the exercise detailed on the following page.

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Activity 2a V:

Praxis

A) Make a cup of tea or coffee. With a notepad and pen at hand from the moment you start, write down at each step how many psychomotor skills are involved, by describing exactly what you have to do. Then make a list of how many things could go wrong if your psychomotor coordination/praxis was impaired by dementia, recognising that skills in other cognitive domains are also necessary in order to complete this task, such as:

- memory (e.g. remembering where the ingredients and the tap are)
- perception (e.g. being able to recognise the kettle and able to judge distances)
- executive functions (starting and ceasing each phase)



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B) When helping clients with personal care where you normally do everything, take the time to find out whether they retain the ability to undertake part of the task. For example, the person may not be able to undo or do up buttons, but may be able to take a blouse off or put one on. He/she may not be able to put toothpaste on the brush but be able to do some of the brushing.

The purpose of this exercise is not just to give you a demonstration of how psychomotor skills may remain partially or in some cases completely intact. It will also help make the business of personal care become a cooperative effort, rather than something you do to the person with dementia. It may be the case that providing all care yourself is quicker, that you feel there may not be enough time to encourage the person to do more for themselves or that taking more time may be frowned upon. However, if you can do such experiments, you are helping to minimise excess disability and helping the person with dementia become more than a passive recipient of your care. If you

do discover that some psychomotor skills remain, as you will, spread the word around to others involved in care of the person. Maximising their independence is likely to improve their quality of life, through assisting them to participate in productive and meaningful activity.

Executive function

Once learned, the cognitive capacities described so far can function automatically or implicitly and do so much of the time. It is our executive functions which enable us to override them and consciously direct what we do, think or even feel – hence the name and the reason they are thought of as higher level activities. They appear to be largely driven from the very front area of the brain (pre-frontal cortex) and are therefore sometimes called frontal functions but, like all other cortical areas, there are extensive links into and networks with, all parts of the brain.

A detailed description of executive functioning can be found in our NES Cognitive Rehabilitation in Dementia Resources.

To demonstrate these concepts in more detail, try the exercises relating to executive functions and awareness which are outlined below:



Activity 2a VI: *Executive functions*

A) To grasp what executive functioning is, it is often useful to think back to times when your executive functions are compromised. One example of this is when you have had strong pain relief medication or other strong medications, perhaps following an injury or surgery. Can you recall the impact this had on your ability to make judgements, plans, focus your attention and your ability to inhibit your responses as necessary? Many people with dementia experience these difficulties on a daily basis.

B) Another exercise to help gain insight into the executive functions and what can happen when these are compromised by dementia, is

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to make yourself aware of them in operation. Of course, in order to do this, you will be using an executive function: your capacity to look objectively at what your brain is doing. You have had to do this in all the exercises so far. Now we look at what your executive functions were doing during the exercises. This is sometimes called meta-cognition because you will be using your executive functions to look at your executive functions.

For example, look at the memory exercise again, where you try and remember what happened the previous evening. You are using your executive functions to consciously direct your memory, at least at the beginning of the exercise until implicit memories start emerging. People with more than moderate dementia struggle to do this. The attention exercises B and C, where you are asked to consciously focus on what you are doing and consciously switch between senses or perceptions, are all about executive functions. You have had to use your executive functions in every exercise, but you may find an aspect of the praxis exercise

gives another useful insight. When you are asked to make a hot drink, each phase requires you to switch to a new action and complete it. If you had impaired executive function because of dementia, you might not be able to switch from, say, turning the kettle on to finding the tea or coffee. You might not be able to start a new action, or stop one – you may just keep repeatedly turning the tap on. This is much more than a memory problem.

C) Now consider people with dementia you know or have known, who have behaved in ways you find puzzling or difficult to respond to. They perhaps become fixated on something they are doing, lack awareness of normal social skills like turn-taking in conversation, are unable to get started on something, or become suddenly angry and may show behaviours which we might not expect such as sudden shouting or hitting out. It is likely that they have impaired executive functions; though damage in other cognitive domains, or the fact that they may have unmet needs like untreated pain

or depression, may also be contributing (see section 6 of this resource for further discussion on distressed behaviour).

D) Ask permission and then sit with someone who has moderate to severe dementia, but who can still converse - even if only in simple sentences. If he/she will permit it, slowly engage him/her in conversation about life where he/she lives. If you persist and allow for language problems, you will find that the person remains aware of many things that are happening to her even if he/she believes that, instead of living in a care home for example, she is living in a hotel with noisy guests. Note that even this distorted belief, shows some awareness of the actual situation.

Then sit with a person in the later or end stages of dementia, after obtaining permission from relatives. After consulting with staff or relatives to see if this is appropriate and not likely to be distressing for the person, hold their hand or provide comfort in other ways such as stroking an

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arm or putting scent on a wrist. This is less certain but, if you persist, you are likely to find that he/she will say or do things now and again which show awareness, like squeezing your hand back, smiling, or saying things like, “Don’t leave me”, or, “Where am I?” or, “Can you tell me who I am?”. Such comments are not uncommon from people in late stage dementia. At some level, the person within remains aware of him/herself, aware that someone is there offering comfort and may even retain the desire to understand what is happening.

Other psychological functions – personality and attachment

We now go on to describe how dementia affects the non-cognitive functions briefly described in Section 1a.

Effects on personality (and how personality affects the way people respond to dementia)

Personality is essentially who we are, the sum total of all our attributes, the product of multiple interacting influences, including from well before we were conceived (i.e. our genetic inheritance), our history, our cognitive capacity, our memories and so on. However, within psychology, it can be described as our characteristic ways of responding across a range of different situations.

Personality tends to remain relatively stable throughout life unless there is major damage to the individual, or a major change in circumstances. Dementia is the most widely prevalent situation where both occur and to an excessive degree.

Many people with dementia retain their basic personality well into their dementia journey. For example, if they were quiet and considerate earlier in life, outgoing and vivacious, shy and withdrawn, aggressive and confrontational, stoical and non-complaining, or had a secure attachment style, they are likely to continue to display these traits. The same characteristics will also affect how they cope with dementia, or the behaviours which subsequently develop. As the disease progresses there are inevitably changes, though it is unclear whether these are directly driven by the disease process, as a reaction to impaired cognitive functions, or both.

Typically, the essential personality is still present, but it becomes progressively modified. This can include:

- a flattening of emotion, where the person is less emotionally responsive

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- a coarsening and less restrained way of expressing emotions
- loss of concern for others
- increased passivity
- apathy or loss of interest in things which previously gave pleasure
- rigidity in thinking.

Some of these changes become apparent before diagnosis and there is evidence that increased passivity, apathy and diminished emotional response occurs earlier in some dementias such as Lewy Body Dementia (see Section 3b). Note that these are tendencies - as we have stressed throughout, there are no hard and fast rules. For example, some people suffer profound personality change early on as a result of the repeated failures and losses which characterise dementia, becoming increasingly withdrawn and fearful (though see section later on mental health difficulties). Some people with Vascular Dementia become more rather than less emotionally responsive and people who display what we call distressed behaviour

(see Section 2c below) are often in the grip of extreme emotions like fear and anger. The main exception to general maintenance of basic personality is one of the Fronto-temporal Dementias, formerly called Picks Disease, where profound personality changes can occur relatively early in the disorder. Because of compromised executive functions, the person with Picks Disease can become disinhibited, including gorging food, being less tactful and less socially inappropriate, occasionally engaging in overt sexual behaviour, becoming highly agitated, neglectful of self-care or aggressive. They can also become socially withdrawn and eventually mute. In more common dementias, the executive functions are also affected, but more gradually over the course of the dementia journey and not usually as dramatically. See also Section 3b.

Attachment style

Part of personality with particular salience for dementia is attachment style. This is something we develop from birth, because of our need as totally helpless infants to

bond with someone (usually our mother) who will meet our needs and keep us safe. In ideal circumstances, the child soon feels sufficiently confident to explore the world, knowing that the same person (or people - usually parents) is available when things get difficult (securely attached).

In others, an insecure attachment style can develop with the person generally anxious through life, never quite feeling safe. Some manage this insecurity by clinging onto others, whereas other insecurely attached individuals systematically reject others due to a fear of being rejected themselves, therefore never becoming close. Overall, however self-sufficient we think we are, throughout life there remains a need for most of us to feel that there is someone to keep us safe. At times of major loss, danger or extreme stress, we may revert to behaviour (sometimes called attachment behaviour) which reflects this.

Thus, people in the later stages of dementia often feel abandoned and many will display

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attachment behaviour such as crying out, searching for parents or for someone to help them, even though they may not be able to tell you what they want when you ask. It is remarkable how many people with moderate to severe dementia believe that their parents are still alive – in some samples as many as 50%. This will be due partly to impaired memory, but it is also likely to reflect a desire for the security parents brought.

Attachment style can also affect the relationship between family caregivers and the person with dementia; the carers of people with dementia who are relatively secure report less burden. Carers who themselves have insecure attachment styles and who were heavily dependent emotionally on their parents, typically have more difficulty adjusting to the role reversal of caring for a parent.

Attachment behaviour can be distressing for staff but what is often required is empathy and some attempts to help the person with



Activity 2b: *Personality and attachment*

dementia feel safe.

A) The best way to gain an insight into personality is to try and answer an essential but rarely asked question:

- **Who is this person?**

People with dementia are often defined by the disease or by the way they behave but, in order to care adequately and empathically for them, you need to find the person beneath. Think about some of the people with dementia that you are working with or caring for. Do you know enough about them, who they were? In many cases the answer is no.

You can never know everything but to at least partially answer the question, “*Who is this person?*” you will need to gather

information:

- from the person themselves directly if they can still communicate or from observation
- from family and friends
- from medical and social history if available
- from your colleagues – who may have different insights.

Many care facilities do have personal histories about each person and you should use this resource, but there can be problems. Firstly, these are often developed soon after admission / referral, when family members may not be thinking as clearly and staff might not have enough experience of the person to know what information they need. Secondly, in too many facilities, few staff read them or feel they have the time to do so.

In intervention studies aimed at improving care and reducing distressed behaviour, encouraging staff to gather this information themselves and share it with colleagues,

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has often been the most important method by which they develop empathy and understanding to help them see the person as a person and not a problem. As a focus group member said after one such intervention, “When you go to a funeral you learn heaps of information about them that makes you think: If only I had known that”. The funeral is too late; you should have this knowledge whilst you are caring for the person.

B) Attachment

Think about people with dementia you know who frequently call out. This is likely to be in a hospital or a care home, because it occurs most often when the dementia is more advanced and the person is away from home.

- Listen to what they are saying if possible.
- Check for obvious reasons why they may be calling out, such as need to urinate, thirst, general discomfort or -distressingly frequently -untreated pain.
- If you have eliminated these common

needs, it is probably attachment behaviour.

Note that staff commonly find this behaviour extremely distressing and that, as a consequence, many people who call out have almost no social interaction, other than reprimands. Thus, there is distress on both sides.

If you yourself are agitated by the person’s calls, consider what you have learned about how attachment behaviour develops and what it would be like to feel totally abandoned and in despair. If you are not agitated by the behaviour yourself other staff may be and they may find it very distressing to listen to the calls repeatedly for a whole shift, every shift. They may find it helpful to learn about the idea of abandonment and attachment behaviour.

It is unlikely that going to the person and comforting them will make the calling out stop; the person will often resume after you leave. However, there is no excuse for not providing comfort whenever you or other

staff can. If you are worried about your visits ‘reinforcing’ the behaviour (often called attention-seeking), don’t be. Firstly, it rarely causes an increase in the behaviour; in fact regular TLC visits can sometimes reduce it, as the person comes to trust that someone will come. Secondly, even if it does increase, being in despair does not mean that the person does not deserve attention.

Emotions, motivations, thoughts and behaviour

Though these crucial aspects of life tend to be separated in psychology, they interact continuously with each other and with many other functions. For the purposes of demonstrating the effects of dementia on these psychological functions, it is most convenient to merge them in one section.

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To illustrate, you see an oncoming car which is too far on your side of a narrow road. You need perception to be able to recognise it as a car and also to judge its speed and how much space and time you have, which will involve rapid thought. At least one emotion will be raised, probably anxiety, but perhaps anger (either of which will lead to an adrenaline surge and a sharp rise in arousal) and this will motivate you to behave in a way which minimises danger (e.g. pull over, flash headlights) - again involving thought. The process will also have involved attention, executive functions, memory and intact psychomotor skills.

People with even mild dementia are less likely to be able to integrate these processes rapidly enough (or at all) in order to keep safe and might be more likely to react only to the arousal in a dangerous way, for example accelerating. As the dementia progresses, they have increasing difficulty integrating the psychological components of even simple situations sufficiently to keep safe. One of the features of good dementia care therefore, is skill in balancing safety, with promoting maximum autonomy for the individual.

Internal events can have a similar effect. For example, memory of something pleasant or unpleasant in the past will come into consciousness and therefore become a thought, which will raise an emotion – its nature and strength dependent upon the memory. This will produce changes in the body, for example a warm glow, a smile or a frown. The effects will combine to motivate you to some action, even if it is only to decide to concentrate on something else. People with dementia experience the same type of phenomenon - perhaps more often

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because the past is often more salient. However, they may not be able to place it in the context of the present and may react with anger, anxiety or pleasure and as if the event has just happened. It is easy to mislabel this as delusional thinking, especially if it leads to behaviour such as aggression.

Other internal events are also relevant such as when you feel a twinge in the back. Intact proprioception enables you to identify this (so it becomes a thought) and memories and thoughts may flood in – for example a flashback to when the injury occurred. Several emotions are also likely, such as annoyance that you have not taken care (a thought) and, almost certainly, at least a slight surge of anxiety and bodily arousal. The combination of events, especially the emotions, will motivate you to adaptive behaviour, for which you will require memory and psychomotor skills, in order to change position or take analgesics, for example.

This is not the case for many people with dementia. Because of impaired

proprioception, they may not even be able to recognise that they are in pain, identify the site of the pain, or they may not be able to think through the need to ask for pain relief or, even if they can, lack the language skills to do so. Instead, because of the bodily arousal and anxiety which pain causes, the person with dementia is likely to become highly agitated and may even rush around trying to escape it rather than rest. That is, the emotion and behaviour is driven by the pain but they are unable to put together the information required to behave in an adaptive way.

These examples illustrate that the ability to integrate emotions/motivations and thoughts to produce adaptive behaviour becomes increasingly disrupted in dementia. Later in the disorder it can affect all aspects of care and leads to particular problems in residential facilities. As it becomes more and more difficult to maintain a logical stream of thought and because memory problems usually mean people with dementia do not know they are in a care home for

the rest of their lives, they have difficulty integrating their perceptions to arrive at the same conclusions as the staff caring for them. Hence, the frequent problems with behaviours that are seen as ‘resistive or aggressive’ in intimate personal care even though, if they were in hospital earlier in life, they would have allowed nurses to bathe and dress them if required. Similar scenarios can occur where a person receiving care in his/her own home does not recognise the need for input from care workers and responds out of anger and frustration to drive them out of the house.

The difficulty integrating profoundly impaired psychological functions affects many other aspects of care. People with dementia have increasing difficulty in undertaking flexible thinking (executive functions) and sustaining a train of thought (attention) to solve novel problems in the same way as before they had dementia. Instead, they are likely to use memory for what has happened in the past but which is not valid now. Thus, for example, people in a care home may interpret cues

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such as staff putting on outdoor clothes and saying goodbye at shift change, as meaning that it is time to go home themselves and become motivated to leave. When prevented, they may become frightened, confused or angry because their multiple impairments – as well as strong emotion – lead them again to misinterpret the situation.

There are a host of other examples. Overall however, we have sought to illustrate the way that emotions and the consequent thoughts are in fact the primary motivators of behaviour, though it is never as linear as we have presented in the examples. It is a continuous interaction. A major requirement for adequate, empathic care is that you develop an understanding of the many psychological processes which are impaired by dementia so that, when someone acts in a way which appears 'unusual' to you, you can use your own capacity for flexible thinking to try and work out how the person may be interpreting (thinking about) what is happening and what emotions are generated to drive their subsequent behaviour. (See the

linked exercise after the next section).

Emotion, behaviour and mental health

A substantial number of people with dementia enter a sustained period of aversive emotions of sufficient intensity to classify them as having a mental health problem. It is impossible to give accurate figures, but it is safe to say that at least 20% of people with more than moderate dementia have clinical levels of either depression or anxiety, or both. Depression is normally thought of as leading to increasingly withdrawn behaviour, apathy and hopelessness, but in dementia, it can also lead to motor agitation expressed in behaviour such as pacing. Anxiety leads to arousal, agitation and a constant state of vigilance. Both lead to excess disability – the people concerned are more impaired than they need be and are even more likely to misinterpret what is happening to them. See Section 4 (or 5) on approaches to these disorders.

Some may also develop hallucinations and delusions, though extreme caution is required before arriving at a diagnosis of

psychotic illness, because of the frequent adverse effects of anti-psychotic medication and because, as already discussed, many aspects of dementia incorporate hallucinations and delusions. Hallucinations are one of the defining symptoms of Lewy Body Dementia and often occur in Vascular Dementia; they also occur in about 30% of people with AD who are depressed. Many people with dementia and anxiety are chronically suspicious, but many apparent delusions, for example a person who thinks they are abandoned, are actually the result of mistakes caused by cognitive impairment.



Activity 2c:

*Emotions, thoughts,
motivation, behaviour*

In the text we have given examples of behaviour including: wanting to go home; suddenly presenting as aggressive because of an unpleasant memory; becoming highly aroused and agitated because of pain; being agitated in intimate personal care.

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All will have involved a continuous and interactive mingling of thoughts, emotions and motivations to produce behaviour which, before they had dementia, would have been unlikely to occur. For example, the person who lashes out in the shower almost certainly thinks he/she is being assaulted, emotions raised could be fear or outrage, the motivation is to prevent it happening or escape. Staff attempting to continue the task also often become aroused (fearful or angry) and the situation escalates.

Now think of other examples where people with dementia behave in ways which put themselves or others in danger; or embarrassing or awkward situations; or which in other ways do not make sense to you. Try and unpick the way they may be interpreting the situation, putting yourself in their shoes. Thus, you must bear in mind that the capacity to make sense of what is going on in the same way as they would have earlier in life, is now severely compromised by memory, language, perceptual and other cognitive impairments, as well as difficulty in

logical thinking.

Try and work out what their thoughts might be (they may even be telling you if you listen carefully to what they are saying); what their emotions are likely to be (you may be able to tell by body language and facial expression); what their motivations are. Bear in mind that they are actually making sense of what is happening as far as they can, but that the capacity to do this in a way which is adaptive for them is severely impaired.

Undertaking the exercise is difficult if you are in the middle of such a situation but, if you practice regularly after such events, you will increase your skills in seeing the world as the person with dementia sees it - an essential requirement for person-centred care. It will enable you to adapt the way you approach people with dementia. For example, if you realise that someone struggling in the shower is not deliberately 'difficult and aggressive' but frightened, it should enable you to approach the task in a way more likely to induce calm. (See also sections on

distressed behaviour and communication).

Look at:

- > [The Cornell Scale for Depression in Dementia \(CSDD\)](#)
- > [the Rating Anxiety in Dementia \(RAID\) Scale](#)

If assessment of depression and anxiety is not already a routine component of your service (and note that very few clinicians assess anxiety), complete the relevant scale for people with dementia whom you think are chronically depressed (CSDD) or anxious (RAID). A score above 10 on the CSDD or above 11 on the RAID is indicative of a clinical level of symptomatology.

