

# Promoting psychological wellbeing for people with dementia and their carers:

An enhanced practice resource





## Welcome

**Welcome to the 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 enable you to apply this learning to your working practice when supporting people with dementia and their families and carers. It can also be used to help signpost you to additional NHS Education for Scotland (NES) educational resources and training programmes.**

This resource aims to build on the learning in Dementia Skilled Improving Practice resource (<https://www.nes.scot.nhs.uk/media/3558858/Dementia%20Skilled%20Resource%202016%20-FINAL-web.pdf>). 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 the [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:** Communication – people living with dementia and caregivers

**Section 4:** Evidence-based psychological interventions in dementia care

**Section 5:** Psychologically informed practice to guide proactive and preventative strategies in dementia care

**Section 6:** Looking after yourself

**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 a way that best suits you, your team or your organisation. The activities that appear throughout 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.

For individual use, you can write into the activity sections throughout and save a copy of this resource (with your own answers) onto your computer (if you are using an online version of the resource). You can also print sections out as you wish. For easy navigation, the menu guide for this resource is available at any time by selecting the tabs on the left hand side of the screen.

Whichever way you use this resource, it is important for you to record the number of hours spent reading the resource and completing individual exercises and tasks. This will act as evidence of developing and maintaining your own level of knowledge and skill for your continuing professional development. This can be done through your TURAS Learn account or equivalent, depending on which learning platform your organisation uses.

We would recommend that you complete all 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 Strategies (2010; 2013; 2017)  
<https://www.gov.scot/binaries/content/documents/govscot/publications/strategy-plan/2017/06/scotlands-national-dementia-strategy-2017-2020/documents/00521773-pdf/00521773-pdf/govscot%3Adocument/00521773.pdf>
- [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](#)  
[https://www.alzscot.org/sites/default/files/2019-07/McLeish\\_Report\\_updated\\_24.01.19\\_Web.pdf](https://www.alzscot.org/sites/default/files/2019-07/McLeish_Report_updated_24.01.19_Web.pdf)

# 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 to make us who we are.**
3. **Demonstrate an understanding of the potential influences of the ageing process on psychological capacity.**

# Section 1

## What makes us who we are?

The person living with dementia is first and foremost an individual and many problems in dementia care arise because of a failure to treat the individual in a person-centred way. Every single person who has a diagnosis of dementia will experience their diagnosis of dementia in their own unique way. Their experience will be influenced by their genetic make up, personality and their life history, to name but a few, along with the interaction of these factors with dementia and the new experiences the diagnosis brings. It is important to keep this in mind when using this resource.

Dementia involves a (usually) slow, gradual loss of multiple human capacities which enable us to make sufficient sense of the *world or environment*<sup>1</sup> and to operate reasonably efficiently and safely within it. For these two reasons, before we consider the effects of dementia we must first outline:

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

## 1a. What are the psychological capacities which make us who we are?

There is an important caution 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 to identify every capacity which goes into making us who 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.

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<sup>1</sup> 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.

# Section 1

The following categories should therefore be seen merely as a means to help us 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.
- **Processing Speed** refers to our ability to identify, discriminate, integrate, make a decision about information, and to respond to visual and verbal information.
- **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.
- **Praxis/psychomotor capacity** is the way we are able to put thoughts into action – from the motor skills and memory required to button our shirts or pick up a pencil right through to building a complex 3-D jigsaw.
- **Executive functions** are regarded as belonging to higher cognitive domains. This means that they are actions and functions typically associated with consciousness. Executive functions enable us to consciously direct what we do or don't do, regulate and monitor our behaviour, make choices or judgements, solve problems and engage in abstract thought. We are able to hold information “in mind” and this is a common underlying factor for actions classified as ‘executive functions’.

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## 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 or relate to others, how we react to feelings of abandonment and our need to be close to others. It also influences our general coping mechanisms for stressful life events; the more secure we are in our attachment style, the more resilient and able we are to manage these type of events.



## 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 event<sup>2</sup> (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.



## 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 coming to the fore of our mind) 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

<sup>2</sup> 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.

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.



## 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 an action that is observable. 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 and monitoring our 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.



## 1b. 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 fairly 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 health conditions;
- our susceptibility to many psychological factors such as personality traits; and
- demographic factors such as longevity.

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 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 completing a complex mathematical equation 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.

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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.**



Similarly, the lifestyles we choose affect health and there has been a concerted effort over many years to encourage people to change lifestyles to improve health, for example by not smoking, engaging in physical 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

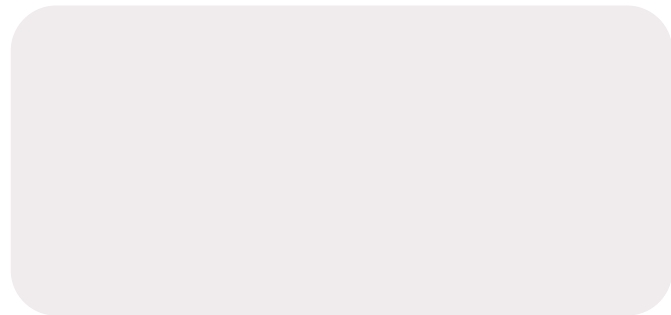
The word *lifestyle* has attained vogue status in recent years with an implicit meaning of a healthy way of living; it sometimes even means home-furnishing! In psychology it retains a much broader meaning. It is the way a person lives and the environment in which this takes place, including relationships. 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

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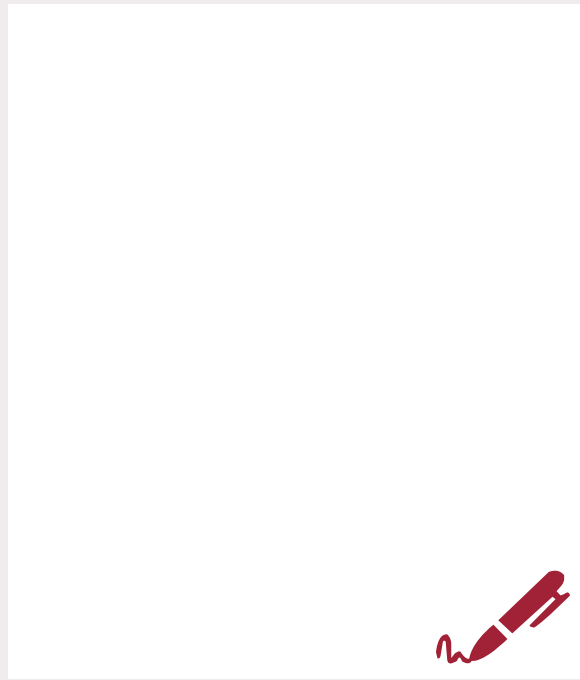
care for one's children, or motivate yourself because of illness, the number of lifestyle options you have is much more limited. These are also more limited if people have minimal experience of other possibilities and/or are innately conservative. This is even more so in communities or societies which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

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.

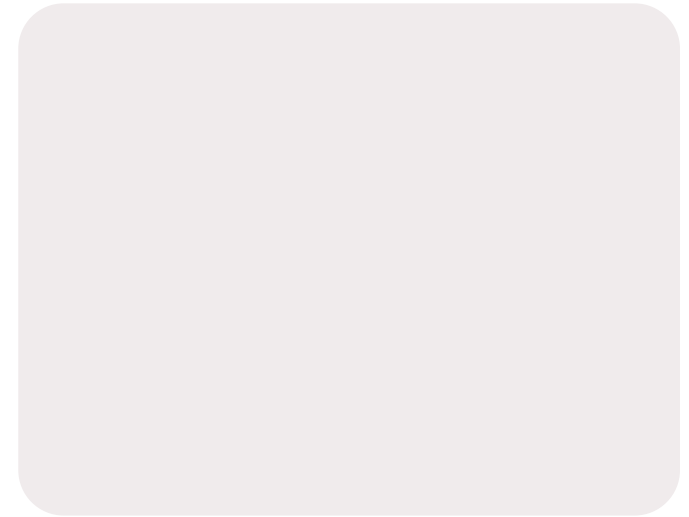


## Activity 1a /1b: What makes us who we are?

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.



- 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?



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## 1c. 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 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.



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## 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 problem solving. 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 they want, it may take longer for them to process the information and respond to what she is saying. This in turn impacts on lifestyle choices and social interactions.

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.



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Think about older people you have been involved with who do not have dementia. Have you ever talked to them as though they are 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 have you seen this or notice this happen?

This is called ageism and we all fall into it sometimes. 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.



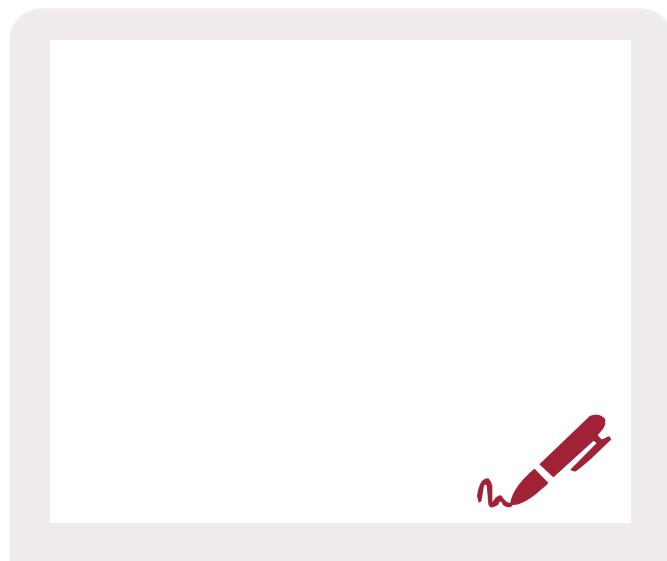
## Changes we should be concerned about

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 the person gets. 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/mental health which is one of the defining features of ageing.

An 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 are less so. Those who are unable to deal with loss, whether this is singular or multiple, may lose confidence in themselves which can mean they are more likely to 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 mood 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 and should have equity of access to psychological services and therapies.

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 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 – this is often referred to as the person having excess disability.



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## Activity 1c ii): Changes outwith the ageing process

Think back to older people you have worked with who have been diagnosed with dementia or a 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 below?



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## Activity 1c iii): Changes outwith the ageing process

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 in this box to list the types of investigations which may be helpful in certain circumstances and what you can do about raising this issue within your service:




### 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 clearly comes within the scope of abnormal ageing. It also describes how the same environmental factors that influence us throughout life, have a powerful effect on the way the dementia is experienced.