The purpose of this exercise is to increase your awareness of mental health difficulties amongst people with dementia and prompt you to consider adapting care practices to try and reduce the level of symptoms, or consider referring on to an older adult mental

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health service. Clinical levels of depression or anxiety in dementia are common causes of excess disability and untreated depression at least is a predictor of greater disability and earlier death. If you find a clinical score, but are a junior member of staff or not yourself an expert in assessing mental health, try and persuade colleagues who have more authority to refer the individual for further assessment.

What influences the presentation and capacities of people with dementia?

In Section 1b, we discussed the four broad factors which influence our psychological capacities: our genetic inheritance, our life experiences, our health and our lifestyle - including our relationships and the environment in which we live.

Genetic Inheritance

Because it is laid down at conception, your genetic inheritance may influence whether or not you develop dementia but, for the commonest disorders, the risk is low. For example, if there has been dementia in your immediate family in the last two generations, there is only a 4% increased risk that you will develop Alzheimer's Disease. Risk of developing some other medical disorders is much higher.

Looked at another way, genetic factors are implicated because, by definition, dementia is a disease which progressively removes many

of the neurons you inherited at conception. However, the primary influences on how the disorder presents and how people respond to it are the three broad environmental factors which have been influencing development since birth. They continue to exert a strong influence after onset of dementia. These are the health, experiences and lifestyle/ environment in which people live.

Health

As already discussed in Section 1 under the headings of 'what we can expect as we get older' and 'what changes we should be concerned about', declining health and physical capacity become increasingly pervasive issues as people enter later life. These lead to a blurring of boundaries and pernicious interactions between physical, mental, social and cognitive health. Thus, depression, mild infections or side effects of medications can mimic dementia; depression

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is a risk factor for medical illness and disability (and maybe dementia); medical illness and disability are major risk factors for depression; and psychosocial variables like social isolation increase risk for both.

These complex interactions become even more salient in dementia. Many people with dementia have co-morbid physical illnesses and at least 20% have co-morbid mental health difficulties (see previous section). Because of what is sometimes called limited cognitive reserve (i.e. their cognitive functions are already depleted), they are even more susceptible than those experiencing normal ageing. If they have depression, mild infections, inappropriate prescription medication, are in pain or discomfort, or have any other medical or mental health problem, they will appear much more impaired than they really are. Similarly, if their psychological needs are not met, poor health and early death is likely to ensue. Minimising excess disability because of poor physical or mental health is a critical, though often incompletely addressed, component of

person-centred care of people with dementia.

Despite the development of an increasing number of medical co-morbidities, once people develop more than moderate dementia and can no longer advocate for themselves, there is a steep decline in the extent to which treatment is offered. Every time a person moves to a new setting this can be exacerbated further, with a serious risk that previous treatment regimens will be ceased, especially if there is a change in GP and previous medical notes are not readily available.



Activity 2b I: Health

For this exercise, we use pain just as an example of under-treatment. Almost everybody over 70 suffers some form of chronic pain but people with dementia are much less likely to receive pain relief. Think about a few people with dementia that you work with or care for:

- Look in the notes for direct evidence of pain.
- Look in the medical history for events which would suggest on-going pain, for example a hip or knee reconstruction or a back operation.
- Look at the person with dementia for signs of pain such as:
 - grimacing
 - a tendency to lash out when certain body areas like the knee are touched
 - inflamed areas
 - a tendency to hobble or favour one leg. This is likely to be more noticeable later in the day.
- You might also use a pain scale to aid your assessment such as:
 - > the Abbey Pain Scale
 - > the Pain Assessment in Advanced Dementia (PAINAD)

There is a very good chance that before long, you will identify people who may

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experience chronic pain which is untreated or undertreated. This can happen when 'PRN' (as required) analgesics are prescribed, due to the difficulties we have already described which make it difficult for people with dementia to make their needs known.

Life experiences

Being diagnosed with dementia is, almost uniformly, a traumatic experience and there will almost inevitably be the risk of considerable distress in the years thereafter. Despite this, many people with dementia have positive experiences, much of it dependent on the way they are treated or helped to cope. Even the way the diagnosis is shared can have a profound effect. Clinicians have worked with people who have been told "You have dementia and there is nothing I can do"; they were still angry a year later. Others spoke of the supportive way the news had been shared, with referral to services which could offer genuine practical and emotional help. For some, getting the diagnosis in this way had been a relief; at last they had an explanation for all the

strange things that had been happening.

Though it applies to the early stages, this example illustrates the general principle that, throughout the dementia journey, the way people are treated has a profound influence on the way they experience and react to the disorder. Unfortunately, simply by virtue of developing dementia, almost everybody will have many unpleasant experiences throughout. For example, they may frequently:

- become confused and anxious
- get lost in unfamiliar places
- lose the ability to say what they want or understand what others are saying
- be unable to undertake previously familiar tasks
- be unable to find important locations like the toilet, in time to use them
- fail in a multitude of other tasks and undertakings

These and many other aversive experiences will occur even without deliberate or unwitting

ill-treatment by anybody else.

However, they may also be treated like children, have people speaking about them as if they are not present, be shouted at, be locked up or even sometimes physically restrained, be given medications that make them drowsy, fall, or develop incontinence and, as faculties decline further, run the risk of aversive experiences such as being physically assisted into a shower by a group of people. Explicit memory may decline, but many people with dementia implicitly remember situations, places or people with whom aversive things have happened. Similarly, they may misinterpret new experiences in light of these implicit memories.

A significant number of people with dementia manage these experiences surprisingly well through the process of progressive decline, though most at some stage, manifest what is often called 'challenging behaviour'. The term 'distressed behaviour' is preferred here, on the basis that it is nearly always a

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manifestation of distress (see Section 6). However, as a result of repeated negative experiences, many people with dementia become anxious, depressed or generally unhappy; withdraw, appearing apathetic and to have given up; or fight (sometimes physically) against what is happening to them. To minimise the risk of this happening, it is essential to treat people with dementia as far as is possible in a way which enables them to continue to have positive experiences, in the same way that even the way the diagnosis is explained can make a positive contribution, in reducing uncertainty and enabling forward planning. Use the exercise below to help you consider how best to interact with a person with dementia. You will also find more information which should assist you in Section 4 on Communication.



Activity 2b II: Life experiences

A) Observe how the people with dementia you work with are treated on a day to day basis by family or other people, including staff. Be aware that you are observing an important component of their daily life experience, especially in settings where contact with staff may be the main social interaction available. You will see a range of interactions ranging from excellent to very poor.

B) Make a note or list of those who treat people with dementia in a way you would like to be treated if you had dementia.

- What is it about their approach which appeals?
- How do they do it?
- What is its effect on the person?

Also make a note of those who interact with people who have dementia in a way you would not like.

- What is its effect?
- How do you think you would respond if treated in this way if you had mild dementia?
- Or if you had severe dementia?

C) Now consider how your own approach compares with those who interact well.

- Can you learn from them?
- Do you think you can improve?
- If so, how are you going to do it?

Be aware that, though some people seem to have good communication skills naturally, most of us have to learn to communicate well with people with dementia of varying severity; it is an acquired but essential skill in dementia care.

Lifestyle, relationships and environment

Initially there need be little change in lifestyle when dementia develops; people can continue many of the activities and relationships which help define who they are. However, there will often be a change in relationships early on, especially if the

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person with dementia has been the partner who provides the main caring and support role. This shifts to the other partner and/or any children and can create difficulties.

Maintaining normal activity as much as possible is very important to wellbeing, but sometimes carers and health professionals can be over-protective, such that the person's activity levels plummet after diagnosis, often leading to depression or physical deconditioning. However, it is a delicate balancing act. Even in the early stages, the principle of maintaining autonomy and independence while keeping the person safe and protecting from failure begins. The two best known examples of keeping people safe are decisions about driving and use of electrical and/or cooking equipment, where it will usually eventually be necessary to find ways to limit or cease these activities.



However, there are many lesser examples of maintaining activity while protecting people from failure and keeping them safe. Ingenuity is required. For example:

- If continuing with sport, friends need to know about the diagnosis and for instance, keep score, or gently redirect the person if he/she becomes distracted and walks away.
- To maintain a daily walk, it may be necessary for someone to accompany the person if the route involves busy roads or there is danger of getting lost.

Dementia friendly risk assessment is needed. The question is not, "Is it unsafe for the person with dementia to do this?", but rather, "What support needs to be put in place so that the person with dementia can do this safely?".

If there has been complete openness about the diagnosis and insight is retained, helping the individual adjust to these changes is always the best approach rather than subterfuge. With driving, the DVLA will need to be informed and may require a driving assessment to be undertaken, but there are a number of ways in which people with dementia can be supported in maintaining

safe mobility. We suggest the following websites for advice on how to maintain or adapt this and other activities:

-  [Alzheimer Scotland](#)
-  [Alzheimer's Society](#)

Over time, the need for exercise, intellectual stimulation and other meaningful activity remains, but it will become increasingly necessary to adapt the ways these are accomplished, to the capacities of the person with dementia. Despite all adjustments there is always a contraction of lifestyle, usually meaning that the person and the carer spend more time at home, some never going out except for medical appointments. Restriction of lifestyle includes social contacts because many people are uncomfortable about dementia, let alone socialising with someone who has the condition. Former friends who want to remain engaged may need advice about how to converse in a positive way with the person. During this process, some carers can become highly stressed or feel

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trapped and may go on to develop clinical levels of depression or anxiety. If this occurs, it is essential that they access treatment and that services make it possible for both family and the person with dementia to escape the home and each other, as well as have the opportunity to undertake rewarding activities together.

The move to a care home or hospital setting if this becomes necessary, is a massive change of lifestyle, relationships and physical environment. For many, especially couples, it is the (often) abrupt termination of a lifestyle developed over 50 years and more. It is important that sufficient support is provided for this major life transition. For some people with dementia and their carers, moving into a care home can be a liberating experience, making life easier because the facility is geared up to their needs and there are increased chances to socialise. This is more likely in good facilities, with sufficient skilled and empathic staff who have a good understanding of dementia.

For some people with dementia however, the move can mean a rapid diminution or total loss of previous lifestyle and quality of life. People with dementia are more likely to develop excess disability in a care home (for example incontinence), either because staff are not yet aware what the person can or can't do, or perhaps because due to time pressures, it is quicker to 'do to' the resident rather than work in mutual cooperation in, for example, morning care. It is possible that the person with dementia may be on inappropriate medication which also leads to excess disability, or will have untreated pain, delirium, or depression.

From a relationships viewpoint life can become lonely and boring. There is abundant data showing that, apart from family visits, many people with more than moderate dementia have very little social interaction other than in personal care and for some maybe not even then. The problem is worse if they present with distressed or distressing behaviours. Sometimes staff may feel they lack the time or even the confidence in

their ability to socialise with people who have dementia. This is a particular problem because, for many, meals and interactions with staff comprise the bulk of their social lives. In later stages, life can consist almost entirely of lying alone in bed or a recliner most of the day and night, punctuated by brief periods of personal care and turns to prevent pressure sores. This lack of activity may be inevitable, but evidence that there is still a person present who remains aware, even in the end stages, means that engaging people (including volunteers) to be with that person a few hours a day is not just humane, but clinically worthwhile.

It is important to stress that the restrictions to lifestyle often attendant on admission to a new setting are not because of ill-will by facilities and staff. The problem is firstly, that these settings can rarely actually be like home. Secondly, there are often insufficient resources to meet the complex cognitive and medical needs of people with dementia. Some facilities do manage to provide excellent care and minimal diminution of

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lifestyle and there have been numerous intervention studies which have managed in various ways to work with staff to provide better care. Many have been successful, at least for the period the intervention was running, so good care is possible despite the difficulties.



Activity 2b III: Lifestyle

In the exercise on personality, you were asked to try and answer a critical but rarely asked question: Who is this person? We suggested that you use multiple sources to build up a picture of the person behind the disease. To gain an understanding of the impact of dementia on lifestyle, relationships and environment, there is an equally powerful follow up question.

- What do you think life is like for this person now, compared with before he or she had dementia?

To answer this question you will need to have undertaken the exercises in Section 2.

If you consider it with your emotions, as well as your intelligence and consider all the impairments discussed in this entire section on *psychological aspects of dementia*, it will provide the grounding to try and answer a third question:

- In which areas can my colleagues and I intervene or change practices, to improve lifestyle for this person?

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Introduction to distressed behaviour in dementia

Previous sections have alluded to the many reasons why people with dementia may behave in ways which are difficult to understand and which challenge the capacity of family members, community staff and care home staff to understand and to manage effectively. Examples of such behaviour include:

- making accusations of stealing because of memory problems
- becoming distressed in busy situations because of impaired ability to focus attention
- becoming aggressive because receptive aphasia turns all speech from others into intolerable babble
- assaulting staff while being assisted to shower because of misinterpretation of what is going on
- avoiding or stepping carefully around apparently safe areas because a dark carpet is perceived as a hole in the floor
- calling out for a long dead parent because of feelings of abandonment

- becoming agitated or aggressive because of escalating pain (which may not be recognised as such because of impaired proprioception or because of loss of capacity to ask for relief)
- trying to 'escape' because staff cues suggest it is time to go home and becoming aggressive when prevented to do so.

In recent years, such behaviours have been subsumed under a syndrome labelled Behavioural and Psychological Symptoms of Dementia (BPSD). The term BPSD tends to be used generically, employed interchangeably with diverse phenomena such as aggression, resisting personal care, sexual disinhibition and nocturnal disturbance, but also with qualitatively distinct factors such as apathy, depression, hallucinations and anxiety, which are better seen as causes of behaviour.

Because of this confusion, since the title BPSD implies that dementia is the direct

cause of the behaviour and because it reinforces the common view that the behaviour is the syndrome to be treated rather than its causes, we use here the term **Distressed Behaviour**. By this, we mean behaviour which is usually (but not always) driven by feelings of distress in the person with dementia and which, equally, causes distress in family members and care staff because it is difficult to deal with and cope with emotionally. Thus, the most common reason family members surrender care to residential facilities is behaviour which challenges their capacity to cope (hence another common name – *challenging behaviour*). In care homes and in-patient settings, similar strains can arise. Distressed behaviour, which tends to be more florid in this setting, is the most common reason care homes seek assistance from outside clinicians.

Apart from stereotypical behaviours such as gorging food associated with Pick's

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Disease (see Section 3b) and behaviours like perseveration in other dementias, it remains unclear how much focal brain damage directly causes the person with dementia to behave in ways which family members and professional staff find stressful. Clearly, destruction of neurons has a role because, in most cases, the person would not have behaved in this way before.

However, the examples presented throughout Section 2 and summarised at the start of this sub-section, all suggest that it is not usually a specific area of brain damage directly driving the behaviour, but the effects of the damaged brain on the person and his or her capacity to function within their environment. Accordingly, we believe the most clinically fruitful way to conceptualise what is happening is the interaction between the following factors.

Factor 1

The impact of dementia and (almost always) medical and physical health co-morbidities on multiple cognitive capacities, making it

progressively more difficult to negotiate and make sense of the world, until a state of almost total dependence is reached.

Factor 2

The devastating effects of dementia in reducing the repertoire and sophistication of the ways people can make their feelings and needs known. This progression can lead, ultimately, to only relatively crude behaviours like screaming or lashing out being available when, for example, someone is in pain or feels threatened in the shower.

Factor 3

The fact that the world and, as the dementia develops, the care world is often not geared up to meet the complex needs which arise from dementia, or interpret the ways these are expressed. This often occurs for reasons which include lack of resources, skills, knowledge and problematical attitudes (the four are usually interlinked).

Factor 4

The emotional response of those exposed to this behaviour, most commonly family members and community, hospital and care

home staff.

In summary, dementia means that situations where distress is likely increase as the disorder develops but, simultaneously, the capacity to express distress and gain help in socially acceptable ways decreases. The capacity of formal and informal carers and care systems to deal with the causes of that distress is limited, partly because those providing the care are themselves distressed.

We describe this as the most clinically fruitful conceptualisation because it exposes the areas where it is possible to intervene, through an individualised formulation-led approach. Thus, looking at Factor 1, nothing can be done about the cognitive damage, but interventions can be applied to physical problems which are causing excess disability.

Though this document is on psychological aspects of dementia, we have no hesitation in nominating untreated conditions such as pain or discomfort; delirium because of medication toxicity or infections; respiratory

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problems; and a host of other medical/bodily conditions; as the most common causes of distressed behaviour. They should always be investigated first.

Looking at Factor 2, it is not possible to help people with dementia re-learn how to express feelings and needs in a sophisticated way. However, it is possible to help family members and staff to become more skilled at recognising:

- firstly, that a lot of behaviour in dementia that they find distressing, is itself an attempt to communicate distress
- secondly, to recognise what unmet needs may lie behind the distress.

Ability to recognise the needs of the person with dementia is an important component of Factor 3, together with changes to the care environment to meet those needs. This includes not only changes to the physical environment, a topic of many texts but, much more commonly, changes in the amount of care provided or the way it is carried out,

especially intimate personal care. After treating or managing physical and medical needs, changing or enriching the care environment is the next most common way of ameliorating distressed behaviour. This is not because care provided is necessarily bad, though sometimes it clearly is. It is most often because those providing care do not have dementia and are, therefore, more likely to be able to change. Working through the rich, multi-faceted care environment, opens up the possibility of improving quality of life and minimising distress in the person with dementia.

Finally, none of this can be done without taking account of Factor 4. It is a critical, but little explored component of ameliorating distressed behaviour. Unless you listen to, understand and empathise with, the distress which the behaviour causes to family members, community staff and care home staff, it is almost impossible to engage them in a dialogue which helps them see behind the behaviour to its causes. These causes often include, at least in part, the way they interact with the person with dementia. That

is, you must engage with them empathically to help them change their own practices and thereby change the care environment.

Thus, carer distress is a clinical target in its own right and, in a significant number of cases where the behaviour is not distressing the person with dementia or is not a manifestation of distress, it is the primary target. We estimate from our experience that making carer distress the primary clinical target applies in at least 40% of cases where the person is still living with family and 25% of cases in care homes. The aim is to help carers and staff perceive the behaviour and the person differently. The questions in the exercises on personality and lifestyle in Section 2b always play some part in producing the change:

- Who is this person?
- What do you think life is like for this person now compared with how it was before?
- In which areas can I and my colleagues intervene or change practices to improve lifestyle for this person?

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Asking such questions, considering the answers in detail and assessing the four factors described previously, contributes to understanding distressed behaviour on an individual basis. The understanding of contributory factors (the 'formulation') leads on to potential for change and for a new perspective.

To further illustrate the kinds of phenomena we are talking about and the interaction between behaviour and carer distress, Tables 1 and 2 show samples of characteristic behaviours which have, respectively, distressed family members and care home staff sufficiently for them to seek help. They are derived from two intervention studies directed by one of the contributors to this resource. They show the most common behaviours which led to referral, in order from the most common down to the least common.

Note that in most cases there was more than one distressed behaviour; we have presented only the behaviour considered

most stressful, by those exposed to it. **Note** also that there are many other ways in which people with dementia communicate distress; we are limited to this real-life data.