# 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.**

## Section 2

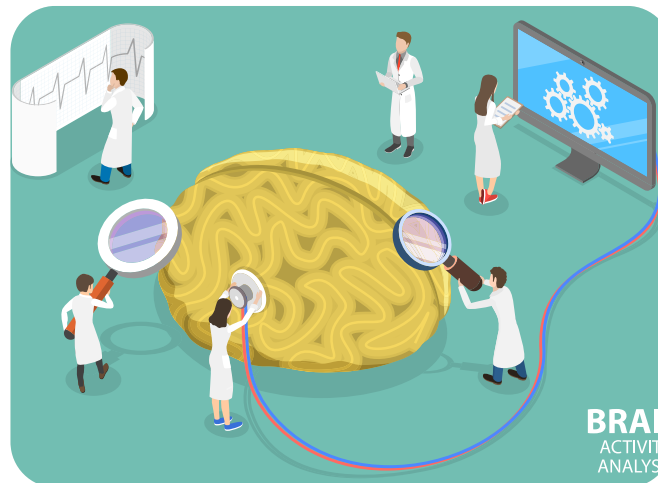
### Understanding dementia from a psychological perspective

Dementia is an umbrella term for the effects of a large range of conditions which progressively and (usually) slowly destroy the cells (neurons) which send information in and around the brain and to 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 tends to be a disorder that is associated with the ageing process. However, this does not mean that because someone is getting older, they will develop dementia. What it does mean is that age is a risk factor, so as the person gets older, their risk of developing a dementia increases, although the number of people that do not develop dementia far outweighs those that do. If we look at this in terms of prevalence rates, this might make things a little clearer. Prevalence rates for those aged between 70-74 living in the UK have a prevalence rate of 3%, this increases to 11% for those aged between 80-84. We can see that age is a risk factor as prevalence rates of dementia increases as the population ages. However, if we look at prevalence rates from a different perspective, we can see that 97% of

those aged between 70-74 and 89% of people aged between 80-84 do not develop dementia. (Prince et al, 2014). This really highlights some of the inaccuracies and misunderstandings surrounding 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 the impact of emotions and mental health on a person with dementia.



### 2a. Psychological aspects of dementia – Cognitive capacity

We are now better understanding the structural change in the brain caused by dementia. Brain cells are progressively destroyed regardless of dementia type. Psychological functions, which include cognitive capacity, emotion and behaviour are affected over time due to this reduction in healthy brain cells. The range of cognitive functions and capacity affected by dementia are often underestimated and not fully appreciated as the focus of health professional input tends to be focused almost entirely on one cognitive domain – memory. This is unfortunate because all cognitive functions are affected to some degree, often profoundly in the advanced stages of dementia.

We will now look at each cognitive domain in turn before moving onto other psychological aspects of dementia important to consider.

#### Memory

There are various forms of memory that are dependent upon different areas of the brain, though these systems work in conjunction with each other.

## Section 2

This means it is possible for a person with dementia to have deficits in some aspects of memory but not in others, depending on what parts of their brain are affected by the disease. The process of remembering newly learnt information includes the encoding, storage and retrieval of the information. A breakdown at any point of this process of learning new information can impact on memory function. Changes in memory tend to be the most common symptom and the first sign that may be indicative of dementia; although this is not the case for all types of dementia.

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 yesterday 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 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 4 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.

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**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), make a note for yourself. If the person looks uneasy or confused, or makes something up, 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 a memory impairment.



**D)** Start planning and practising methods of having a conversation without asking direct 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.



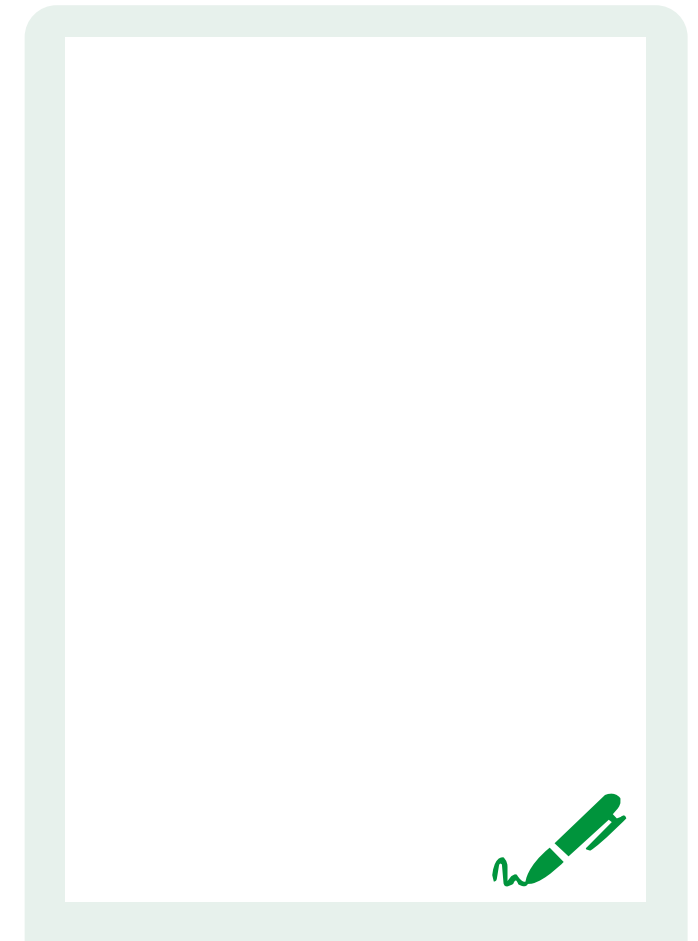
**Attention**  
Attention refers to our ability to focus on one or more things at one time, ignore distractions and sustain our concentration over time.

For example, to hold a conversation, particularly in a busy environment, requires attention skills that enable us to focus on one element of sensory input (the person speaking) and ignore everything else (other people speaking around us). Reading a book also requires sustained attention, to concentrate on reading the book over a long period of time.

Like other cognitive domains, attention is not just one cognitive process and depends on several systems in the brain. The attention systems include:

- Alertness (arousal) - the ability to maintain readiness to respond;
- Executive attention - the ability to focus on one thing, ignore distractions and maintain attention over time; and
- Orientation - the ability to attend to stimuli in the visual environment, i.e. recognise where things are in relation to you.

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.