Click on the links below to view the relevant information:

[▶ Table 1: Behaviours family carers reported leading to seeking help](#)

[▶ Table 2: Behaviours care home staff reported leading to seeking help](#)

It is clear that there are differences between the tables and this can be used to reiterate important points already made:

1. Firstly, behaviour tends to more florid in care facilities than for people living at home, with more screaming and physical aggression reported - mostly related to intimate personal care.
 - a) This is partly because distressed behaviour is a frequent reason why family members surrender care in the

first place, but also because dementia is usually more advanced in care home residents.

b) However, there is no doubt that the effect of being in a care facility itself has an impact on behaviour. Being in unfamiliar surroundings, with people you do not know is likely to increase the feelings of vulnerability in certain situations.

c) The more extreme manifestations of distress (for example screaming many hours a day) are rarely described in the literature on psychosocial interventions, but may be encountered in long-term care environments.

2. Secondly, many of the behaviours in Table 1 which led to home carers making referrals are what can be considered normal phenomena in dementia and are not 'challenging' to staff in care homes. They include:
 - a) motor restlessness
 - b) repetitive actions
 - c) being unable to recognise people

Table 1: Behaviours family carers reported leading to seeking help

Behaviour which led to referral by family carers	Number of cases referred	Percent
Resistance to care, generally being uncooperative	19	13.3%
Being paranoid, suspicious, making unjustified accusations	16	11.2%
Aggression (mostly verbal) and anger	16	11.2%
Restlessness/anxiety/wandering aimlessly	13	9.1%
Repetitive actions or questions	9	6.3%
Eating problems	9	6.3%
Incontinence or other toileting problems	8	5.6%
Actions which put the person with dementia in danger	8	5.6%
Disorientation to place	8	5.6%
Sleep disturbance	7	4.9%
Delusions	6	4.2%
Unable to recognise family members or friends	6	4.2%
Depression/frequently upset	5	3.5%
Refusal to take medication	4	2.8%
Shadowing, constantly seeking attention	3	2.1%
Disinhibition, undressing in public	3	2.1%
Complaining	3	2.1%
Total	143	100%

Table 2: Behaviours care home staff reported leading to seeking help

Behaviour which led to referral by care home staff	Number of cases referred	Percent
Physical resistance to personal care	7	21%
Loud verbal disruption/screaming or yelling	6	18%
Frequent demands of staff /repetitive questions	5	15%
Physical aggression not related to personal care	4	12%
Intrusive, damaging or dangerous wandering	3	9%
Verbal aggression	2	6%
Sexual disinhibition	2	6%
Repetitive behaviours	1	3%
Problems with feeding	1	3%
Distress due to hallucinations	1	3%
Unspecified agitation, emotional lability	1	3%
Total	33	99%

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They are challenging to family members and friends because they are different from how the person was in the past; this is why family carers are often distressed by the person's apathy and lack of purposeful occupation - it can be such a change from a person who was once full of energy and drive. However, care staff are often used to these aspects of behaviour and do not see these as remarkable.

This illustrates a crucial point. Regardless of setting, there are vast differences between family carers and professional staff in which behaviours distress them. Though there are some behaviours which almost everybody finds problematic – such as screaming, repetitive questions and physical aggression unconnected to personal care, for most situations there is great variability.

Given the same behaviour by the same person with dementia, one staff member might regard the individual as impossible to look after and dread coming to work, while another may not see this as a problem at all. Staff who are less distressed by behaviour, tend to be more experienced and skilled, dementia-literate and have more empathy and understanding.

This is why intervening at the level of carer or staff distress is so fruitful. In any situation, especially in a care home, there will always be one or two individuals who already understand the person with dementia, what needs are being expressed and know what to do in response to these. This is quite apart from the fact that the same staff are less likely to experience the behaviour. This illustrates, again, that in most cases, the behaviour is not directly driven by the dementia as the term BPSD would suggest, but involves an interaction between the person and the care environment. It therefore also illustrates that there is room to move. If one staff member can manage both practically and emotionally, it means that others can too. This is why adjustments to the care environment – the way care is carried out, in combination with supporting family members or staff both emotionally and practically, is the most common type of successful psychosocial intervention after dealing with medical and physical issues.

Distressed behaviour is discussed further in Sections 4 and 5.

Summary

In the first part of this section, you have looked at the gradual and progressively more profound effects that dementia can have on a host of different psychological functions. Often, people mistakenly hold the view that only memory is impaired in dementia. Apart from the fact that multiple systems are impaired, from language, the ability to initiate or suppress behaviour, to the ability to make logical links, there is no way that anybody ever completely loses their memory. What happens is that memory becomes increasingly inefficient and disordered, but even in the end stages, someone who calls out for their mother or reaches out a hand to be held, retains a memory that these actions have provided comfort in the past.

In the next sub-section we looked at factors which influence how dementia is experienced and variables that help determine which way the balance between pleasant and aversive experiences pans out. In the final section we introduced the topic of distressed behaviour in dementia.

Section 3

Assessment of dementia and introduction to the most common dementias



Section 3

Assessment of dementia and introduction to the most common dementias

Learning Objectives

By the end of this section you will be able to:

1. Outline and evaluate best practice in the engagement and subsequent assessment of people living with dementia.
2. Demonstrate sensitivity and awareness in the process of engaging with people living with dementia
3. Apply person centred principles of assessment within a multidisciplinary context.
4. Understand when to request a comprehensive assessment.
5. Determine the different causes and types of dementia and the differing impact on the life experience for the person with dementia.

Recognising dementia

At first sight it appears straightforward to recognise when a person is developing a dementia. We can simply apply the

diagnostic criteria:

- Has there been a change in memory and thinking and other abilities?
- Is the person having difficulties with self-care?

But in practice, it can be difficult to answer these questions. Exactly how much change in memory is required? What is the threshold for a dementia diagnosis to be considered? Are the difficulties with self-care due to physical health problems, or perhaps due to low mood?

Diagnosis is a process of applying a category label to a person, placing a person in a box, in a sense. Consider, however, what we know about most dementia disorders. They involve the loss of, or damage to, neurones and to pathways connecting various aspects of the brain. This loss typically takes place gradually, over a period of time (some estimate that changes begin to occur as many as 10 years before symptoms become apparent). Thus, dementia is not an overnight process and there are likely to be gradations of change and impairment. The question then becomes, at what stage should

the judgement be made to apply a diagnosis of dementia?

The availability of numerous dementia screening tools, which provide a cut-off point for dementia, offer a misleading certainty to the assessment process. Scores on these tests are influenced by the person's educational level, their mood and their physical health. Used in a one-off assessment they do not provide any indication of change over time, which is the key determinant of evaluating the cognitive aspect of the diagnostic criteria. For example, a person with a high educational level may continue to score full marks on such a test, long after more detailed neuropsychological assessment has confirmed the presence of a dementia. Conversely, a person who has been below average intellectually throughout their life may score below the cut-off point on the test, despite having shown no cognitive change. Studies suggest that it is such people who are most likely to be misdiagnosed as having a dementia.

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When encountering a person who appears to have a cognitive impairment, a crucial question to ask is “when did this start?” If the answer is “yesterday” or “last week”, then a diagnosis of dementia is unlikely – it is much more probable that the person has, or has had, a physical health problem leading to some level of delirium (or ‘acute confusional state’). Information from someone who knows the person well can be valuable in helping to establish the time-course of the difficulties and is built into some assessment tools such as:

the GP COG Dementia test

Our discussion on the interactions and blurring of boundaries between medical, physical, cognitive and emotional health in Section 2 is also relevant here.

If there are so many pitfalls to diagnosis, why is there such a drive to achieve early diagnosis, with public awareness campaigns urging people to seek help at the first signs of memory loss? The benefits of early diagnosis

are said to include:

- Access to available treatments that may slow down the rate of deterioration. This is usually discussed in terms of medication, but can also include psychosocial interventions, including memory strategies and peer support groups.
- Opportunities to make plans for the future, including advance directives, powers of attorney etc. and to ensure all affairs are in order.
- An explanation for the person and their supporters of the problems that have been experienced.
- Opportunities to acquire information about the condition as well as services and benefits that may be available.
- The identification of other factors that may be reducing the person’s function and abilities, such as health problems, medication and mood.

The diagnostic assessment may, of course, result in the person not receiving a diagnosis

of dementia and there is value in detecting and potentially treating, an alternative cause for the person’s difficulties. Alternative causes can include depression, thyroid problems, vitamin deficiencies or, as is occasionally the case, a brain tumour.

In other instances, the diagnosis of a ‘Mild Cognitive Impairment’ (MCI) may be given. Essentially, this indicates to the person that objective tests of memory and/or other functions have confirmed the person’s perception that there is some impairment, but that the extent of the impairment and its effects on everyday life are judged as less than would be required for a dementia diagnosis. The message to the person is that they have an increased risk of developing a dementia (there are hugely varied statistics on the probable conversion rate of MCI to dementia but some suggest the figure is as high as 50% to develop a dementia within 5 years) and that perhaps they should be assessed regularly to monitor this possibility. (See more detail on MCI below in Section 3b). The benefits of diagnosis listed above

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may also apply. Although no medications are currently available, psychological and social interventions may be useful.

The risk of encouraging early diagnosis is that more and more people will be identified as having MCI, at a time when relatively few interventions are available and when there is little certainty regarding predicting which of those people with MCI will go on to develop a dementia. Many more may come forward for assessment where even the label of MCI cannot be said to apply. The difficulty is that we all do experience changes as we get older, but we have no benchmark against which to compare these changes. Whilst a 40 year old attributes a memory lapse to stress, a 70 year old is more likely to attribute a similar lapse to either the effects of ageing or to the memory disorders that he or she has seen in others or in the media. They might ask themselves: “How many times do I need to burn a saucepan dry before considering I have a problem? How many names of familiar people do I fail to recall when I meet them, before I wonder whether this really is

exactly what all people my age experience?” These attributions and the way we think about or seek to explain (to ourselves and/or others) what we are experiencing, influence whether we will seek help, or simply carry on and hope for the best.

As research continues to identify ‘biomarkers’ for Alzheimer’s and other dementias, the issue of how early should a diagnosis be made, will become even more complex. These biomarkers may take the form of a blood test or other physical investigation such as tapping spinal fluid through a lumbar puncture. Such biomarkers offer promise in identifying the disease condition long before any symptoms of dementia are present. This could however, create a scenario where a person could have a ‘diagnosis’ of Alzheimer’s Disease (the physical and biological changes) before they have a dementia (the outward manifestation of problems of cognition and self care). In the past we have been able to say that dementia is an umbrella term, including Alzheimer’s and other conditions described

below in section 3c, with all Alzheimer’s being a dementia, but not all dementia being Alzheimer’s. This new approach could lead to a separation of the two constructs.

Making a diagnosis of Alzheimer’s before any symptoms of dementia appear raises ethical issues if there is no treatment or intervention available that would make a difference to the person. The time for a diagnosis is the point where it makes a difference – even in the current situation this will differ from person to person. Not everyone will want information or will want to make plans – if they are coping with their difficulties, is diagnosis necessarily helpful? It may be preferable to talk of ‘timely’ rather than ‘early’ diagnosis, fitting the assessment to the expressed needs and preferences of the person and his/her supporters.

It is evident that recognising dementia is not always an easy matter and involves judgements about where to draw the line between ‘normal’ changes related to ‘ageing’ and those that can be attributed to

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the dementias. (We have seen previously that most cognitive changes are not due to 'ageing' as such, but to a variety of other processes, including changes in health and sensory abilities). This raises the question of when further assessment might be indicated. The following criteria might be suggested as good reasons to pursue further assessment:

- The person has difficulty with several of the following:
 - remembering recent events
 - knowing the names of familiar people
 - knowing the time
 - knowing where they are
 - following a conversation
 - carrying out basic everyday tasks such as dressing or making a cup of tea?
- The person is reporting changes in memory and other aspects of day to day life
- Someone who knows the person well reports changes in the person's memory and/or personality, affecting aspects of day to day life
- The problems have developed gradually

over a period of six months or more

- There is a family history of dementia
- The person is not currently experiencing severe depression or another mental health difficulty
- The person is not currently experiencing an acute physical illness

It is generally recommended that a diagnostic assessment for a dementia be conducted by a specialist service, such as a Memory Clinic or a Memory Assessment Service. Best practice in this area is described by the NICE-SCIE  [Guideline for dementia care \(2006\)](#) and SIGN Guideline 86 on the  [Management of patients with dementia \(2006\)](#). The assessment should incorporate the following components – their extent may vary from case to case, but each should be considered in each case:

- Pre-assessment counselling:
 - What does the person expect from the assessment?
 - What information do they want to be fed back to them?
 - Do they appreciate the potential

implications of an assessment e.g. in relation to driving?

- How do they wish any diagnosis that is made, to be shared with them?
- Who else do they want with them?
- The person's physical health, including consideration of medication use (prescribed and non-prescribed); and use of alcohol and other drugs. This usually involves a number of blood tests.
- The history of their current difficulties, their nature and extent, with information from the person and others who know the person well.
- The person's day to day function and fulfilment of their current roles.
- The person's memory and other cognitive function, typically using standardised, validated tests.
- The person's mood, including depression and anxiety.
- The effect of the difficulties on others close to the person.
- A brain scan (particularly to assist in the diagnosis of type of dementia).

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In some services, the assessment may be carried out in one or two visits to a clinic; other services visit the person at home, to gain a clearer picture of the effects on daily life. For someone whose dementia is already well-advanced before a diagnosis has been made, the process may be carried out within a few days by a specialist Nurse or Doctor. For someone where the difficulties are mild and the person has a high educational level, a number of other professionals may be involved, such as a Clinical Psychologist, Neuropsychologist or an Occupational Therapist; and the process may take a number of months and involve a repeat assessment to monitor whether change has occurred.

Good practice would indicate that a feedback session should be arranged according to the person's preferences and wishes, where the results of the assessment would be fed back and the diagnosis discussed, with written information provided to back up and elaborate on what was discussed. A follow-up appointment should be arranged after a brief

period to allow discussion of the person's reaction to the feedback and any issues arising from this for the person or for others involved. Information regarding relevant services and benefits and sources of support would also be provided at this juncture and any available interventions discussed.

The type of dementia can make some difference to the nature of the difficulties experienced and may influence the choice of intervention. It is accordingly considered good practice to seek to make a diagnosis of dementia type. However, it must be acknowledged that these distinctions can be difficult, even with the assistance of brain scans of various types. There is increasing evidence that in the oldest age groups (who form the majority of people with dementia), changes associated with both Alzheimer's Disease and Vascular Dementia are found at post-mortem in the brains of the majority of people who had a dementia during life. Mixed Alzheimer's and Vascular Dementia is accordingly the likely post-mortem diagnosis for most older people with dementia. This is

described later in this section.



Activity 3a:

Is the diagnosis of dementia always helpful?

The proposed benefits of early diagnosis have been listed above. Are there any potential negative aspects of an early diagnosis? Can you add to our list below?

1. Misdiagnosis will be more likely at an early stage and the person may be incorrectly labelled as having a dementia
- 2.
- 3.
- 4.
- 5.

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Other potential negative aspects that you might have considered are:

- Others may use the label of 'dementia' to 'explain' any problems that arise, rather than looking carefully for reasons.
- The person may find it more difficult to obtain insurance for travel etc.
- Decision making may be taken away from the person with dementia on the basis of the diagnosis.
- The person may be encouraged or forced to attend special 'dementia services' rather than continue with mainstream activities.

Compare the list of benefits with the list of negatives you have drawn up – do you agree the benefits outweigh the negatives? If not, what would need to happen to tip the balance?

Common types of Dementia

The prevalence of dementia rises with age. Less than 1% of people aged 60-64 develop dementia, while 24-30% of people aged 85 and over are affected. Reiterating the point made at the start of Section 2, this means that dementia is not a common part of ageing: 70% of people over 85 do not have it. That is, age does not cause dementia; it merely increases the risk of developing one of the dementing disorders. There are well over a hundred such disorders, from the universally known Alzheimer's Disease to forms few have heard of such as Binswanger's Disease – a rare form of Vascular Dementia.

Some of the uncertainties about diagnosis have already been raised in Section 3a, including the need to use a range of tests rather than a simple screening tool; to test over time rather than at one point (or at least get a history of decline); and the need to treat physical and mental health difficulties

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which can masquerade as dementia (see also material on blurring of diagnostic boundaries in Section 2). A further caveat is to acknowledge that we do not know as much about dementia as the proliferation of scientific and medical terms might suggest.

The reasons include:

- The continuing debate about whether classifications of different dementias actually represent distinct diseases. For example, patients with Lewy Body Dementia were, until relatively recently, thought to have Alzheimer's Disease. We can expect new discoveries which will change classifications further.
- The fact that the root cause of many dementias is unknown.
- Diagnosis is difficult in life and, even at post-mortem, brains often bear the pathologies of several different dementias. Further, only a small proportion of people who have had dementia have their brains analysed at post-mortem.

- The brains of a significant number of people who have been high functioning throughout life, with no clinical indications of dementia, have been found on autopsy to have pathological features consistent with well-developed dementia.
- Data like age of onset and survival rates are imprecise, because they are dependent upon when diagnosis takes place. This can vary widely, from the first inklings that something is wrong, to well into the disease.

Despite these caveats, we feel that it is useful to introduce you to the six most common types of dementia as currently understood, if only to reiterate the point that there are different types. The popular view that it is all about Alzheimer's Disease (AD) is simply incorrect. Besides AD we describe Vascular Dementia, Mixed Dementia, Lewy Body Dementia, Fronto-temporal Dementia and Alcohol-related Dementia. We also comment on Mild Cognitive Impairment and Young Onset Dementia – dementia that occurs earlier in life.

Alzheimer's Disease (AD)

Alzheimer's Disease (AD) belongs to a group of dementias characterised as degenerative neurological disorders. It is the most common dementia and occurs slightly more often in women. Problems in identification, including the fact that a definitive diagnosis can only be obtained at post-mortem (though this is likely to change soon), permit estimates only. However, AD is thought to be responsible for 50-70% of dementia cases either alone or in combination with other dementias (see Mixed Dementia below). The root cause remains unknown, though at autopsy the brain of a typical Alzheimer's patient shows the same damage reported by Alois Alzheimer in 1906: twisted fibres within the neurons called neurofibrillary tangles; and plaques - dead or dying accumulations of neurons containing a protein (beta-amyloid), which is normally useful to the body, but is toxic to brain cells. There is also a shortage of chemicals (neurotransmitters) which assist neurons to transmit information; the one most commonly studied in AD is acetylcholine.

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The genetic risk is low. That is, if it has been present in earlier generations, there is only a slightly increased risk that you will develop the disease. However there is a very small sub-set of cases called familial Alzheimer's Disease, where the risk of developing the disorder is very high. The familial form normally develops earlier in life – making it a Young Onset Dementia. The link between common Alzheimer's Disease and the familial form is unclear.

Though it can occur as early as 40, AD proper usually manifests itself in later life, with prevalence rising in people in their 70s and 80s. It is an insidious process and has always been present for some time before it is detected. The most common early symptom is memory impairment, with difficulty learning and recalling new information. Language impairment is also common early on, but is less obvious. Over time, the damage becomes global, with all cognitive and other psychological functions and bodily capacities eventually compromised until the person becomes

helpless, unless death from other causes intervenes first. (See Section 2 for more detailed descriptions of how dementia, regardless of type, can affect each psychological domain). Median time from diagnosis to death is about 8 years, though there is some debate about how accurate this is, because many people who die relatively quickly do not make it into the statistics. Conversely, some people can live much longer with the disease depending on other conditions – especially level of general health.

There is currently no cure for Alzheimer's Disease, though there are medications available which can lessen the memory deficits in some cases. Detailed discussion of their effectiveness is beyond the scope of this document, but similar effects can be obtained with some of the techniques described in Section 5. A major point which applies not only to Alzheimer's Disease, but to all dementias, is that it is important to avoid excess disability. Many people with dementia are more impaired than they need

be because of the way they are cared for, because of untreated conditions, or because of medications which have side effects worse than the problem the treatment is for. Addressing excess disability and generic approaches to good dementia care are discussed in more detail in Section 5.

Vascular Dementia (VaD)

Vascular Dementia (VaD) is the second most common dementing disorder. There are regional differences but in Europe, between 20 and 40% of people with dementia have VaD. It occurs slightly more often in men than women. VaD is caused by blockages in the blood supply and therefore the supply of oxygen to neurons. Loss of oxygen kills brain cells after only a few seconds, leaving damaged areas of tissue (infarcts). The best known popular example is major stroke, which causes impairment to the parts of the brain which have been deprived of oxygen. If there is no progressive decline thereafter it is not strictly dementia; many people improve after stroke but may retain discrete or focal areas of cognitive or physical impairment.

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In a quarter to one third of cases of stroke, lesser strokes continue to occur and there is the progressive decline characteristic of VaD. However, the most common forms of Vascular Dementia do not involve major stroke at all, but a series of mini-strokes (sometimes called silent strokes) which, over time, leave multiple infarcts through the brain. It used to be called Multi-Infarct Dementia for this reason, but it is now recognised that there are a number of processes which do not involve infarcts which can reduce or damage the blood supply within the brain. Early diagnostic criteria specified step-wise progression (mini-strokes sufficiently serious to produce observable steps in the patient's decline) but it is more often the same pattern of insidious gradual progression as seen in Alzheimer's Disease. VaD also often affects the same areas as AD, with memory and language problems apparent early, developing to global impairment over time.

Accordingly, AD and VaD are often indistinguishable except at post-mortem,

though there are some features which make VaD more likely. Note that they are not definitive because they do not occur in all cases and can be found in other dementias.

They are:

- stepwise progression – a minority of cases
- existing vascular disease or presence of strong risk factors for vascular disease
- emotional lability – a tendency to cry easily, become apathetic or irritated
- the presence of hallucinations – in a minority of cases and can occur in other dementias
- unsteadiness of gait and balance problems (this can occur in other dementias)
- frequent dizzy spells, or episodes where there is transient confusion, slurring of words etc.

Diagnostic problems are compounded by the fact that Alzheimer's Disease and Vascular Dementia often co-occur (see next item).

However, it is definitely worth investigating with a full medical work-up by a Geriatrician, Neurologist or Old Age Psychiatrist. Like Alzheimer's Disease it cannot be cured but, if VaD is suspected, it is possible to reduce risk for further vascular damage by medical and lifestyle changes. These can include the introduction of anti-hypertensive medication and improved diet and exercise. For this reason and because of increasing focus throughout life on lifestyle choices to reduce risk of vascular disease, the numbers of people diagnosed with VaD may not be increasing at the same rate as those with degenerative neurological disorders like AD.

Mixed Dementia

At autopsy, between 28% and 45% of patients prove to have had two and, very occasionally, more dementing disorders. Given that they have the highest prevalence, combined VaD and AD is what is usually meant by Mixed Dementia. There is serious debate over whether there may be a common underlying vascular pathology but, at present, they are regarded as the

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co-occurrence of different disorders. The presentation in life may combine elements of AD and VaD. Given the frequency of Mixed Dementia and the fact that vascular factors are implicated in all dementias, it remains good advice for patients to adopt lifestyle changes which reduce the risk of vascular disease.

Lewy-Body Dementia (LBD)

LBD is another of the degenerative neurological disorders and is thought to be responsible for 10-20% of cases of dementia. It occurs more frequently in men than women and was identified only relatively recently, after clinicians became alarmed at the large number of people with what was then thought to be AD, who became extremely ill or even died following prescription of antipsychotics / neuroleptics. Neuroleptic hypersensitivity remains part of the diagnostic criteria. In LBD, neurons are disrupted or destroyed by accumulations of protein (collectively called Lewy bodies after the person who discovered these). Lewy bodies are also heavily implicated

in Parkinson's Disease and there is some overlap between the conditions. A number of people with Parkinson's go on to develop dementia. Parkinson's-related Dementia may simply differ from LBD in that, in the former condition, the movement disorder arises first, whereas in the latter, it develops after the cognitive changes. Sometimes those with Parkinson's who later develop dementia are indeed classified as having LBD. LBD can sometimes appear more suddenly than AD and VaD, but the course thereafter is usually gradual. Mean time from diagnosis to death is about 6 years.

In the early stages, LBD can be mistaken for AD, although memory impairment is less often the first indication. Over time, symptoms more associated with Parkinson's Disease become more apparent. Though it tends to be under-diagnosed and many medical practitioners have never heard of it, LBD has a number of characteristic features.

These are:

- fluctuating consciousness, attention and alertness hour to hour – this can resemble delirium. (In AD and VaD consciousness tends to be more stable)
- visual hallucinations, often well-formed and detailed
- motor features of Parkinson's such as unsteady gait, frequent falls,
- clumsiness
- hypersensitivity to antipsychotics/ neuroleptics
- frequent fainting

Failure to diagnose LBD can have serious or even fatal consequences if the treating doctor thinks the hallucinations are evidence of psychosis and prescribes anti-psychotics. There is no cure for LBD and treatment is mainly restricted to ameliorating the symptoms, as with other dementias. Examples specific to LBD are physiotherapy or massage for Parkinsonian stiffness; and avoiding arguments with patients about what they are seeing, when they are experiencing hallucinations. Some drugs have been tried but results are inconclusive. Generic

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approaches to good dementia care are discussed later in Sections 4 and 5.

Fronto-temporal Dementia (FTD)

As its name implies, FTD is the term for illnesses which cause degeneration in the frontal lobes - chiefly responsible for executive functions, including planning, inhibition/social control and logical thought; and the temporal lobes - the areas of the brain with particular responsibility for language. A number of disorders are subsumed under it but the most prominent, because it is associated with behaviour change, is what has usually been described as Pick's Disease. It is now sometimes called Behavioural Variant FTD. It is relatively rare, but it is the second or third most common cause of Young Onset Dementia (onset between 40 and 65). Other FTD dementias are even rarer. The most consistently placed under the FTD banner are *primary progressive aphasia* and *semantic dementia*, both of which have profound effects on ability to produce or understand language. There is enormous variability in FTD, with some

patients declining rapidly, but median survival after diagnosis is roughly 6 years.

Because it does such damage to the executive functions, the primary symptoms of Behavioural Variant FTD are:

- inappropriate social behaviour, involving lack of tact, empathy or social warmth, making patients appear selfish.
- lack of insight into their own behaviour and that of others
- agitation and distractibility or, conversely, withdrawal and blunted emotions
- lack of inhibition, sometimes accompanied by increased overt interest in sex
- neglect of personal hygiene and inability to self-care
- repetitive or compulsive behaviour, such as tapping or gorging food (sometimes even consuming non-food items like detergent or boot polish)
- those affected may become mute or semi-mute in later stages

No cure is currently available for Fronto-

temporal Dementia and management is largely a matter of negotiating around symptoms – for example avoiding confrontation, keeping food out of sight and continuously helping carers and staff understand that the functions which normally control how we act are damaged and that the behaviour is not under the person's control. That is, it is not malevolence driving the behaviour. See Section 4 and 5 for generic approaches to dementia care.

Alcohol-related Dementia

This has been described as the silent dementia epidemic. A common consequence of long-term alcohol abuse is dementia and this is likely to increase as consumption of alcohol in the UK continues to climb. The exact causal factors are unclear and there is evidence that moderate consumption of alcohol is protective against dementia. Furthermore, development of dementia following long-term alcohol abuse is not inevitable and, when it occurs, it may include other causal factors such as poor nutrition, hypertension, or head injuries consequent

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upon a chaotic lifestyle. Diagnosis is difficult unless patients are hospitalised, as they must have been without alcohol for about two months before any accurate assessment can be made, something which rarely occurs.

Despite these difficulties, it is estimated that it comprises up to 10% of cases of dementia. The impact is probably greater, partly because heavy drinking over sustained periods increases the risk for all dementias; and also due to the fact that heavy drinkers have lower life expectancy and many therefore die before the age where the possibility of dementia crosses the minds of health professionals signing death certificates. The primary damage is to the frontal lobes, so the executive functions such as planning, inhibition and social appropriateness are compromised as well as memory. The more extreme manifestations of Behavioural Variant FTD rarely occur in Alcohol-related Dementia. A particular feature of Alcohol-related Dementia is that, after long abstinence, the disorder is not necessarily progressive and there may even

be some improvement.

Korsakoff's Syndrome

This disorder is mainly caused by a deficiency in thiamine but it occurs most commonly amongst heavy drinkers. It primarily affects memory for recent events, so the relationship with Alcohol-related Dementia is still the subject of debate. The memory deficit is not usually as severe as in the main dementias and treatment with thiamine can reduce symptoms.

Mild Cognitive Impairment

Between 3 and 19% of people over the age of 65 have subtle but measurable cognitive deficits which have limited or no impact on their ability to function. There have been many labels in the past but this is now generally known as Mild Cognitive Impairment (MCI). It is not necessarily a staging post on the way to dementia because roughly half these people do not go on to develop dementia. Some even improve. Conversely, just over half have developed dementia within five years, at a rate of

between 16-18% per year. That is, given a hundred people with MCI, 16 to 18 will be diagnosed with dementia after a year. For these individuals, MCI can be seen as the very early stages of dementia, or at least as a risk factor for dementia. As yet there are no clear indicators predicting who will progress from MCI to dementia. The importance of detection of MCI is that it can focus the mind on early intervention, in particular, reducing risk factors for vascular disease through medication (e.g. antihypertensive drugs if required) and lifestyle changes such as improved diet, increased exercise or reducing recreational consumption of toxins like tobacco or alcohol. This is good practice whether or not the individual would have gone on to develop dementia.

A note on Young Onset Dementia

As already noted, dementia is relatively uncommon in the 60-65 year age group but there are still a substantial number of cases. There is also a significant minority who develop dementia even earlier, in their fifties and sometimes their forties. Formerly, these

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individuals might have been described as having a 'pre-senile' dementia. Consistent with its status as the most prevalent, Alzheimer's Disease is the commonest cause of dementia in younger people, but accounts for only about a third, compared with half to two thirds of dementias later in life. The other common causes are VaD, LBD, FTD and Alcohol-related Dementia.

It is important for health and social care professionals to be aware of Young Onset Dementia because it presents unique challenges, including its detection. Faced with a healthy person in their fifties, few doctors think of dementia and diagnosis can take several years. Misdiagnosis and treatment as a mental health disorder (especially depression or psychosis), or as the result of stress, is particularly common. Secondly, most Young Onset Dementia sufferers are still at work and still bringing up a family, creating multiple, severe financial and social problems. For example, the patient may lose his/her job because of 'incompetence', severely affecting both

self-esteem and cash flow. Those under 65 are often not eligible for the same financial help as older people, or even support from specialist dementia services, because many services have traditionally had a cut-off of 65 years. Even the services provided can be uncongenial to a younger person, or not meet their needs, because they may be mixing in groups with people 40 years older. There are an increasing number of specialist services for younger people with dementia but there is not yet sufficient provision to meet demand.



Reflection

- Consider people with dementia you have known / come into contact with. Do you know what type of dementia they had?
- What difference does knowing the type of dementia make to how you work with him/her?
- Having read the descriptions of different types of dementia, can you think of people who may have had Lewy Body Dementia or Fronto-temporal Dementia, even if they did not have that diagnosis?

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Activity 3b:

Different types of dementia

What are the difficulties associated with working with people with Alcohol-related dementia?

Think about people with Young Onset Dementia; if you work in a service mainly for older people, what do you think it would be like to be a younger person using that service?

Summary

In this section we hope to have introduced you to some of the tricky clinical, practical and moral issues connected with assessment and helped you realise that, despite a plethora of scientific terms that make it sound as though medicine is on top of dementia, there is still a lot of imprecision in diagnosis. This is partly because dementia science develops slowly and incrementally, but also because of the multiple factors which often combine to make this process very complex, a fact re-iterated throughout this module. There remains a popular view that, armed with a Mini-Mental Status Exam, it is possible for anybody to diagnose dementia. This is not the case.

Section 4

Communication - people with dementia and caregivers

Non-verbal communication
A focus for communication
Feelings
Watching the way we speak
Three-way communication
Distressed behaviour

Section 4

Communication - people with dementia and caregivers

Learning Objectives

By the end of this section you will be able to:

1. Understand and apply effective communication strategies and techniques to engage sensitively and empathically in building a rapport with the person with dementia.
2. Explore strategies to improve the quality of communication.
3. Learn ways to engage and respond to complex communication situations.
4. Apply a range of communication techniques to alleviate stress and distress.

Communication

In this section, we focus on communication with people with dementia and caregivers. Usually, we don't necessarily give much thought to how we communicate - it's an automatic process to chat with friends or family, or to interact with staff in shops or bars. We adapt our communication without thinking, to explain or to get across what we want to say, but this is a two-way process, with others adapting to how we communicate. In dementia, we need to reflect on how best to achieve effective communication. We will look at the role of non-verbal communication; of communication of emotions; of the importance of communicating respectfully; and of involving families. Finally, we will consider how communication difficulties may contribute to distressed behaviour.

A model of communication

Good communication is at the heart of person-centred care and forms the basis of all good relationships. We all spend much of our time communicating and perhaps we consider ourselves as fairly skilled in this respect, interacting easily with friends and family. It is with people with dementia that the gaps in our capabilities can become evident, as we struggle to establish lines of common understanding and we find our messages become distorted and misinterpreted.

The golden rule of good communication is, of course, that it is a two-way process. It involves listening just as much as it involves talking. Even when (especially when) we have a message to convey, we need to be listening to the person with dementia, checking out whether they are receiving the message, whether they are understanding it and how they are reacting to it.

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Please remember that:

- First you need to make contact with the other person. This may be achieved by making eye contact, or by a touch on the person's hand. There is nothing to be gained by transmitting a message unless the other person is receiving the signal.
- There needs to be clear turn taking. Talking across each other will not result in clear communication. When you talk you need to speak clearly, pronouncing your words distinctly – not mumbling or speaking at such a speed that your speech sounds garbled.
- The person receiving the information needs to listen carefully to the other person. Tuning into what the person with dementia is saying can sometimes be difficult. You might find yourself thinking, 'Who are they talking about? What do the fragments of sentences mean?' The better we know the person, their interests and life story, the more likely we are to be able to 'tune in' and make sense of the person's attempts to communicate.

Listening is an active, effortful process – requiring our full, focused attention – not a half-hearted nod and a smile whilst we have half an eye on something else happening across the room.

It makes sense of course to ensure that any barriers to communication are addressed as a priority. These may include:

- visual difficulties – does the person have the correct spectacles, if needed? Are they clean?
- hearing difficulties – does the person have a hearing aid? Are the batteries working? Does the person have a problem with ear wax?
- speech difficulties – does the person have dental problems?
- noisy environment – can background noises be reduced to make communication easier? Is there sufficient light so that you can see each other well? Can the person see your mouth clearly – they may lip read.
- if the person is sitting, come down to

their level to talk with them, rather than looming over them. If necessary, re-arrange the furniture to make this easier – it can be difficult to crouch down for an extended period!

Top communication tips can be found at:

 [Dementia Skilled Resource - Module 2](#)

In dementia it is often the case that patients do not have very specific language difficulties, but rather a mixture of different forms of language and communication difficulties. In this resource we will not focus too much on language difficulties, but as they can have a profound affect on a person's functioning and emotional wellbeing it is important that a speech and language therapist is involved in providing advice on maximising communication abilities.

Language functions support social communication. Receptive language skills are concerned with understanding written or spoken language. Expressive language skills

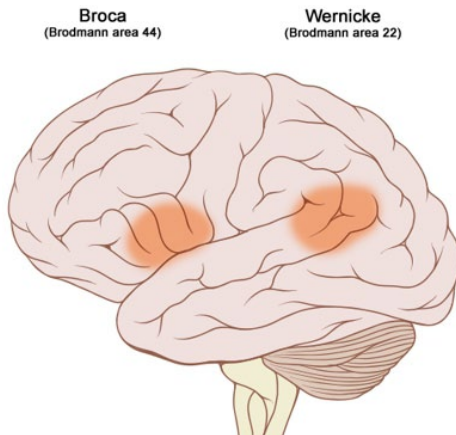
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are concerned with the expression of written or spoken language. Many areas of the brain are involved in language. Two key areas are:

- Broca's area which is critical for speech output.
- Wernicke's area which is critical to understanding language

There are various forms of language impairment. The classic distinction is between Broca's aphasia and Wernicke's aphasia:



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- Broca's aphasia: The main difficulty is with the expression of language. Spoken output is not fluent, often short sentences/words without normal grammar. Comprehension of language is better.
- Wernicke's aphasia: The main difficulty is with comprehension of language. Speech may be fluent, but does not make sense, and person may use wrong sounds.

Cognitive communication skills are the abilities, in addition to specific language skills, which we use to engage in effective social communication. This includes non-verbal communication; the ability to understand humour and sarcasm; to recognise the emotional content of language; and knowledge of conversational rules (e.g. turn-taking).

Given that individuals with dementia will each have a slightly different set of cognitive strengths and weaknesses, across a variety of domains, it is important therefore to

request a thorough assessment in order to develop communication strategies that are appropriate for that individual. Below are some examples of the ways in which language impairments can affect communication:

- Some people may have difficulty in comprehension of language and as such, their speech appears to be fluent but their responses make little sense to the person listening, since the individual has not understood what has been said to them initially.
- Another example is where the person has non fluent language and poor grammar but the content is meaningful, indicating an expressive language difficulty. When we listen carefully, we can often piece together a rough understanding of the key points the individual is attempting to convey.
- Other individuals may have difficulty in their ability to understand words because their knowledge of the meaning of words has been lost. In this example, telling

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the person to remember to heat up their soup on the hob may be meaningless because they no longer know what a 'hob' is.

It is important in these and similar situations to seek assessments from speech & language specialists, to aid in understanding the nature of, and responding appropriately to, communication difficulties.

Non-verbal communication

Luckily, we do not usually have to rely only on the spoken word for our communication. Non-verbal communication or body language provides an immensely useful means of enhancing communication with the person with dementia. Even when we are having difficulty in making sense of the words being spoken, we may observe the person's posture, facial expression, eye movements, hand movements and listen to their tone of voice and intonation. We must remember that non-verbal communication is also a two-way street and recognise that the signals we give to the person with dementia may be just

as powerful as our words.

Consider a situation where you approach a person with dementia with a view to carrying out some physical care task with them. Suppose you heard some bad news this morning and this is on your mind when you come into work and begin to approach a person with dementia. You may not be aware of it but your expression may be reflecting your thoughts and you may be frowning, sighing, rushing toward the person. The person with dementia is not a mind reader – they may see your face and conclude that your intent is potentially unpleasant, if not malicious. As you approach, they strike out to protect themselves from the threat they perceive from you. If you had approached with a warm smile on your face, your reception might have been different....