## Section 2



### 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.

**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 other than mild dementia cannot switch in this way.

## Section 2



**D)** Take time to notice when people with moderate to severe dementia have difficulty with their attention.

For example:

- 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; and
- 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.

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 when you want or need to. If you think the environment is too stimulating, reflect on the possible changes which could be made to your practise or to the environment you work in to reduce the impact of the person's attentional difficulties. It will also enable you to engage in proactive approaches to avoid or reduce the potential distress for people with impaired attention.



### Language

Language functions include the ability to understand written or spoken language, i.e. reading and listening to a conversation, and to express language by speaking and writing. It also includes knowledge of word meanings, objects, people and facts about the world, i.e. knowing that a dog has four legs, is furry and barks; this is referred to as semantic memory. People with semantic memory difficulties tend to present with language problems, for example, word finding difficulties, often referred to as a 'tip of the tongue' phenomenon.

Effective communication also requires the ability to understand 'non-verbal' communication such as understanding humour and sarcasm; recognising emotions in faces and speech; and understanding conversation rules (e.g. turn-taking).

## Section 2

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



### Activity 2a iii): Language



**A)** Consider what would happen if, in addition to not being able to access the correct word, like many people with dementia, you frequently said the wrong word (e.g. lion for dog).

- How do you think this would impact on how you communicated with others?
- How do you think you would feel and what would you do if you were aware of this difficulty?



Reflect on your answers to these questions to gain an appreciation of what it might feel like for those with dementia you are working with.

**B)** Listen carefully to people with dementia who may be hesitant in their speech, 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 and give them time to communicate, they are making sense. You may be able to understand some of what they are saying if you give them time.

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 refers to the brain processes that enable us to make sense, experience and understand the world around us through the information received by our five senses: touch, smell, vision, hearing, taste.



- visual perception allows us to see, recognise and understand objects, people, and places;



- spatial perception enables us to know where we are in relation to objects in the world and to act in relation to objects in space;



- auditory perception enables us to hear and understand what we are hearing;



- somatosensory perception enables us to experience the sensations of touch, temperature and body position (proprioception), which in turn allow us to understand the physical environment;



- olfactory perception enables us to experience and interpret different smells; and



- gustatory perception enables us to taste and interpret different tastes.



## Section 2

As with memory, many parts of the brain are involved in perception. Sensory information arrives from each of the sense organs (eyes, ears, skin, etc.) to various parts of the brain and is processed so that its meaning can be understood. We are able to focus in on any one sense at a time, for example, enjoying the smell of freshly cut grass, savoring the taste of a bite of food.



### 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 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.



## Section 2



**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 around them. If there is an area the person avoids, or where he or she becomes distressed or hesitant, try walking slowly through this area to try and see what they might be seeing, or hearing. You may find that there are too many confusing stimuli for someone with impaired perception, for example, a mirror at the end of a corridor or on the back of a door – 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 or make changes to your environment to reduce the likelihood that perceptual difficulties are impacting on their emotional wellbeing and less intimidating/anxiety provoking for the person with dementia. This enables you to work proactively.



### 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 in a certain way or to carry out tasks. For psychological purposes, praxis or psychomotor capacity refers to the ability to perform tasks involving fine motor skills, i.e. buttoning a shirt and hand-eye coordination, i.e. eating food with a knife and fork.

## Section 2

To demonstrate how complex tasks can be for people with praxis difficulties, try the following exercise:

### 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); and
- executive functions (starting and ceasing each phase).



**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 may be able to do some of the brushing.



## Section 2

The purpose of this exercise is not just to give you a demonstration of how psychomotor skills may remain intact, partially intact or in some cases impaired. It is to help make tasks, such as those involving personal care a more collaborative effort, where the person with dementia is actively involved in steps of the task rather than something being done 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 complete tasks together, you are helping to minimise excess disability and help 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 through assisting the person with dementia to participate in productive and meaningful activity, you are more likely to improve their quality of life and have a positive impact on the person's overall wellbeing.



### Executive function

Executive functions are the cognitive skills needed to solve problems, make plans/decisions, and regulate behaviour in order to achieve goals. They appear to be largely driven from the very front area of the brain (pre-frontal cortex within the frontal lobes) and are therefore sometimes called frontal functions but, unlike all other cortical areas, there are extensive links into and networks with, all parts of the brain. Different regions of the frontal lobes are considered to be important for different aspects of executive functioning (though there is not complete agreement on this issue). For example, one region is important for planning and problem solving, one is important for initiation of action, one for regulation, controlling and monitoring of behaviour and finally another is important for the ability to remember to do things in the future. Personality is also seen as being part of executive functions, as is insight and awareness.

These functions tend to be thought of as higher level activities. It can be helpful to think of executive functions like a chief executive of a big organisation: planning, organising, delegating tasks to their staff to complete effectively and efficiently.

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.



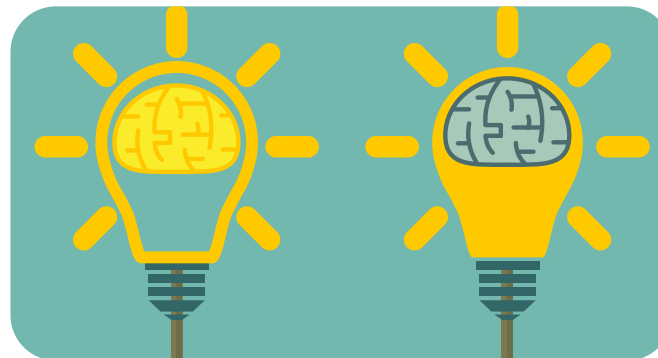
## Section 2

**B)** Another exercise to help gain insight into the executive functions and what can happen when these are compromised by dementia, is to make yourself aware of them in operation, i.e., to become aware of what you're doing. 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 exercises so far. Now we look at what your executive functions were doing during these exercises. Being able to become consciously or objectively aware of what you're thinking, i.e., your own thought processes, is called meta-cognition.