The better we know the person with dementia, the better we are able to find effective ways of interacting with them. Some people find a gentle touch on the hand comforting – others find it a threat and

withdraw. Some people like a hug – others prefer a more formal handshake. Some prefer the formal form of address, such as Mr or Mrs, while others are happy to be called by their first name (which is sometimes different from their 'official' name). The key is to tailor our interactions to their preferences.

A focus for communication

The memory problems experienced by a person with dementia mean that communication is often more effective when there is a tangible focus for the conversation – an object, a picture or photograph, some food or drink, some music or even the smell of cooking. This helps ensure that both parties in the conversation are discussing the same topic and maintains attention and focus.

For example, if you have a recent photograph to hand of the person's daughter, this will assist as you discuss her visit earlier that day. In some dementia care settings, staff wear a belt with a number of pockets on it, each containing potential conversation

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triggers – a picture, a small object, a piece of fruit, a ball, a harmonica etc. In other settings, there is lots of ‘clutter’ – objects to interact with, to engage interest, to raise a smile. There could be a collection of interesting objects designed to provide a focus for communication such as hats and scarves, a football rattle, a sewing machine, some soft toys, some old style dresses, or some musical instruments. Similarly, keeping a photo wallet or the person’s life story book easily to hand, will also serve as a tangible focus to enable interaction to flow.

Feelings

We have talked about the need to actively listen. One of the most important aspects of listening is to listen to the person’s feelings as well as to their words. If you are to respond appropriately to the person, hearing the emotional message behind the words is, in effect, more important than the words themselves. For example, the person is telling you that their mother is coming soon – but what are they really communicating? If you simply see this as evidence of confusion

(assuming the person is of an age where you can be fairly certain their mother is not actually planning to visit), you are missing the communication of an emotion. The emotion may be one of insecurity, or of desiring the presence of a parent figure who embodies safety and security. The need for attachment is a powerful driver for behaviour that demonstrates seeking safety and security (see section 2).

Other feelings may be expressed of course, from pleasure to disgust, from satisfaction to frustration, from sadness and loss to anger and rage. Good listening hears these feelings behind the words – the words may, or may not, fit with the underlying feelings, but unless we acknowledge these feelings, we will not have real communication and contact with the person with dementia. Sitting with the person, acknowledging their sadness, fear, anger or any other feelings and offering support so that the person feels heard, provides validation for the emotions. The actual words used, cease to be important. Whether the person’s mother is alive right

now is irrelevant, the feeling remains true; the sense of wanting to be ‘at home’ is none the less real and relevant, simply because they are already at the place where they live; the sense of wanting to be free and not hemmed in, can remain strong even though the person is having difficulty walking a few yards.

Validating a person’s feelings

Sometimes people feel the need to ‘put the person right’ or correct the person’s apparently ‘confused’ view of the world. Confrontation and correction is rarely helpful. Sometimes people are able, with guidance, to check out the facts for themselves, from a calendar, diary or their life story book, perhaps. Often however, what defuses the potential for confrontation is to hear the feeling expressed behind the words and simply respond to that – there is no need to lie, because feelings are beyond the realm of fact and correction.

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Activity 4a: *Validating responses*

Remember a validating response has not to be correctional but addresses the valid emotions behind what the person is saying. For each of the interactions described briefly below, try to supply a validating response:

Person with dementia	Correction	Validation
My mother is coming.	Your mother? You're 85, so she'd be over 100. Didn't she die years ago?	Your mother? It sounds like you must be missing her. I think I saw a picture of her in your room - let's go and see if we can find it.
Let me out, I'm going home (resident in a care home).	This is your home! You've lived here for 3 years.	
Where are the children? I need to get them from school.	Your children are all grown up now – don't you remember, Bill came yesterday.	
June, why aren't you at home?	I'm not June, she's your daughter; I'm Rose one of your carers.	
Get off me, I don't need to go to the toilet (has been incontinent of urine).	You are soaking wet, you should have asked to go to the toilet. I'll have to change you now.	

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How difficult did you find it to come up with a validating response? Can you think of times recently when you've corrected someone and it might have been better to respond to the feeling rather than the facts?

Watching the way we speak

In communicating with people with dementia, it is possible to slip into a patronising form of language that treats the person as a child, rather than an adult. It is characterised by higher pitch and volume and by the use of terms of endearment and inappropriate collective pronouns. Examples include, "Have some juice for me, my darling"; "Ivy, please don't hit Florence, that's very naughty". "Come on lovely, it's time for our medication". If talking down to children is probably not a good idea, then talking down to people with dementia is disastrous at every level. Even if the person appears to understand little of what you are saying, your tone of voice will trigger a reaction at an emotional level and there is evidence that the person is likely to be more resistive to care. Being aware of our own and others' tone of communication is of real importance.



Three-way communication

A further area where communication often goes awry is when the person with dementia is accompanied by a relative. We need to be careful to ensure that we do not simply direct questions to the relative, leaving the person with dementia with the sense that they are being left out of the discussion or being talked about.

Relatives and other caregivers have their own needs and perspectives and it is often useful to offer time alone with them, so that they can speak freely regarding whatever is on their mind and can discuss issues they may feel uncomfortable discussing with the person with dementia present.

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The same opportunity should, of course, be afforded to the person with dementia. The aim should be to, wherever possible, find ways of then discussing difficult issues openly together – having already shared them in private, it can sometimes be possible for the staff member to act as mediator ensuring all parties have a voice and are heard by the others involved.

Distressed behaviour

As already discussed in Section 2c, it is helpful to consider many examples of distressed behaviour as difficulties in communication. Sometimes the difficulty lies with what we are communicating to the person with dementia, as in the example above where our non-verbal communication inadvertently gives the wrong message to the person with dementia – in the example, a message of threat rather than of willingness to help. Or our tone may come across as too controlling or ‘bossy’ and lead to understandable resistance from a person with dementia who values independence and autonomy.

Sometimes the difficulty lies in our failure to hear or understand what the person with dementia is communicating to us through their behaviour. Take the person with dementia who is screaming out repeatedly - is this simply an expression of their advanced dementia, or is it possible they are communicating pain and discomfort? Or the person who is restless and agitated - could it be that they are looking for a toilet? We have previously described needs for safety and security, needs for affection, privacy, comfort, or refreshment - all may find expression through behaviour that becomes labelled as ‘challenging’. It is challenging, of course; it throws down a challenge to us to ‘listen’ more carefully, to identify and respond to the unmet need that is being expressed. This is why it is so important to assess carefully (to really ‘listen’) before considering any ‘interventions’.

In sections 5 and 6 we describe how to approach distressed behaviour. However, it is worth reiterating here that our own communication style, both with the person

with dementia and our colleagues, can feed into any difficulties experienced, both by the person with dementia and their supporters. We need to reflect on the extent to which it is our reaction, or the reaction of others, that is the difficulty. Good communication between staff members and others involved, to ensure we provide a consistent approach, is essential. Insights gained by one member of staff need to be shared with others and the person with dementia provided with a social environment which responds predictably and consistently in a respectful, person-centred manner.

Where staff develop good communication skills with people with dementia, where they listen attentively and respond to the feelings behind the words, then much distressed behaviour can be prevented, eliminating much unnecessary distress and difficulty for all concerned. On the other hand, where communication is patronising, controlling or confrontational then there is likely to be more distressed behaviour, as people with dementia respond in a perfectly normal and

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understandable human manner to situations that are perceived as a threat to them and their wellbeing.



Activity 4b: *Communication*

You may need to develop the skills described in this section. Conversing with people with dementia in a respectful and empathic way rarely comes naturally. Many staff are able to do this during care tasks, however it is important to be aware of times when people inadvertently slip into unhelpful styles of interaction. These can include: using directive language, or overlooking the person with dementia by talking to other colleagues during personal care, rather than to the person with dementia they are working with. There is abundant evidence that, in particular in wards and care homes, people with dementia have severely limited social contact (see also Section 2b on lifestyle) and that communication during personal care is a very important opportunity for positive social interaction.

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Sometimes staff talk to each other or concentrate on tasks rather than the person because they need support to learn how to converse with people who have dementia. You may want to look at specific resources on communication, but in the meantime try an activity similar to the Life Experience exercise in Section 2.

A) Observe how people you work with talk to people with dementia or be with them (i.e. not necessarily involving speech). Look at those who have a good relationship with the person and show respect regardless of the level of dementia. What do they do? For example is it a matter of pace, gentle approach, using touch where appropriate? What do they say? Do you think you could learn from them? If so, ask them how they do it. You will probably find that it is a matter of skills, knowing the person well and attitude – that they do respect the person.

B) Observe other people you work with who do not have good relationships. Why do you think this is? Are they using patronizing language? Do they just want to get the job done? Are they frightened of people with dementia,

or contemptuous of them? Do they not understand dementia? They may need support rather than censure but, in any case, we are not suggesting you say anything or report them, unless there is clear evidence of elder abuse. This exercise is to increase your skills, not theirs. Consider the following questions: What effect does the way they communicate have on the person with dementia? What might you feel or do if they communicated with you in this way, whether or not you had dementia?

C) If you work in a ward or care home, think about your clients who have moderate to severe dementia. Can you calculate how many minutes a day each one has in any social interaction other than in personal care? You may be surprised. Many studies have shown that it may be less than two minutes in total and, if they also have distressed behaviour, many of those interactions may be negative. If you find that one or more residents are in this position, what could you do about it?

D) If you think you need to improve your skills in talking socially with or just being with people

who have dementia, start to practice now. You may experience some false and sometimes embarrassing starts because, as noted in Section 2a, many of us start conversations with questions about facts – an often unhelpful approach for people with dementia. You may find that being involved in an activity such as a walk in a pleasant place (where there is something about which you and the person with dementia can exchange experiences) helps break the ice. It can have a powerful effect on perceptions.

One observed example of good practice is where new management in a care home holds the sensible view that ‘activity’ means everything the person does throughout the day and not just something that the diversional therapist arranges. Staff have therefore been encouraged to spend much more social time with residents and some have admitted that they have already discovered things (including residual intact capabilities) that they never knew about, even though they had been caring for these residents for years.

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Activity 4c:

Self assessment quick quiz

Check whether you have understood the main points so far. Answer true or false to the following questions:

1. Everyone with dementia will appreciate a touch on the hand to let them know you are there for them.
2. It is often best to validate the person's feelings and meaning of their words, rather than trying to repeatedly correct them.
3. It is always best to correct the person when they make mistakes.
4. If someone has a language impairment they will be unable to understand what words mean and unable to express themselves clearly.

Summary

In this section, we have highlighted the critical role communication skills play at all levels in empathic and person-centred care, because the ability to communicate verbally is severely affected in dementia. Thus, when trying to understand what someone with dementia is communicating to you, you need to be listening with all your senses and feelings – sometimes 'listening to the music and not the words', because the face value of the words may bear no relation to what the person is trying to communicate. Similarly, when you are trying to communicate something to a person with dementia, you may have to develop a multitude of skills to ensure that your interactions are respectful and empathic. The way you communicate is likely to have a major effect on your relationship with the people under your care and has the potential to reduce or prevent distressed behaviour or, conversely, to trigger it.

Section 5

Evidence-based psychological interventions in dementia care

Cognitive Stimulation Therapy (CST)

Reminiscence approaches - group and individual including life story work

Cognitive rehabilitation

CBT for anxiety and depression

Multi-sensory stimulation

Section 5

Evidence-based psychological interventions in dementia care

Learning objectives

By the end of this section you will be able to:

1. Become familiar with evidence-based psychological interventions that can have a positive impact on the wellbeing of the person with dementia.
2. Understand what is involved to deliver the following evidence-based interventions.
3. Learn who the interventions are appropriate for and when.

Evidence-based Psychological Interventions

In recent years a range of psychological interventions for people with dementia and their carers have been developed and evaluated. Here we provide a brief introduction to a number of these psychological interventions.

As a general guide it is important to remember that activities must be meaningful to the individual you are working with. A helpful starting point can be to talk to the person with dementia and their relative or close friend, to establish their interests and hobbies past and present. This might also give you an insight into their personality - are they more of an introvert or an extrovert? Do they enjoy socialising and social group activities? Do they enjoy quiet, solitary activities such as reading or listening to music? If they used to get a sense of achievement from gardening, trying to select elements of this that are practical and achievable given their current abilities, is a way of re-introducing this pleasurable activity back into their lives. This might

mean adapting the activity by, for instance, assisting them to plant up a small flowerpot which can be kept in their room. You may need to prompt or assist them, if necessary, to feed and water the plant regularly and remove any dead leaves or blooms. As you see from this example, creating opportunities for people to engage in meaningful activity does not have to involve special events such as getting in 'entertainment' like a singer or dance act. This might be one person's idea of great fun, but for another it might be less than enjoyable or they might prefer other ways of occupying their time, with more everyday activities. Although identifying past and present hobbies can be a great starting point for developing activities for people with dementia, this does not mean that the person should not engage in any new activities at all. Instead, careful consideration is necessary to gauge whether any proposed new activity is pleasurable and stimulating for that person.

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Cognitive Stimulation Therapy (CST)

CST is currently recommended by SIGN 86 and NICE (2006) guidelines for the management of dementia as an evidence-based intervention. Clare et al (2004) defines cognitive stimulation as engagement in a range of activities and discussions (usually in a group) aimed at general enhancement of cognitive and social functioning. A formal manualised package of CST exists which was developed and researched by Spector and colleagues (2003). Typically, CST consists of small group sessions, for 4 or 5 people with dementia with one or two staff facilitating the group. Group sessions last for 45 minutes to 1 hour and are usually held twice a week, but can take place less or more frequently than this, depending on resources. Each session starts with a warm-up exercise, some orientating discussion and a group song. A different main topic is used in each session, geared to the abilities and interests of group members. Manuals such as 'Making a Difference' are available setting out session plans (see <http://www.cstdementia.com> for

more information). Typical sessions include word games, discussion of themes such as childhood, activities involving the use of our senses and so on. Each session concludes with refreshments and a recap of the content of the session and discussion of the next group session, to help group members look forward to next time. The manual includes 14 session plans which are usually delivered over a seven week period and covers:

Session 1	Physical Games
Session 2	Sound
Session 3	My Life
Session 4	Food
Session 5	Current Affairs
Session 6	Faces/ scenes
Session 7	Associated words, discussion
Session 8	Being creative
Session 9	Categorising Objects
Session 10	Orientation
Session 11	Using money
Session 12	Number game
Session 13	Word game
Session 14	Team games, quiz

The manual outlines the considerations you need to take account of when setting up and delivering a CST group.

A key feature of CST groups is that there are always tangible triggers to guide discussion. The aim is to not to test the memory of group members, but to draw out implicit memories by seeking their opinions and views. CST continually encourages new ideas, thoughts and associations, rather than just recall of previously learned information. The activities make use of positive aspects of reality orientation, whilst ensuring it is implemented in a sensitive and respectful manner. The activities are also designed to use generalised cognitive ability, rather than attempt to improve or rehabilitate one aspect of cognition.

CST is primarily aimed at people with mild to moderate dementia, who retain some ability to communicate verbally. People with severe, uncorrected impairments of hearing and vision may find a group context difficult, as will people with dementia whose distress

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is so great that they are unable to sit with others for more than a few minutes. CST can be delivered by staff or volunteers who have appropriate attitudes and who follow the guidelines in the manual. No professional qualification is required, but NHS Education for Scotland has offered a series of training workshops to equip appropriate health and social care staff with the skills to develop and deliver CST groups in their work role. It may be useful to enquire regarding the possibility of more of this training being made available in the future, or to liaise with colleagues to see if you can develop these skills yourself by facilitating these groups alongside colleagues.

CST can reduce excess disability, by tapping into the strengths of the person with dementia, in a relaxing social environment. There is some suggestion that people's verbal skills improve, with the opportunity to converse and talk with others, which may be a contrast to their experiences outside the group.



Randomised Controlled Trials have identified that CST leads to improvements in cognitive function of a similar magnitude to those achieved with the current dementia medications that are available. In those taking the medication, these effects are additional to those of the medication. Improvements in self-reported quality of life and in social communication have also been reported.

A recent Cochrane review (Woods et al., 2012) systematically reviewed the available evidence regarding cognitive stimulation, to identify its effectiveness. The review included 15 research trials with a total of 718 participants. The findings suggested that cognitive stimulation has a beneficial effect on the memory and cognitive test scores of people with dementia. Although based on a smaller number of studies, there was also

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evidence that the people with dementia who took part, reported improved quality of life. They were reported to communicate and interact more effectively than previously. No evidence was found of improvements in the mood of participants, their ability to care for themselves or function independently, and there was no reduction in behaviour experienced as difficult by staff or carers. Family carers, including those who were trained to deliver the intervention, did not report increased levels of strain or burden. A 'maintenance' CST manual has also been developed, entitled 'Making a Difference 2' which includes 24 sessions of CST, delivered on a weekly basis, as well as additional material from the original CST manual and sessions that include 'useful tips', 'thinking cards', 'art discussion', 'visual clips' and 'household treasures'.



Remember Point

Cognitive stimulation is intended to be an enjoyable social experience, not a test of individuals' memory or ability. Individual CST interventions are being trialled and in a few areas, family members are being trained to carry out sessions with people with dementia living at home.

Sources for more information:

- Manuals available from Hawker Publications. Training DVD included. For more information click on this link to the CST web-site:

 <http://www.cstdementia.com/>

Reminiscence approaches - group and individual, including life story work

A wide range of reminiscence based approaches are in use in dementia care. All have in common, a focus on bringing to mind memories of events from throughout a person's life.

- Reminiscence groups – typically involve 5 or 6 people with dementia and 1 or 2 facilitators. Each session may have a particular focus, often working through the life span chronologically e.g. childhood, schooldays, teenage years, first job, families, holidays etc. A number of memory triggers will be available – pictures, objects, music and film clips etc. – relevant to the topic. The aim is for group members to share stories, to enjoy telling and listening, to be prompted by other people's memories. In a group context, the focus will not be on any one person's life story, although personal memories related to shared experiences will be encouraged.

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- Individual reminiscence work is carried out on a one to one basis and will again involve the use of memory triggers, although these are likely to be more personal and specific to the individual. Typically, sessions will be chronological. Usually a tangible output from the sessions is produced. This may be a life story book, a memory box or a digital life story book (e.g. a presentation on a DVD with pictures, music and commentary). Life review therapy takes a similar form, but emphasises the person evaluating their memories, rather than producing a factual account. This process of evaluation incorporates the range of emotional reactions to life experiences.
- 'Remembering Yesterday, Caring Today' (RYCT) groups involve family members, as well as people with dementia, in a large group experience. This can involve as many as 12 people with dementia and 12 carers, along with 2 facilitators and 6 volunteers. A manual is available for this approach (see sources for more information). The sessions cover the



typical themes across the lifespan, but there is an emphasis on enacting memories and sharing in small groups, in addition to the activities typically found in group reminiscence.

Reminiscence work targets people with mild to moderate dementia and, in RYCT groups, family carers. No professional qualification is needed to work on a life story book with a person with dementia or to lead a small reminiscence group. Supervision is recommended for those undertaking life review therapy. Supervision refers to

the opportunity to discuss and reflect on the work undertaken, with an experienced practitioner. RYCT groups have been led by a range of professionals including: Nurses, Social Workers, Occupational Therapists and Clinical Psychologists; and by those from a creative arts background.