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, is all connected to 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 to 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 making rude comments about a person's appearance when in conversation, are unable to get started on something, or become suddenly angry or sexually promiscuous which is out of character for them in terms of their personality traits. It is likely that they have impaired executive functions.



### 2b. 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 the person has experienced a significant trauma, significant brain damage, or a major change in circumstances. Dementia is the most widely prevalent condition where both significant brain damage and change in circumstances occur and to an excessive degree.

## Section 2

Many people living with dementia retain their basic personality well into the advanced stages of the dementia. For example, if they were quiet and considerate, outgoing and vivacious, shy and withdrawn, aggressive and confrontational, stoical and non-complaining, they are most likely to continue to display these traits. The same characteristics will also affect how well the person copes and adjusts to having a diagnosis of dementia, or the behaviours and difficulties 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.

The person's personality does not change as result of having dementia. However, over time, there will be some changes to parts of their personality that can lead to the person behaving in a way that is not typical for them. Some examples include:

- a flattening of emotion, where the person is less emotionally responsive;
- 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; and
- concrete thinking, i.e., having fixed ways of seeing or understanding something.

Some of these changes may have been noticed before a diagnosis of dementia was given. Some types of dementia are also more likely to affect personality, although there are no hard and fast rules. For example, increased passivity, apathy and flattened emotional responses can occur earlier in Lewy Body dementia. Other people may experience profound personality change because of the loss that characterises dementia, becoming increasingly withdrawn and fearful (see later section on mental health difficulties). Some may be more emotionally responsive and demonstrate distressed behaviour.

## Section 2

Changes in personality are especially noticeable in someone with a diagnosis of Frontotemporal Dementia (FTD), formerly called Picks Disease. Profound personality changes can occur relatively early in the disorder. Because of compromised executive functions, the person with Frontotemporal Dementia can become disinhibited (i.e. less tactful, make rude comments, less aware of social norms, impulsive), apathetic (i.e. loss of interest in previous hobbies, indifferent to what is going on around them), becoming highly agitated, neglectful of self-care. 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.



### Attachment style

Attachment style is part of personality that is important to consider when working with people with dementia. We develop attachments, or close bonds, to others from birth because we need to rely on others (usually our mother) to meet our needs and keep us safe. In ideal circumstances, a child will feel confident in exploring the world, safe in the knowledge that the same person (or people) will be there when things get difficult. This is called a secure attachment.

For other people, stressful or difficult early life experiences impact on the way they bond with others in quite a negative way. An insecure attachment style can cause people to be generally anxious throughout their life, never quite feeling safe or secure in their surroundings. Some people manage this insecurity by clinging to others while others systematically reject others due to a fear of being rejected themselves.

At times of uncertainty, stress, or danger we are more likely to behave in ways that are closely linked to our attachment styles. Attachment styles are important to consider in the context of dementia because they will affect the way each individual builds relationships with staff and carers and how confident and comfortable they feel when doing so. They will also influence how the person responds to stress, anxiety or fear.



Thus, people in the later stages of dementia often feel abandoned and many will display 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 behaviour can be distressing for staff but what is often required is empathy and some attempts to help the person with dementia feel safe and secure.



## Section 2

### Activity 2b): Personality and attachment



- 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 their behaviour. However, it is essential to consider the whole person if we are to provide good person-centred care. Knowing the person well provides a context to understand the person's behaviour and lends itself to increased quality of life for the person living with dementia and reduced stress for caregivers.

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.

Some people may have a '[getting to know me](#)' document (Alzheimer Scotland) or similar. This will be a helpful document to use when beginning the process of gathering important information about the person with dementia. However, it is important to ensure that families are included in this process, it is kept up to date and that all those involved with caring for the person are aware of the information and incorporate it into their practice.

In research studies looking at improving care for people with dementia, staff involvement in gathering life history information has been shown to be the most important method to help understand the person and develop empathy for that person. It enables people to see them as a person and not a problem.



#### **B) Attachment**

Think about a person living with dementia who you know to frequently call or shout out. Often people who call out repetitively often have little interaction as staff find the behaviour stressful as they do not know what the person wants or how to respond.

After listening to what the person is saying, and eliminating comfort needs like needing the toilet, hunger, thirst or discomfort/pain, consider whether it could be attachment behaviour that is leading to frequently calling or shouting out. It may be that the person is looking for contact, reassurance or a sense of safety and security from others.

Going to the person and providing comfort and reassurance may not stop them from calling out in the future, and the behaviour will often resume after you leave. However, providing this when you can will contribute to the person being generally more settled (as ignoring their behaviour will likely make them more distressed) and they will most likely benefit from spending some time with you. Often this behaviour is thought of as attention seeking and staff are concerned that they may 'reinforce' the behaviour. Regular proactive visits can sometimes reduce the behaviour and may lead to a more trusting relationship.



### 2c) Emotions, motivations, thoughts and behaviour

Though these crucial aspects of life tend to be separated in psychology, they interact continuously with each other and 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.



**To illustrate the impact of perception on behaviour, imagine you are stuck in a chair and can't move but you are not sure why. Then someone you don't know is approaching you, is invading your personal space and you are not able to work out what their intentions are. How do you think you would feel? What would you do?**

**Someone living with dementia may not be able to reason through this scenario and their response will likely be to behave in a way that minimises danger or keeps them safe.**

Often when people living with dementia become distressed staff will say 'there was no trigger'. This is most likely due to the trigger being internal, for example, a sensation or a memory. This coupled with an environment that doesn't make sense to the person will result in an emotional response. Depending on what this emotional response is, it is likely there will be a release of adrenaline and activation of the fight or flight system where the person will behave in a way that minimises danger and keeps them safe, for example, hitting out at others, or shouting.