Reminiscence and life review therapy are thought to stimulate the person's autobiographical memory – memory for their life experiences – and in so doing, may assist maintenance of identity, self esteem and wellbeing. In group contexts, social interaction is likely to be beneficial and is assisted by the reminiscence themes. In RYCT, it is hoped that the relationship with the carer may be enhanced by the shared activity and memory. Life story books, memory boxes or digital life story books may assist communication and conversation with staff and family members, as well as acting as a prompt for autobiographical memory. Again, this can reduce excess disability. Some positive results have been reported for reminiscence groups in relation to

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improvements in cognition and mood.

Sources for more information

- Available from Jessica Kingsley Publishers:

 [Remembering Yesterday, Caring Today: Reminiscence in Dementia Care: A Guide to Good Practice](#)

Cognitive rehabilitation

One popular definition of rehabilitation is: “Any intervention, strategy or technique which intends to enable clients or patients and their families, to live with, manage, bypass, reduce or come to terms with deficits precipitated by injury to the brain” (Wilson, 1997). When we view it in this way it can make sense for us to talk about cognitive rehabilitation in the context of dementia. Cognitive rehabilitation usually involves assisting the person to achieve individualised goals according to their strengths and difficulties.

Please see our forthcoming resource - Cognitive Rehabilitation in Dementia: A resource for staff - for further information on the theory and practical application of techniques.

Cognitive rehabilitation is an individualised approach, in which the therapist works with the person with dementia on goals set by the person with dementia (with input from family where appropriate). Cognitive rehabilitation may include a wide variety of techniques, depending on the goals and the person’s profile of abilities. Memory strategies are often used e.g. learning to use a diary or a memory aid. If anxiety or lack of confidence is a barrier to achieving the goal, this will also be addressed e.g. through a graded approach which gradually builds confidence in certain feared situations or through anxiety management techniques. Where possible, minimal demands are made on the person’s memory and learning ability. Where new learning is required, the following strategies may be used:

- Spaced retrieval - a learning method simple in theory, but sometimes difficult in practice. The person is taught one item at a time. The interval between presentation of the item and the person being asked to recall it is gradually increased (e.g. 15 seconds; 30 seconds; 1 minute; 2 minutes etc.). If the person is unable to recall at a certain interval, the interval is reduced on the next trial and then built up again. If the item can be held in memory for 10 -15 minutes, it often becomes well-established.
- Errorless learning – here the aim is to guide the person to always achieve the correct response during the learning process, so that incorrect answers do not interfere. This can be achieved by prompting e.g. with the first few letters of the word to be remembered, or with some other agreed cue. This is often incorporated in spaced retrieval, so that before the retention interval is reduced, prompting will be used to help the person retrieve the correct response.

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It is important to stress that selecting the appropriate goal is paramount – if the person has difficulty remembering what day it is, there is no point spending hours teaching him/her ‘Today is Tuesday’, whereas teaching the person how to use their calendar to find out the information they want could be a better investment of effort.

Who is it for? People with mild dementia.

Therapists are usually occupational therapists or clinical psychologists, but the approach could be used by other professionals who are appropriately trained. Supervision from an experienced practitioner is desirable.

How does it work? Mainly through reduction of excess disability, but uses the person’s residual abilities as effectively as possible.

What are its effects? Studies suggest that people with mild dementia are able to achieve their goals using this approach. Spaced retrieval has been used to help people with distressed behaviour to find

information they require to reduce distress in themselves or others e.g. to find information for themselves rather than ask repeated questions.

Sources for more information

- NES Cognitive Rehabilitation in Dementia Resources

CBT for anxiety and depression

Cognitive behavioural therapy (CBT) is widely used with adults who are anxious or depressed. CBT focuses on the links between thinking (especially negative thoughts), mood and behaviour.

Let us consider the case of Ellen who many of you will have met in:

- [the Dementia Skilled - Improving Practice Resource](#)

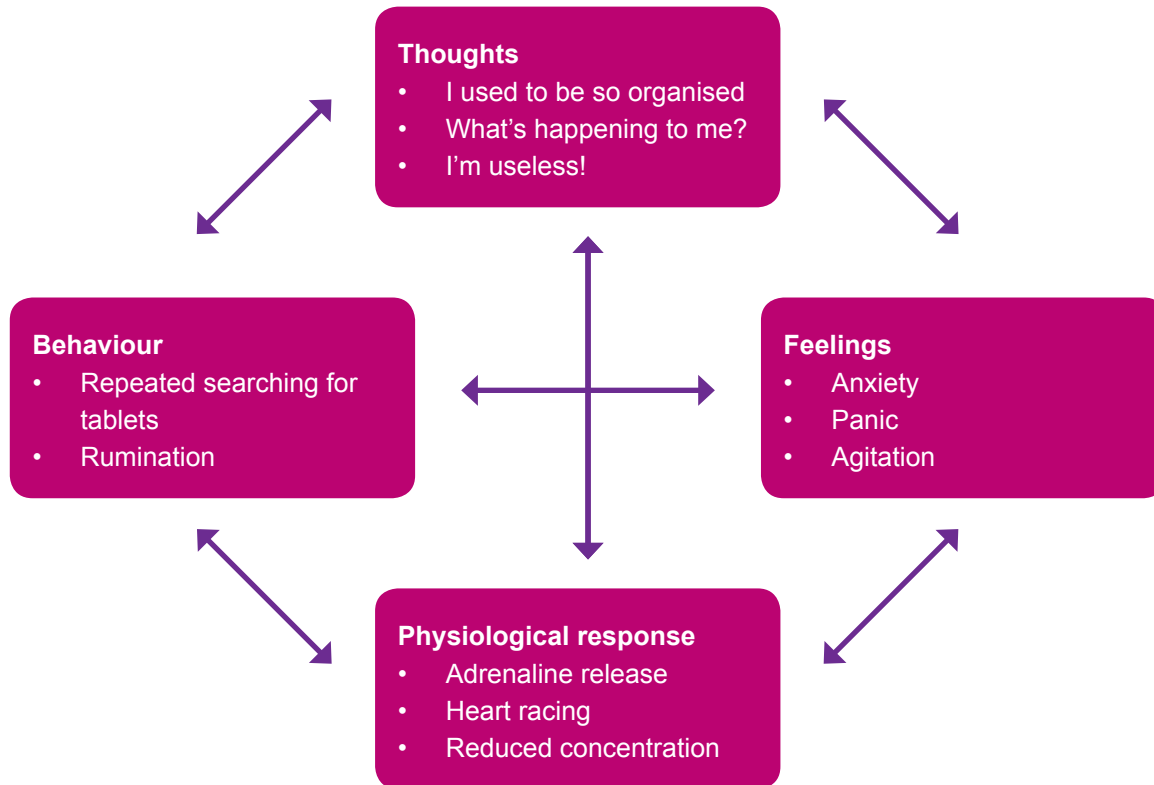


Ellen Banks, is an 80 year old lady with a diagnosis of dementia who lives at home and receives day care in the form of a lunch club. Her husband died 6 years ago. She has three children and 4 grandchildren. She has always been busy and enjoyed using her skills to support the family business and organise the family’s home life. She receives a great deal of support from her daughter Caroline. Recently Ellen has become anxious about losing her tablets.

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When Ellen forgets where her tablets are we can hypothesise what her thoughts, feelings, behaviours and physiological responses might look like?



In this example, Ellen's thoughts are affecting her feelings; and as she begins to feel anxious this triggers a fight or flight response; the physiological aspects of this include release of adrenaline which has a number of physical effects; she tries to keep searching for her tablets in attempt to 'stay in control'; however because her concentration is now reduced due to her anxiety, she becomes more flustered in her search; this only fuels her negative thoughts further and serves to confirm her belief that 'I'm useless'.

CBT can be adapted in a number of ways for use with people with dementia. There are a number of resources available to aid those trained in CBT to adapt this for working with older people and older people with dementia. Relaxation techniques (such as progressive muscular relaxation) and engagement in pleasurable activities are aspects of CBT that can readily be applied. In individual or group CBT sessions it is possible to identify negative thinking styles which the person typically uses to review situations and to work collaboratively in exploring alternative

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ways of viewing and thinking about the situation.

Who is it for? CBT is useful for people with mild dementia who have co-morbid anxiety or depression. Therapists require accredited training and supervision in CBT. Family carers have been taught to use problem solving skills to engage the person in more pleasurable activities to lift mood.

How does it work? CBT improves mood and anxiety by influencing cognitions to be more realistic, and less hopeless or negative; and by helping to change behaviour to make this more active, stimulating and enjoyable.

What are its effects? Some evidence of improved mood and anxiety.

Sources for more information

- James, I. A. (2010) Cognitive Behavioural Therapy with Older People: Interventions for Those With and Without Dementia. London: Jessica Kingsley Publishers

- Laidlaw, K., Thompson, L., Gallagher-Thompson, D & Dick-Siskin, L (2003) Cognitive Behaviour Therapy with Older People. John Wiley & Sons, England

Multi-sensory stimulation

What is it? Sometimes described as 'Snoezelen', this approach involves providing a variety of sensory stimulation. Often special equipment is used such as lava lamps, aromatherapy burners, tactile materials etc. Low cost alternatives are feasible, including hand massage and rummage boxes full of different materials. This approach is applied in a variety of settings and formats (e.g. groups or one to one sessions).



Remember Point

It is important to balance the need for stimulation with the need to avoid overstimulation or as Kovach's (2000) 'sensoristasis model' suggests to balance stimulating and calming activity for people with dementia. For some people with dementia they may have a 'reduced threshold' for stress, i.e. they are less able to tolerate multiple demands. Therefore, the use of multi-sensory stimulation should be carefully considered, perhaps testing the individual's ability to engage with one source of stimulation at a time and gradually adding other sources if appropriate, such as a combination of music and calming light. It is not likely to be helpful to take a person with dementia from a sensory deprived environment directly into a multisensory room.

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It is important to use a person centred approach, using your knowledge of the person's history to inform choice of stimulation and recognising and responding to cues which inform whether person is happy/not happy/stressed/distressed with the situation?



Activity 5a: Overstimulation

Let's imagine the risks of overstimulation for ourselves. Imagine you have been asleep in the back of a car, gently dreaming about your last holiday by the sea, when suddenly the door is thrown open and with a start, you jolt awake. You step out onto the pavement, where you are faced with bright Christmas lights, the sound of 'Jingle Bells' blaring out of the doorway of a nearby shop, you smell cheap air freshener from another doorway and are sandwiched between two shoppers rushing to get to the sale at the next shop.

How do you think you might feel?

It's likely that you would feel rather overwhelmed and this feeling of being overwhelmed is likely to give way to agitation or an need for escape.

Who is it for? Multi-sensory stimulation is for people with severe dementia. It can be used by a wide range of staff, but some training is desirable.

How does it work? It is thought that this approach is beneficial as it focuses on the person's sensori-motor abilities, rather than intellectual abilities which may be impaired. It may help people with dementia who are distressed, to be more relaxed since the stimulation often has an arousal reducing quality. It may also help by focusing attention on external stimuli rather than on other internal needs. In addition, it may help staff

interact with and see a response in people who are often thought to be unresponsive.

What are its effects? A Cochrane review in 2009 found no significant effects on behaviour, mood or interactions of people with dementia, however the review notes that the variability in a) how this is approach is implemented and b) with what population (stage of dementia) this is used, makes comparison across studies difficult. The review concludes that additional, methodologically sound studies must be conducted, in order to develop the evidence base for this approach.

Summary

In this section, we have highlighted some of the key interventions available to improve quality of life for people with dementia. We have explored who these approaches are suitable for. We have reviewed the appropriate and inappropriate use of these techniques.

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Psychological approaches to distressed behaviour

Infections and impaction
Pain
Diet

Recording distressed behaviour
Frequency charts
Functional Analysis

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Psychological approaches to distressed behaviour

Learning objectives

By the end of this section you will be able to:

1. Recognise the role of formulation-led approaches to distressed behaviour.
2. Understand the stages involved in gathering information to inform the formulation.
3. Analyse how and where to focus interventions.

For an introduction to stress and distress in dementia please see module four of the NHS Education for Scotland resource:

 [Dementia Skilled - Improving Practice](#)

Formulation-led Interventions to Distressed Behaviour

What is it? These are approaches that are case-specific and emphasise the need for careful assessment, rather than simply trying a standard intervention. These are *individualised, formulation-led approaches*, in that the individual intervention plan is based on an understanding of the person and the variety of factors influencing him or her.

Behaviours which cause concern to both family and staff carers may often usefully be viewed as an attempt by people with dementia to communicate their own needs and distress (Cohen-Mansfield 2000). However, often, the ability to communicate needs and distress may be severely reduced by the dementia, as well as by the unfamiliarity of the situation. We have suggested many medical, physical and environmental reasons (especially the care environment) why people with dementia may become distressed but, equally, many reasons why carers and staff can become distressed by certain behaviours.

We have also been at pains throughout to stress that each person is very different, whether or not they have dementia. For these reasons, a case-specific approach is required. This is more than a 'person-centred' approach - it is an individualised, formulation-led approach. This means that each individual will have their own specific underlying factors that may be triggering, maintaining or exacerbating distress. No two people will be the exact same. Professionally, this may appear contrary to received wisdom since within healthcare, we are often taught that scientific evidence shows that treatment X is better than treatment Y for condition Z and are keen to provide such standardised, evidence-based treatments to our clients. We have used this scientific approach to develop and deliver evidenced-based treatments which have improved healthcare. Without the use of this approach, we would not have researched the best available treatments for cancer, diabetes, and heart disease. However,

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when intervening in response to distress in the context of dementia, it is important to adapt our thinking to some extent. It is important to recognise that distress is not a unitary concept or a 'medical' difficulty that will resolve easily with one treatment regime (unless for example, it is a simple case of a UTI causing agitation). Historically, antipsychotic and other medications have been used. For 80% of people who have been prescribed them, this is not the best 'treatment'. They do not address the underlying cause and additionally, cause negative side effects.

Each person with a diagnosis of dementia will be unique in their ability to perceive, understand and communicate. Similarly, they will differ in terms of the underlying causes, triggers or maintaining factors influencing the distress they experience or the capacity for this to be reduced. In order to maximise the effectiveness of any interventions we deliver, we need to understand this complexity.

A recurrent theme and recommendation in

the dementia literature relating to stress and distress, is the importance of individualised treatment approaches (Cohen-Mansfield, 2001).

The  **Standards of Care for Dementia** (2001) state that individuals with dementia and their carers, have the right to access a range of treatment and care that is likely to be of benefit, including a range of non-pharmacological treatments. Research has shown that interventions offering support, with individualised psychological intervention as part of a programme promoting person-centred care and good practice; provides a viable alternative to neuroleptic medication for treating behavioural symptoms in patients

¹ *Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial (2006) Jane Fossey, Clive Ballard, Edmund Juszcak, Ian James, Nicola Alder, Robin Jacoby, Robert Howard. BMJ, doi:10.1136/bmj.38782.575868.7C*

with dementia (Fossey et al, 2006)¹. Of course, it is essential that prior to utilising such an approach, that contributing physical factors are excluded/addressed and that we also consider whether carer distress should be reviewed. Let's look at excluding physical factors first:

Exclusion of medical/physical factors

Untreated physical conditions are the most common cause of distressed behaviour.

These include:

- infections (chest, urine, skin for example)
- constipation
- dehydration
- respiratory problems
- pain
- skin irritations
- medication interactions (many people with dementia are on a large number of medications, some of which may have adverse effects)
- general discomfort (e.g. from being left in one position for more than 45 minutes).

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The medical history may give clues. If the onset of distress has been relatively sudden, medical/physical causes are more likely. It can be helpful for services to have a checklist of these known factors, which they can exclude as a matter of routine investigation when individuals present with sudden onset of stress or distress. The earlier you can intervene to reduce these symptoms, the quicker they are likely to resolve.

- Do you or your service have a checklist you can use?
- If not, is that something you may wish to develop together?

Infections and impaction

To assess urine infections, it may be difficult to obtain a sample from individuals with dementia. However, carers may be able to assist you in considering if this is a problem. For example, has the individual been incontinent recently when they are normally able to attend to their toileting needs independently? Is there an unpleasant

odour when they use the toilet? Can staff obtain a swab from clothing or incontinence pad? If you are concerned there may be an infection, contact a medical practitioner to assess whether treatment such as antibiotic medication is required. SIGN guidelines on the treatment of urine infections can be found at  <http://www.sign.ac.uk/pdf/sign88.pdf>

Bowel monitoring: Monitoring bowel movements can be helpful to ascertain whether someone is constipated, and charts can be the simplest method to collate this information. The Framework from Sydney West Area Health Service is an excellent example of good practice:

[Bowel Management Decision-Making Framework](#)



Activity 6a: *Medical / physical factors*

- Do you ask carers about bowel movements or potential constipation?
- If not, why not? Is this something you and your service could look at?

Pain

To assess other difficulties such as pain, a number of observational considerations can be made. Traditionally, we would expect the person to be wincing in pain when they are attending to self-care tasks, holding, rubbing or protecting an area of their body. However, we know that each individual does not respond to pain in the same way and dementia can influence how an individual will communicate pain. Although groaning and agitation may be a result of pain in one individual, it may cause another individual to withdraw and become more confused. It is vital to know the individual well, in order

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to observe any differences or changes in behaviour, wellbeing, or ability. We cannot assume pain is the most likely cause of distress - this should be assessed from clinical experience, observations and carer reports.

For individuals who have moderate language abilities and, for example, are able to understand and respond verbally to questions it may be helpful to simply ask, “are you in pain?” or “are you sore?” “where does it hurt?” or “show me?”. In addition, a number of screening tools can be used to monitor pain in individuals with conditions likely to cause pain, such as osteoarthritis or other chronic long term conditions. Examples of such tools include the DOLOPLUS-2, a tool that can be used on a number of comparable occasions to monitor presentation and, potentially, improvement or decline over time. This is helpful for monitoring whether pain relief has had an impact on symptoms. The Abbey Pain Tool or the PAINAD can also be used for individuals with more advanced dementia, who may experience difficulty

in verbalising their pain. However, many of the symptoms being assessed by these measures may indicate other causes such as infection or acute confusion, rather than pain and it is important to attempt to differentiate these.

An effective approach to pain management in people with dementia is to assume that they do have pain if they have conditions or have had recent medical procedures that are typically associated with pain. It is important to take a proactive approach in pain assessment and management.



Activity 6b: Pain

- Within the team in which you work, do you routinely assess pain?
- If not, why not?

- How often do you consider pain in people who are withdrawn or who display apathy?
- Is pain something that is considered for someone who has become acutely agitated or aggressive only?

Diet

Monitoring dietary Intake is essential in order to identify any other medical issues such as reduced sodium levels which can cause acute confusion. Lack of fibre can cause constipation, impaction and confusion. Therefore, ensuring that someone has a balanced nutritional diet can reduce the likelihood of acute confusional states or delirium. Food intake diaries can be helpful to monitor nutrition. Primary and secondary care dieticians are accessible in the NHS and it may be worthwhile identifying who the dietician is for your client group and service.

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Activity 6c: Diet

- Do you know who your local dietician is, or which Dietetics service you can refer your patients to?
- Do you ever refer patients to the dietician?
- If not, why not?
- Consider the reasons why you haven't referred anyone in the past. Given what you have learned, can you think of circumstances where it might be helpful to refer to dietetic colleagues? Can you think of clients who might have benefited from such a referral?

Carer distress

If you have identified that the behaviour is not a manifestation of distress and does not distress the person with dementia, it will be

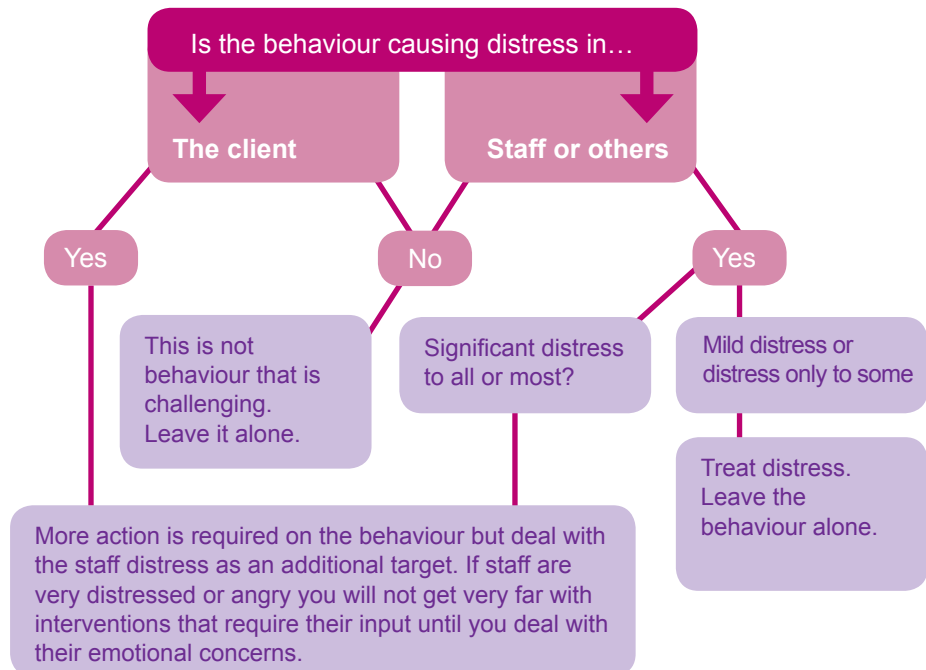
sufficient in a significant minority of cases to ameliorate the distress of family members or care staff, by helping them to see the behaviour in context. You will want to know:

- Who is distressed by the behaviour and what is it that distresses them?

- Who is not distressed? How do they see the situation?

You may find the attached decision tree useful in determining whether you address causes of carer distress, causes of the behaviour, or both.

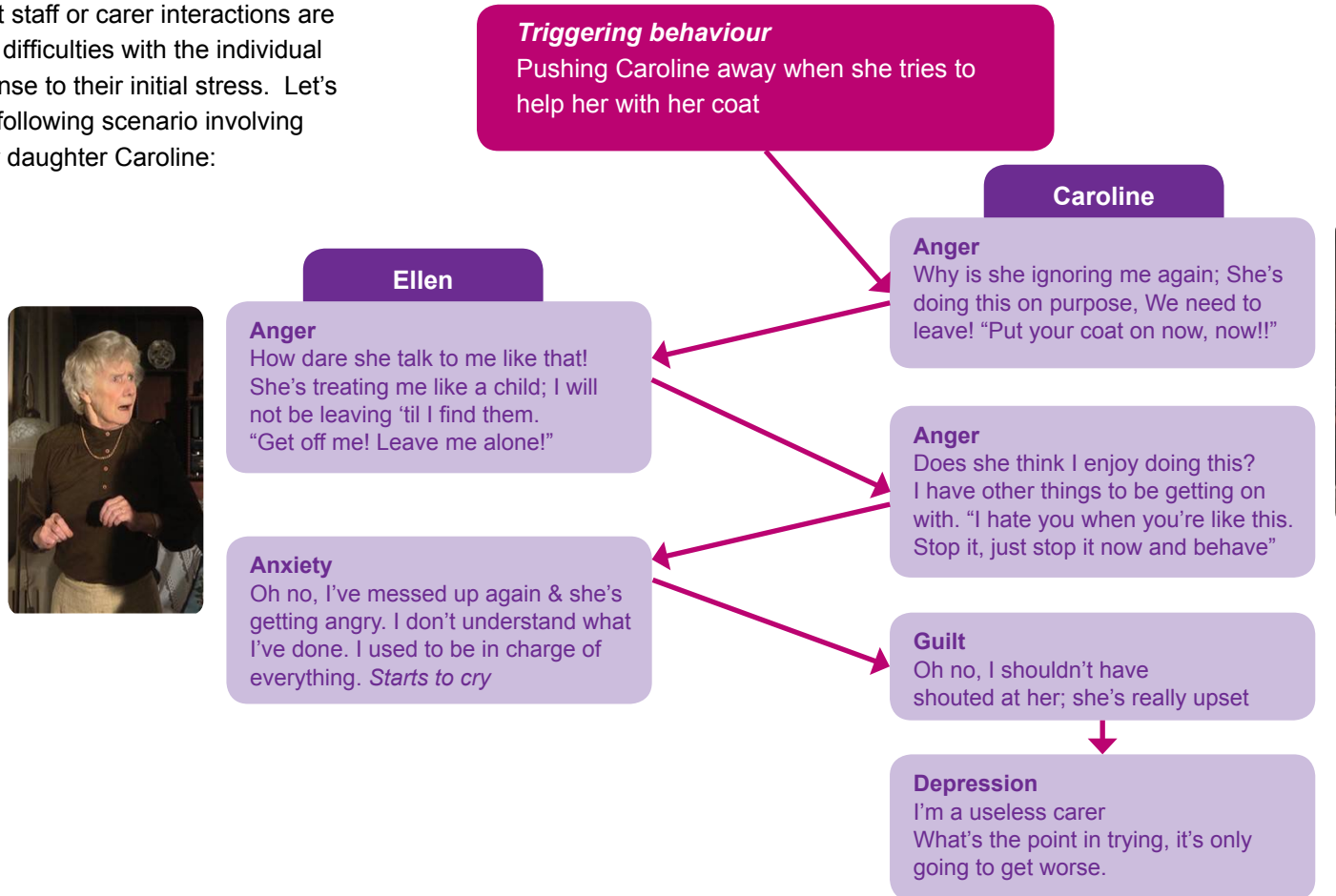
The Decision Tree (Bird, Heal, Barnett & Davidson, Bangor University)



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It may be that staff or carer interactions are exacerbating difficulties with the individual in their response to their initial stress. Let's consider the following scenario involving Ellen and her daughter Caroline:



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This example demonstrates the way in which not only is communication a two-way process, but our communication is affected by our emotions and the emotions of others. In this scenario, if you were working with the carer (Caroline) you might want to break down the interaction that you observed and sensitively help her to understand that Ellen is not ignoring her intentionally, to facilitate her own acceptance of the diagnosis, and to receive some support for her emotional reaction to Ellen's diagnosis and difficulties. Assessing caregiver burden or stress, or indeed their mental health, can indicate when you have to intervene, or offer intervention to assist them in their caring role.

Therefore, it is important to consider staff or carer stress and distress and how this is impacting on the distress displayed by the individual with dementia, before and during formulation-led interventions.

There are a number of approaches and resources available to reduce carer distress. These include carer support groups, group

based educational workshops, educational literature and specialist referral for support from health and social care professionals. The NES Caregiver resource details a range of approaches, provides useful guidance on identifying carer distress and information on how to reduce stress and distress in carers. This can be given to caregivers to assist them in their ability to intervene and access professional support to reduce stress and distress (for both the individual with dementia and themselves).

Who is it for? Carers of people with dementia, of any severity who show distress.

How does it work? The NES caregiver resource increases carer knowledge of the causes and maintaining factors of stress and distress in dementia. In addition it provides strategies to reduce carer distress. Often the main effect is on family carers and care staff. They become less upset or irritated by the behaviour as they understand it more fully and recognise the factors involved in causing stress and distress.

What are its effects? Distressed behaviour can be reduced, using this individualised approach. Nothing works for everyone, nor all the time, but significant improvements have been documented in a number of cases where this approach has been implemented.

Sources of more information

- NES Caregiver Resource

Formulation-led interventions in response to stress and distress

Following assessment and exclusion of all physical health factors, if the distress continues, a formulation-led approach should then be utilised by qualified health professionals. If carer distress has been identified then this should also be addressed and may form part of the formulation. The evidence-base shows that using an individualised, formulation-led approach is the most effective method of understanding and reducing stress and distress in people

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with dementia. This can be carried out in a number of ways. NES has begun to train health and social care staff working with people with dementia, in the formulation-led approach used by specialists working in Newcastle (Dr Ian James and Lorna MacKenzie). The NES training has utilised a Training for Trainers model whereby staff are trained to roll out training to colleagues within their local area.

This model of formulation-led interventions involves working closely and empathically with family and staff (so that any intervention makes sense to them), in order to clarify and understand both the causes of the behaviour and/or why it is a problem. Some of the questions that need to be addressed are shown in Box 1.

Box 1

- Who is distressed by it and what is causing it to be distressing?
- What exactly is the distressed behaviour?
- What triggers the distress?
- What is contributing to the distress?
- What reduces the distress in each situation?
- Which of the variables in this case, in this specific setting, is amenable to change such that distress is reduced for the maximum number of people involved?
- What is the unmet need that the individual is trying to communicate?
- How can we meet the need?

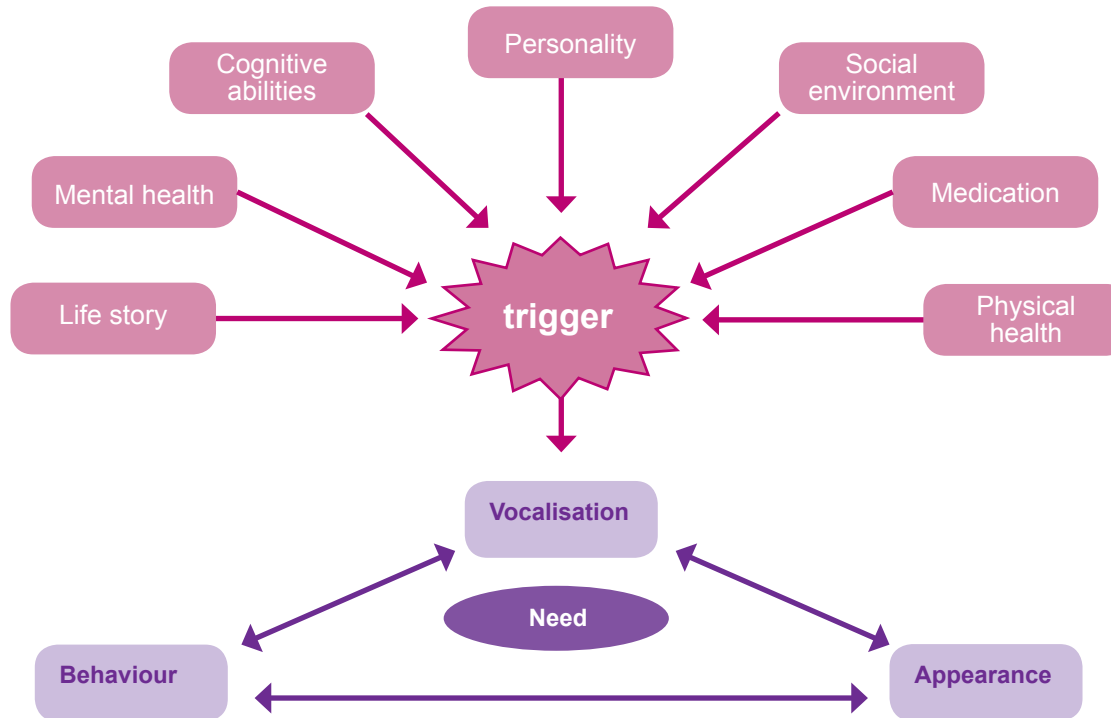
A 'formulation' is a tool used by clinicians to relate theory to practice and can best be understood as an hypothesis, or set of hypotheses to be tested. Developing a formulation, requires us to become inquisitive detectives, putting the pieces together to form a narrative about the person and the stress/distress. If we can develop a theory (or a formulation) as to why the individual is experiencing distress, we can target interventions to tackle the underlying causes and measure whether this was effective in reducing distress.

One such formulation-led model that can be used is the Newcastle Clinical Model (James 2011). The model includes the range of information known to be important to consider, such as physical and mental health, the environment, as well as the life story and personality of the person, to assist our understanding of the thoughts, emotions, and beliefs underlying the person's stress or distress.

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The Newcastle Clinical Model (James 2011)



This approach to assessment and intervention ensures that the care plan or intervention put in place is:

- Embedded within person-centred principles
- Encompasses potential thoughts or cognitions the person may be experiencing
- Includes functional analysis of the person's behaviour
- Encompasses consideration of potential unmet needs
- Includes the response/interaction of other people to the situation
- Includes environmental factors
- Is carer-focused

The formulation seeks to provide working solutions to the questions posed. These are not final answers – some of the questions may need to be re-visited or new insights may emerge. Based on this formulation, an action or intervention plan is drawn up. There may be actions relating to the person's

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health (e.g. increase pain relief); to the care approach (e.g. when the person resists care, leave and return later); and the care environment (e.g. address the needs of the family carer who is depressed).

Information must be gathered from the person with dementia by observation or conversation, from family, care workers and other professionals involved, via interview or functional analysis, and from medical files and notes. It is important to listen to everyone's story in order to understand their perceptions, attitudes and beliefs specific to the distress.

The information collected should contain:

- 1. Physical health** – past and present
As detailed above, and other relevant history such as has the person had a stroke that impacts on their understanding, communication or mobility? Do they have a condition which causes pain and that may reduce their tolerance levels?

2. Mental health - past and present
Depression and/or anxiety are common causes of distressed behaviour. Be aware that depression in particular can have an atypical presentation in dementia (e.g. hallucinations occur in 30% of cases). See also Section 2b.

Often, apathy is overlooked as it is not overtly distressing for staff in the way that other presentations such as aggression or pacing might be. However, apathy is also a sign that the person with dementia is distressed and this needs to be identified as early as possible. The following questions may offer a helpful starting point to your assessment:

- Is there a history of depression or other mental health problems that mean the person is at higher risk of developing a recurrence of mental health problems?
- Did the person cope with difficulties in life by using coping strategies such as internalisation or avoidance?
- Is the individual withdrawing now

because that is what they did previously when depressed?

- Was the person a 'born worrier' or do they have a history of anxiety problems? Has their anxiety and worry been exacerbated because they are unable to activate their previous coping strategies such as reassurance-seeking?
- 3. Medication** – has this been reviewed by a pharmacist or medical/nursing practitioner?
 - 4. Personality, life history, previous lifestyle** – Who is this person?
Obtaining this information will help you understand more about the life history and personal attributes that influence who this person is, what they value or find upsetting. For example, if we learn that Betty has always found it difficult to leave her home without first checking five times that she had switched off all electrical switches, this helps us to understand that Betty was previously an anxious woman with some obsessional

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traits. It will be important to consider whether other people have been trying to prevent her from performing her 'routines' which actually help her feel safer and more calm? Similarly, this knowledge will also help us work with Betty since we will be aware she is perhaps more likely to feel anxious and vulnerable than some other people. Being actively involved in gathering this information often helps change attitudes of some staff to people with dementia (See also Section 2b).

Other relevant information to gather under this heading includes personal habits, routines, preferences or important events earlier in the person's life (e.g. previous occupation and work pattern, or traumatic experiences) that might help to explain their current behaviour.

- 5. Current lifestyle and/or physical environment** What is this person's life like now, compared with before he/she had dementia? What is their environment like physically and socially? (See also Section 2b)

What is a typical day? Important information to gather under this heading includes many factors such as level of social relationships or loneliness; level of activity (boredom is a common trigger for distress); level of autonomy; how care is carried out; quality of interactions with staff; whether there is a mismatch between what the person is being asked to do and level of impairment. (Note that unrealistic expectations can include both expecting too much or making the person dependent by expecting too little)

Information to collate regarding the physical environment includes: the level of noise; general level of busyness and bustle; level of light and space – room to roam, outside access; opportunities for privacy and a feeling of security; ease of finding important locations (e.g. room, toilet and dining room); and ease of finding a family member or care staff. The physical environment can be an environment that triggers agitation, stress or distress or can be calm, relaxation-inducing, comfortable and rewarding.

- 6. Cognitive Abilities** – current strengths and difficulties.

Consider the type of dementia the person has been diagnosed with, their language abilities, as well as their memory, attention and orientation. How are impairments limiting someone day-to-day?

Gathering the information

When gathering information from a variety of sources it is important to consider using effective communication skills, for example, how you listen and consider the following:

- Allow individuals to give their views on why the behaviour is happening.
- Allow them to hear themselves tell the story – this can produce change in itself.
- Note relevant beliefs and emotions - for example, "she wants attention" "he was a policeman and is trying to crowd control because he is authoritative".
- Listen to assess how much stress the difficulties are putting on the carer/staff member/service.
- It is helpful to assess the capabilities of

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the carers and resources they have at their disposal.

- Ensure that you speak to more than one individual. Speak to the person with dementia themselves if their communication allows, main carers, qualified and unqualified staff, family members, GP, psychiatrist and any other relevant individuals.
- Collate background information that helps put the difficulties into context via case-note file review, life review storybook, family members, ward round information etc.

Also consider your communication style and practice these techniques:

- Ask only **open questions** - closed questions reduce the amount of information you will gain.....
- Encourage elaboration e.g. “Can you tell me a bit more about that?”
- Avoid brief answers by remaining quiet after a brief response....let them have time to think, then expand their answer and fill the silence

- Affirming - acknowledge the positive “It sounds like you are trying a number of good strategies”, and be encouraging.
- Listen reflectively - more than JUST keeping quiet, be a mirror to demonstrate understanding of meaning; use statements reflecting back what you have heard “so it seems constant to you?”; not always solely asking questions like a detective examining a crime scene!
- Summarising - checking and correcting mutual understanding – not jumping in and giving potential theories as to the cause of the stress or distress too quickly, which may put others on the defensive.

Recording distressed behaviours

It is important to assess the severity, frequency and intensity of distressed behaviours. A baseline measure of this can monitor any change (improvement or otherwise) during and after any formulation-led intervention. A number of standardised and reliable scales can

be used with permission from the author. For example, the Challenging Behaviour Scale (CBS; Moniz-Cook et al, 2001); the Neuropsychiatric Inventory (Cummings et al, 1994); or the Cohen-Mansfield Agitation Inventory (Cohen-Mansfield, 1991) to name a few.

Frequency Charts

For distressed behaviours such as shouting, screaming or repetitive behaviours, frequency charts can be a reliable method of assessing if there are any particular times of the day or even days of the week when the distressed behaviours are worse or better. By identifying patterns, you can begin to consider what occurred on a particular day or for instance, why a person shouts “No!” more often after lunch. Have a look at the example on the following page:

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Activity 6d: Information gathering

Review the frequency chart below. What patterns can you find for Margaret?