These examples illustrate that the ability to integrate emotions, and thoughts to produce adaptive behaviour becomes increasingly disrupted in dementia. Later in the disease, it can affect all aspects of care and leads to particular problems in residential facilities. People living with dementia will increasingly rely on their 'gut instinct' as the disease progresses and they are less able to process complex information or think through situations or problems fully. This means that they are less likely or able to change their behaviour, or adapt their behaviour to help them to function in their environment.

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. Instead, people will be more likely to respond in an automatic way, potentially with resistive or self protective behaviour. For example, prior to having a diagnosis of dementia, the person may have allowed staff in a general hospital to support them with personal care after an operation. In this situation, they would understand their environment, would have insight that they needed help, and would feel safe and secure. A person with dementia may not have this level of insight and may not be able to understand the intentions of staff. You can see how this could lead them to misinterpret the situation and respond with self protective behaviour.

## Section 2

Difficulties making sense of information and solving problems mean that people with dementia will try to understand their environment or solve new problems with memory for what has happened in the past. People may therefore interpret cues from the environment, such as staff putting on their coats and saying goodbye at the end of their shift as a cue that it is time to go home. They may then become confused, frightened or angry when they are told they cannot go home or are prevented from leaving.

Understanding how psychological processes can be affected by dementia will enable you to have a better understanding of a person and their behaviour. This will help you to respond to them in a way that is helpful to them and minimises any distress.

### Emotion, behaviour and mental health

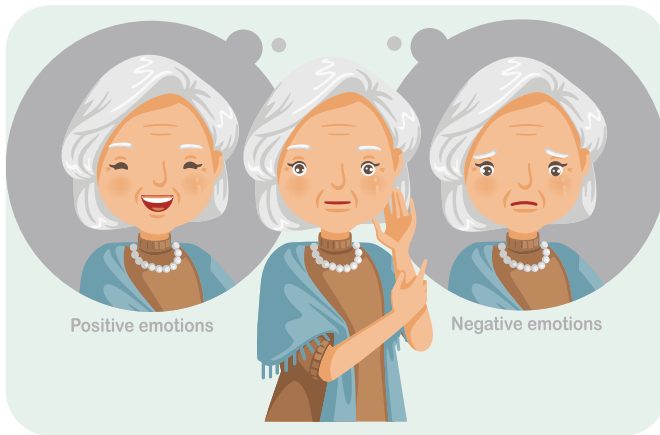
A substantial number of people with dementia enter a sustained period of aversive emotions of sufficient intensity to classify them as having a mental health problem. It is impossible to give accurate figures, but it is safe to say that at least 20% of people with more than moderate dementia have clinical levels of either depression or anxiety, or both. Depression can occur in all types of dementia, but it appears to be most common in those with Vascular Dementia. One study from the Alzheimer's Society suggested that up to 40% of those living with dementia also experience symptoms of depression.



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.

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 approximately 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 misunderstandings or misinterpretations caused by cognitive impairment.

## Section 2



It is also important to consider whether the person with dementia had experienced mental health difficulties, such as depression or anxiety prior to them receiving a diagnosis of dementia. Dementia and mental health problems are not mutually exclusive, and there is a subset of the UK population living with both. This group consists of people living with existing mental health problems who develop dementia, and people living with dementia who develop mental health problems (Mental Health Foundation, 2016). Those that had a pre-existing mental health condition may experience their diagnosis of dementia differently from those who have not had a mental health condition before developing dementia. This highlights the need and importance of knowing the person well, both in terms of their physical and mental health.

### 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. 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 may think 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 living 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. To be able to do this you must bear in mind that the capacity to make sense of what is going on, is now severely compromised by memory, language, perceptual and other cognitive impairments, including difficulties 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.

## Section 2

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 living 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.

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 symptoms.

Look at the [Cornell Scale for Depression in Dementia \(CSDD\)](#) and the [Rating Anxiety in Dementia \(RAID\) Scale](#)

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 health service. Clinical levels of depression or anxiety in dementia are common causes of excess disability and untreated depression is a predictor of greater disability and earlier death.



### 2d. 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 most common types of dementias, 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 conditions 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 disease 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, 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 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, component of person-centred care of people with dementia.

## Section 2

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 such as the [Abbey Pain Scale](#) or the [Pain Assessment in Advanced Dementia \(PAINAD\) Scale](#) to aid your assessment.

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



## Section 2

### Life experiences

The person's life experience will almost certainly influence their experience of dementia. Factors such as those mentioned earlier in this section, for example, personality, attachment style and mental health will all interact and affect the experience of dementia. This needs to be considered when working with a person living with dementia.

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 a high risk of aversive experiences such as being man-handled by several people to get them into a shower. Explicit or conscious memory may decline, but many people with dementia implicitly (subconsciously) remember situations, places or people with whom aversive things have happened. The emotion attached to these events is felt and remembered, despite not consciously remembering the specific details of the event. Similarly, they may misinterpret new experiences in light of these implicit (subconscious), emotive memories.

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A significant number of people living with dementia manage these experiences surprisingly well, though most at some stage, manifest what is called 'stress and distress' due to these aversive experiences. The term 'distressed behaviour' is also used. In the past, the term 'challenging behaviour' was used to describe this type of behaviour, but due to a significant shift in dialogue, education and staff understanding this term is very rarely used, if at all.

As a result of repeated negative, aversive 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 living with dementia as far as is possible in a way which enables them to continue to have positive experiences. To do this, it is important to know and understand who the person is, for example, what their likes and dislikes are, what type of job they did if they used to work. By knowing this information, you are working in a proactive, person centred way and reducing the likelihood of distressed behaviour arising.

Use the exercise below to help you consider how best to interact with a person living with dementia. You will also find more information which should assist you in section 3 on Communication.



### Activity 2b ii): Life experiences



- A)** Observe how the people living with dementia 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.



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

- What was it about their approach that you liked?
- How do they do it?
- What is its effect on the person?

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

- What was it about this interaction that you didn't like?
- What was its effect?
- How do you think you would respond if treated in this way?
- Would this response change if you had a diagnosis of dementia?

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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 person living 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 and routine 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 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 living with dementia to do this?", but rather, "What support needs to be put in place so that the person living 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 living with dementia can be supported in maintaining safe mobility. We suggest the [Alzheimer Scotland](#) or [Alzheimer's Society](#) websites for advice on how to maintain or adapt this and other activities.

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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 living 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 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 living 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 living 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 living with dementia however, the move can mean a rapid diminution or total loss of previous lifestyle and quality of life. People living 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 living with dementia may be on inappropriate medication which also leads to excess disability, or will have untreated pain, delirium, or depression.



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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 living with 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 be like home. Secondly, there are often insufficient resources to meet the complex cognitive and medical needs of people living with dementia. Some facilities do manage to provide excellent care and minimal diminution of 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 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?**



### Activity 2b iii): Lifestyle

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 I and my colleagues intervene or change practices, to improve lifestyle for this person?**

## 2e. Introduction to distressed behaviour in dementia

Previous sections have alluded to the many reasons why people living 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 dead parent because of feelings of abandonment

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- 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 living 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 disinhibition associated with Frontotemporal Dementia (FTD) and behaviours like perseveration in other dementias, it remains unclear how much focal brain damage **directly** causes the person living 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 understand 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,

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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 to 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 problems; and a host of other medical conditions; as the most common causes of distressed behaviour. They should always be investigated and ruled out 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 living 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 living with dementia.

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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 living 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 living 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?***

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.



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**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 living with dementia communicate distress; we are limited to this real-life data.

**Table 1: Behaviours family carers reported leading to seeking help**

Behaviour which led to referral by family carers	Number of cases referred	Per cent
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%
<b>Total</b>	<b>143</b>	<b>100%</b>

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

Behaviour which led to referral by care home staff	Number of cases referred	Per cent
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%

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.

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- 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:
- motor restlessness
  - repetitive actions
  - being unable to recognise people

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 living 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.

Proactive and preventative approaches to reduce the likelihood of distressed behaviour are 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.

# SECTION 3: Communication – people living 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.**

## Section 3

### Communication

In this section, we focus on communication with people living 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.

### 3a. 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 living 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, how they are reacting to it.

Thinking about using a two-way radio can be a useful way to understand the processes involved in effective communication.



#### 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.

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- The person receiving the information needs to listen carefully to the other person. Tuning into what the person living 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.
- 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!

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? When did they last have an eye test?
- hearing difficulties – does the person have a hearing aid? Are the batteries working? Does the person have a problem with ear wax? When did they last have a hearing test?
- speech difficulties – does the person have dental problems? When did they last have a dentist appointment?

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 effect 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.

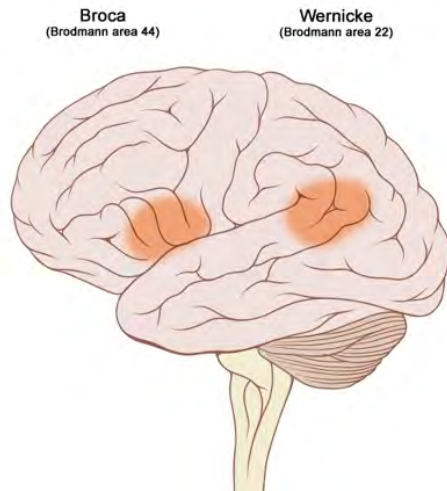
Language functions support social communication. Receptive language skills are concerned with understanding written or spoken language. Expressive language skills are concerned with the expression of written or spoken language.

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

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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/understanding 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 the wrong word or sounds.

Cognitive communication skills are the abilities, additional 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 people living with dementia will each have a slightly different set of cognitive strengths and weaknesses, across a variety of areas within the brain it is important therefore to request a thorough assessment in order to develop communication strategies that are appropriate for that person. Below are some examples of the ways in which language impairments can affect communication:

- Some people may have difficulty in understanding language and as such, their speech appears to be fluent but their responses or conversations make little sense to those who are listening, since the person 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 person 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 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 and language specialists, to aid in understanding the nature of, and responding appropriately to, communication difficulties.

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### 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 living 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 living with dementia may be just as powerful as our words.

Consider a situation where you approach a person living 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 living 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 living 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 know the person well and to tailor our interactions to their preferences.

### A focus for communication

The memory problems experienced by a person living 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 to 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 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. Some care home settings are beginning to use individual activity bags, with items specific to that person, knowing they'll be of interest and stimulate conversation. 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.





### Validating 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 living 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' or to feel 'safe and secure' 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.

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 3a)i: Validating responses



For each of the interactions described briefly below, try to supply a validating response:

Person living 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? 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.	

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?