	Date 12/12/11		Individual: Margaret Brown		Behaviour being recorded: Shouting 'No!'				
	5 - 7	7 - 9	9 - 11	11 - 1	1 - 3	3 - 5	5 - 7	7 - 9	Total
Monday					I	III			4
Tuesday					II	###	I		8
Wednesday				I	I	III	I		6
Thursday					### ##	II			12
Friday				I	III	IIII	II		10
Saturday				II	III	III			8
Sunday						III	III		6
Total	0	0	0	4	20	23	7	0	

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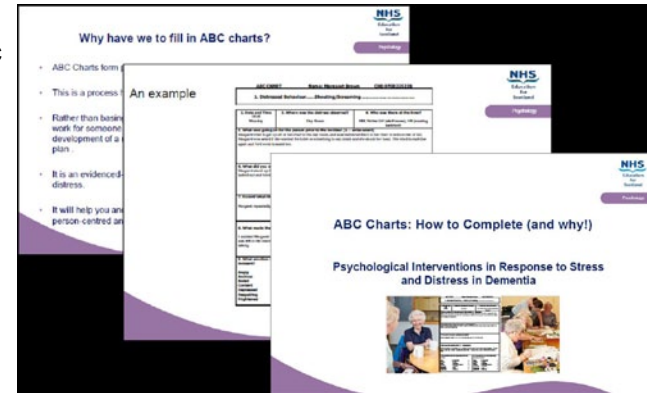
Functional Analysis

A functional analysis of the behaviour itself is also undertaken as part of the assessment contributing to the formulation. A recent Cochrane review (Moniz-Cook et al, 2012) noted emerging beneficial effects on distressed behaviours, where multi-component psychosocial interventions have used functional analysis as part of the programme of care.

Functional analysis requires consideration of when and where the distressed behaviour happens, who is involved and so on, but goes beyond a simple ABC (antecedents – behaviour – consequences) approach, by recognising that the trigger may be an internal thought or experience. Facial expressions and verbalisations can give clues as to what the person may be feeling (anxiety, depression, hopelessness to name a few) and thinking, all clues to understanding what the unmet need is. These may include, for example, pain escalating over a sustained period; a memory and associated developing thoughts;

or a growing anxiety, connected with feelings of abandonment which only tips over to panic after several hours. In these circumstances, the time the behaviour occurs may bear no relation to anything immediately observable. In addition, some distressed behaviours may continue for hours, so an immediate antecedent is meaningless. In other cases, the cause may be relatively easy to work out (for example when lashing out in the shower only occurs with a few staff) so there is no need for extensive monitoring. Numerous ABC charts exist and locally these may differ.

In your health board area and/or local authority, people will be trained in the use of functional analysis. In most health board areas people will be able to receive training or indeed be trained to be a trainer by NES in responding to stress & distress in dementia. As part of the NES training attendees are given a comprehensive guide to training others in the use of functional analysis.



Briefly, functional analysis includes the formal, scientific examination of what occurred, before, during and after the episode, observation or incident. When those involved in caring for the person with dementia have identified the need for further assessment of distressed behaviour and have completed functional analysis, it is time to develop the formulation. A formulation can be devised by a trained professional who has examined all the information; however it

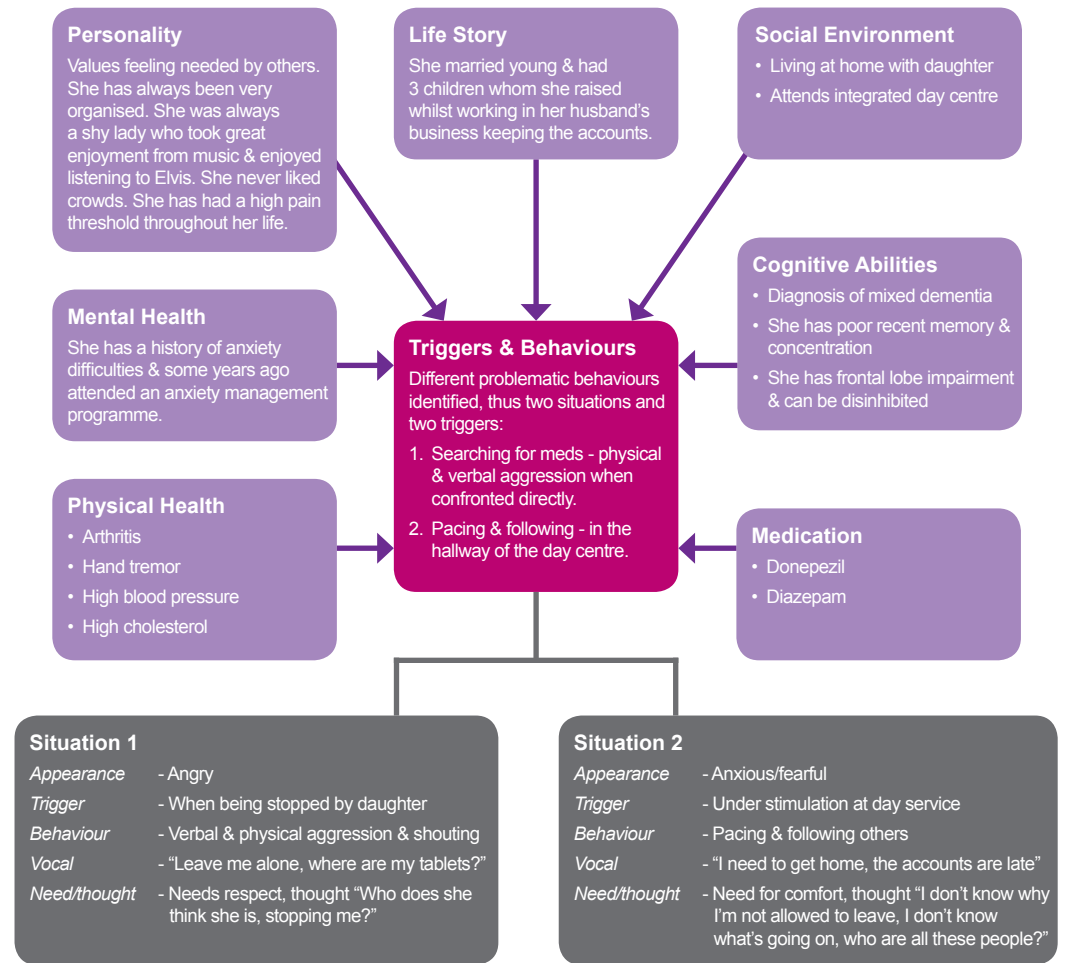
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is best to be done via an Information Sharing Session. This is a meeting between all health and social care professionals that know the person well, and family members, friends or other carers who can contribute their observations and knowledge of the individual.

A trained professional will lead the information sharing session, to assist all attendees to agree and clarify the information obtained through the assessment process and the group will develop the formulation together.

A sample formulation can be found opposite for an individual Ellen. Ellen has been pacing and following members of staff at the day centre, causing staff some stress. She also became verbally aggressive towards her daughter Caroline when Caroline tried to redirect her attention away from a search for mislaid medication. Following a review of Ellen's medical case notes, interviews with her daughter and day care staff, and functional analysis (reviewing ABC charts), an information sharing session with all relevant individuals was arranged. This enabled discussion of the information gathered and everyone contributed to an agreed formulation to explain what may be causing or contributing to Ellen's distressed behaviour.



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Following the formulation being agreed by all individuals involved in the care of Ellen, an intervention plan or care plan, is then developed. This allows all concerned to understand and follow the agreed approach to be taken when working with Ellen, to prevent distress, and to respond appropriately when this does occur.



Activity 16e:

Using a formulation-led approach

Can you see how the information you would normally gain in your own assessments and interactions with individuals with dementia could fit into this model of formulation?

Do you consider yourself to be a professional that could make a valuable contribution to this process during the information sharing session? You may be asked by another health or social care professional to attend an information sharing session in your current role. Now you have the framework,

you can begin to consider these elements before you attend.

The interventions agreed on during the formulation or information sharing session should link to the **unmet** need that was agreed as being communicated by the individual in distress. For example, if it was identified that Jim's unmet need was for comfort, psychosocial interventions to provide comfort should be considered and agreed upon that, reflect and are consistent with Jim's life story, personality, likes and dislikes.

If you review the intervention plan for Ellen below, can you see how the interventions have been developed by the group at the information sharing session after developing the formulation?

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Intervention phase

Phase 1 of Interventions: Suggested strategies to utilise for Ellen – pacing & following

Early warning signs: From the ABC charts we noticed that Ellen tended to start tapping her hand on the chair's armrest, tapping her feet on the floor or patting herself, shortly before she began pacing or following...

<p>Preventing triggers for stress & distress</p>	<ul style="list-style-type: none"> • Triggers for Ellen's pacing and following others seem to be inactivity & under stimulation. This period of inactivity leads to a build up of anxiety which she responds to by pacing and following (normally after lunch). She also does not like crowds of people and lots of noise appears to be another triggering factor. • Try to make sure she is engaged in stimulating activity. She used to keep the books for her husband's company and enjoys feeling that she is contributing in a meaningful way. Therefore, could she have a role in the day service such as ticking people's names off a sheet when they arrive? Ellen also likes to keep her home organised. Therefore, could she be prompted to help staff put things away after lunch? • Staff may need to prompt her to engage in activities such as simple crosswords. • When the day service is very full, have planned quiet times throughout her day. Ellen should be directed to a quiet lounge area where there are fewer clients, but staff should ensure that she has an activity she enjoys to focus on. Previously, because staff realised she did not like crowds, they tended to move her into a quiet sitting room, however she was not engaged in an activity. • When Ellen is anxious she follows staff and tries to leave. It is important to reduce the stimuli prompting her desire to go home, by making any staff changeovers throughout the day very subtle, and avoiding drawing attention to the fact that people are leaving i.e. not saying goodbye in front of Ellen.
<p>What to do when Ellen begins pacing and following others</p>	<ul style="list-style-type: none"> • Ellen needs comfort & to reduce her anxiety. However, do not try to meet this need by directly touching Ellen as she often has pain. Instead, make eye contact and state "You're ok Ellen, you're at the day centre today" to reassure her. Alternatively, you could use the Simulated Presence Therapy recording that Caroline provided, to remind her that she is at the day service today and she will be going home and seeing her [Caroline] tonight. • Say to Ellen "Ellen I can see that you're upset. Would you like to do some relaxed breathing together to make you feel better?" Sit in front of Ellen and model some basic breathing exercises. • Use distraction if required – Use Ellen's 'memory box' to engage her in pleasurable activity.

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Phase 1 of Interventions: Suggested strategies to utilise for Ellen - verbal & physical aggression

Early warning signs: It may be that when Ellen has been quiet for a period of time this may be an early warning sign that her levels of emotional arousal are risinglet us see if this is the case?

<p>Preventing triggers for stress & distress</p>	<ul style="list-style-type: none"> • Triggers for Ellen becoming verbally & physically aggressive are thought to include people touching her, or stopping her engaging in activities such as searching for tablets. • Ask yourself if there is any risk in letting Ellen engage in this activity? Assess the risk, but only intervene if there is a risk. • Do not touch her to stop her. Instead, try to acknowledge her distress by saying “You seem worried Ellen. Can I help you with something?” • If she is searching for tablets, try to establish if she is in pain “Are you sore? Can I help you?” Consider whether you can help reduce discomfort e.g. offer a hot water bottle to soothe aches and pains. • Maintain a calm approach and make good use of non-verbal communication (smile, be patient) • Schedule activities providing cognitive stimulation e.g. shared activity such as completing a crossword on a one to one basis.
<p>What to do when Ellen is aggressive due to you stopping her</p>	<ul style="list-style-type: none"> • Assess risk - give her physical space. • Meet her need for respect by acknowledging her anger “I’m sorry that you’re upset just now, can I help with something?” Allow her to search if there is no risk to self or others in her carrying on. • Then use distraction if she is becoming fixated and distress is increasing because she can’t find them. Distract by move her away from searching i.e. engage her in a discussion about family using photographs around the room as an object to focus attention on, or listen to her favourite Elvis CD together to provide a source of shared activity.

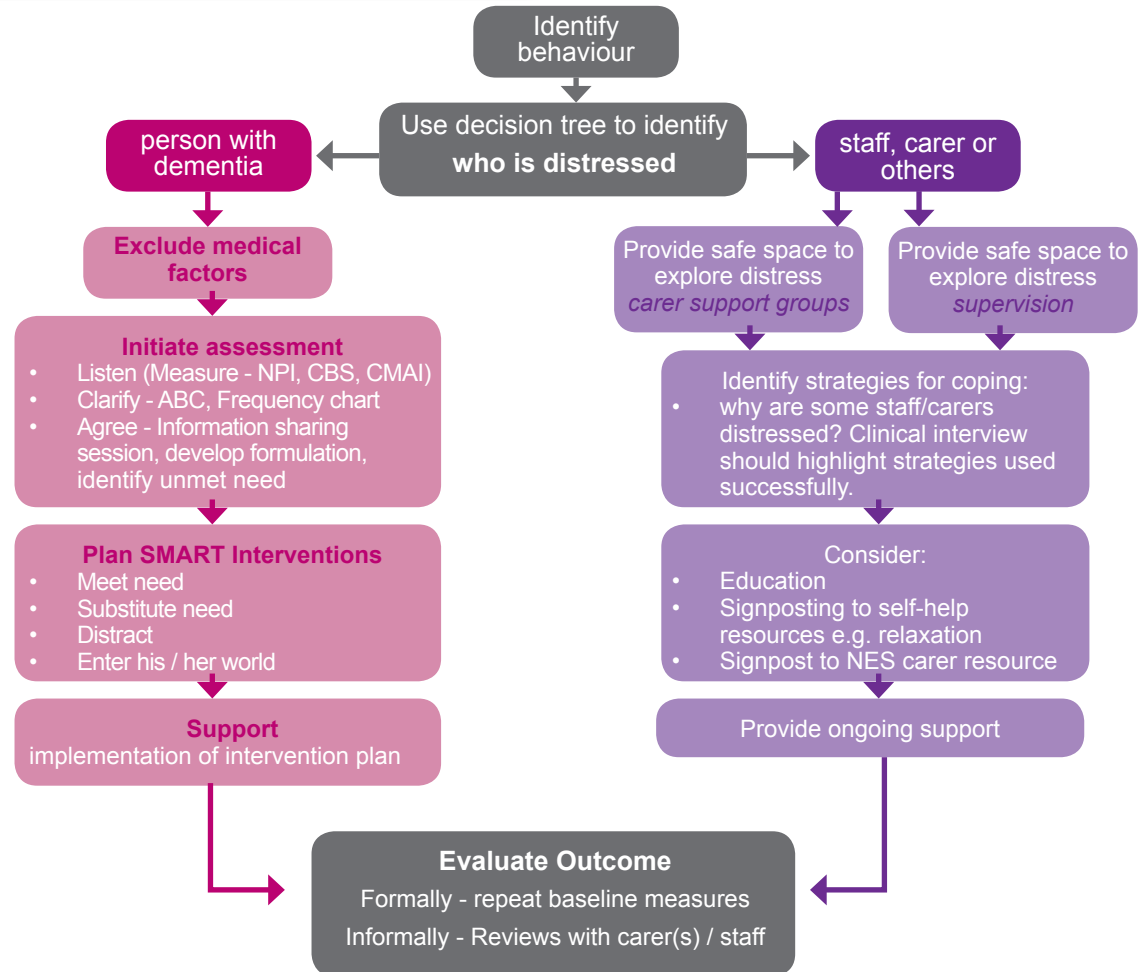
Section 6

Psychological approaches to distressed behaviour

All individuals involved in Ellen's care should access the intervention plan in an easily accessible place and indicate that they have read and understood this. A period of time should be agreed in which to trial the agreed intervention plan, such as a week. During this period, all individuals implement the intervention plan to prevent distress and in response to any distress which Ellen appears to experience. The team should closely monitor Ellen's response.

Feedback to the individual, who has led the information sharing session and formulation-led intervention, will ensure that the intervention plan will be modified and adapted to take into account what did or didn't work.

The flow chart to the right is a summary of the processes involved in undertaking formulation-led psychological approaches to stress and distress in dementia. This can be used as a prompt or a checklist. As previously mentioned, NES training in this way of working is being rolled out across Scotland.



Section 6

Psychological approaches to distressed behaviour

Sources for more information

- James, I (2011) Understanding Behaviour in Dementia that Challenges: A Guide to Assessment and Treatment (Bradford Dementia Group Good Practice Guides) Jessica Kingsley Publishers, London

Summary

In this section, we have looked at the role of formulation-led approaches in response to distressed behaviour. We have introduced a psychological model of formulation and explored the decision making process involved in identifying who is distressed and therefore, where to focus the intervention. We have outlined the steps involved in gathering and interpreting information to complete this process.

Section 7
Other resources



Section 7

Other resources

Although there are many other resources available, the list below may provide a useful starting point.

These initial resources are key to underpinning your understanding of the resource:

- [Scotland's National Dementia Strategy: One year on report](#)
- [Promoting Excellence: A framework for all health and social services staff working with people with dementia, their families and carers.](#)
- [Dementia Skilled - improving practice resource](#) (the enhanced resource builds upon this skilled level resource for staff)

NHS Education for Scotland (NES) Resources & Scottish Social Services Council published resources:

- [Dementia Informed Practice DVD](#)
- [Dementia Skilled - improving practice resource](#)
- [Acute Care Dementia Learning Resource](#)
 - [Cognitive Rehabilitation in Dementia Resource: A guide for Staff](#)
 - [Cognitive Rehabilitation in Dementia Resource: A guide for Carers and individuals with dementia](#)
 - [Dementia: A caregiver resource](#)

Useful websites & sources of information

- [SIGN – guideline on the management of patients with dementia: Sign 86](#)
- [Social Care Institute for Excellence](#)
- [NICE guideline and SCIE Guideline for dementia care \(2006\)](#)
- [Alzheimer's Scotland: Action on Dementia - Alzheimer Scotland](#)
- [Alzheimer's Society: Alzheimer's Society - Leading the fight against dementia](#)

Dementia Design

- [Dementia Services Development Centre](#)
- [Enhancing the Healing Environment - The King's Fund](#)

Section 7

Other resources

Miscellaneous

- > [CST web-site: An Introduction to Cognitive Stimulation Therapy - CST](#)
- > [Dementia Activity Tool Kits](#)
- > [Wisdem](#) Understanding dementia, improving quality of life
- > [Lifestory Network](#)
- > [ARTZ is Artists for Alzheimer's](#)

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Moniz Cook, E., Swift ,K., James, I., Malouf. R., De Vugt, M & Verhey, F (2012) Functional analysis-based interventions for challenging behaviour in dementia (Review). *The Cochrane Collaboration*. JohnWiley & Sons, Ltd.

Spector, A., Thorfrimsen, L., Woods, B., Royan, L., Davies, S., Butterworth, M & Orrell, M (2003) Efficacy of an evidence-based cognitive stimulation programme for people with dementia: Randomised controlled trial. *BJP* September: 183: 248-254; doi: 10.1192/03-23

Wilson BA. 1997. Cognitive rehabilitation: how it is and how it might be. *Journal of the International Neuropsychological Society* 3:487-496.

Woods B, Aguirre E, Spector AE, Orrell M. (2012) Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database of Systematic Reviews*, Issue 2. Art. No.: CD005562. DOI: 10.1002/14651858.CD005562.pub2.

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