## Section 3

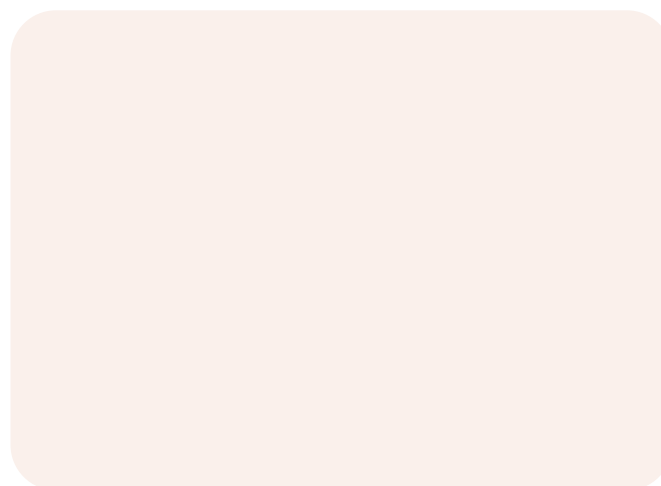
### Watching the way we speak

In communicating with people living 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 more juice – that’s a good boy!”, “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 living 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

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. The same opportunity should, of course, be afforded to the person

living with dementia. The aim should be to, wherever possible, find ways for them to discuss difficult issues openly together. It can sometimes be possible for the staff member to act as a mediator ensuring all parties have a voice and are heard by others involved.



### Distressed behaviour

As already discussed in section 2, 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 living with dementia, as in the example above where our non-verbal communication inadvertently gives the wrong message to the person living 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 living with dementia who values independence and autonomy.

Sometimes the difficulty is linked to our failure to hear or understand what the person living with dementia is communicating to us through their behaviour. Let’s consider the person living 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 4 and 5 we describe how to engage with proactive strategies to prevent the likelihood of distressed behaviour arising. However, it is worth reiterating here that our own communication style, both with

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the person living with dementia and our colleagues, can feed into any difficulties experienced, both by the person with dementia and their carers. 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 living 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 living with dementia, where they listen attentively and respond to the feelings behind the words, then this is engaging with a proactive approach which is reducing the likelihood of the person living with dementia becoming distressed, eliminating unnecessary distress and difficulty for all concerned. On the other hand, where communication is patronising, controlling or confrontational then there is likely to be a trigger for distressed behaviour, as people living with dementia respond in a perfectly normal and understandable human manner to situations that are perceived as a threat to them and their wellbeing.



### **Activity 3b)i: Communication**



**You may need to develop the skills described in this section. Conversing with people living with dementia in a respectful way 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 living with dementia by talking to other colleagues during personal care, rather than to the person they are working with. There is abundant evidence that, in particular in wards and care homes, people living 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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If you or your colleagues identify a learning need in relation to developing communication skills, you may want to look at specific resources on communication. NES have developed a number of resources which you may find helpful. Please refer to the final section of NES resources available.

The following exercises are helpful to complete as they enable us to gain a better understanding of what the person's experiences of dementia are.



- A)** Observe how people you work with talk to people living 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 those 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

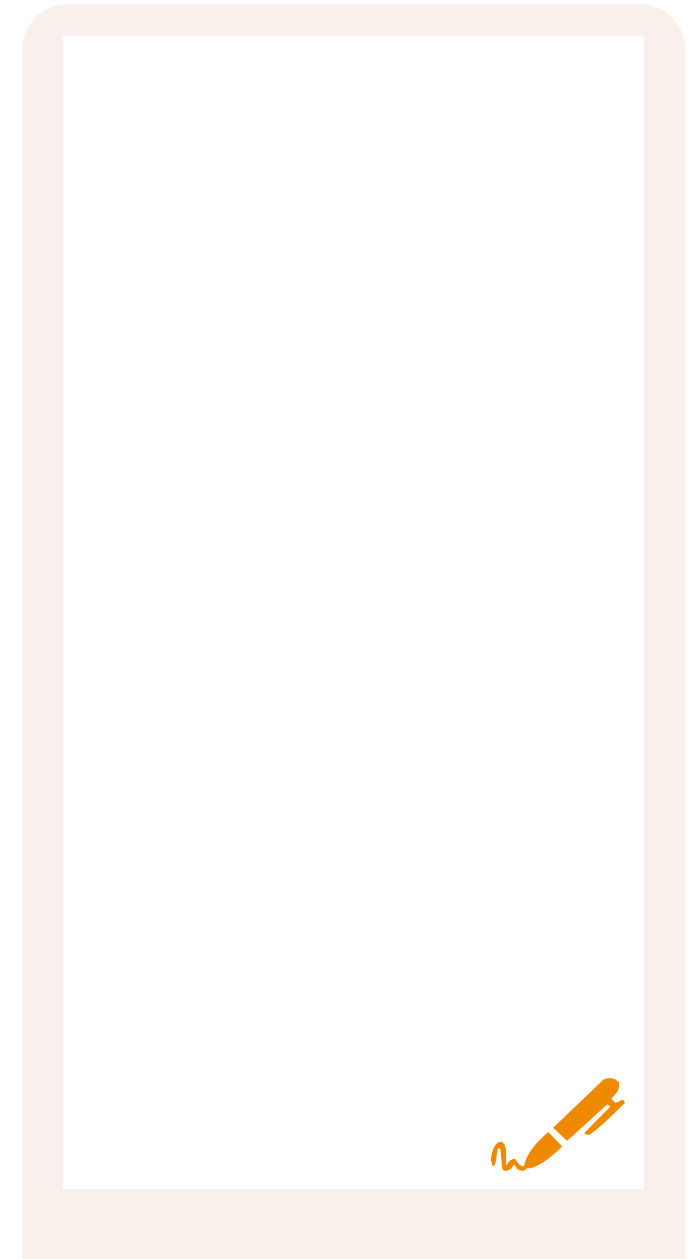
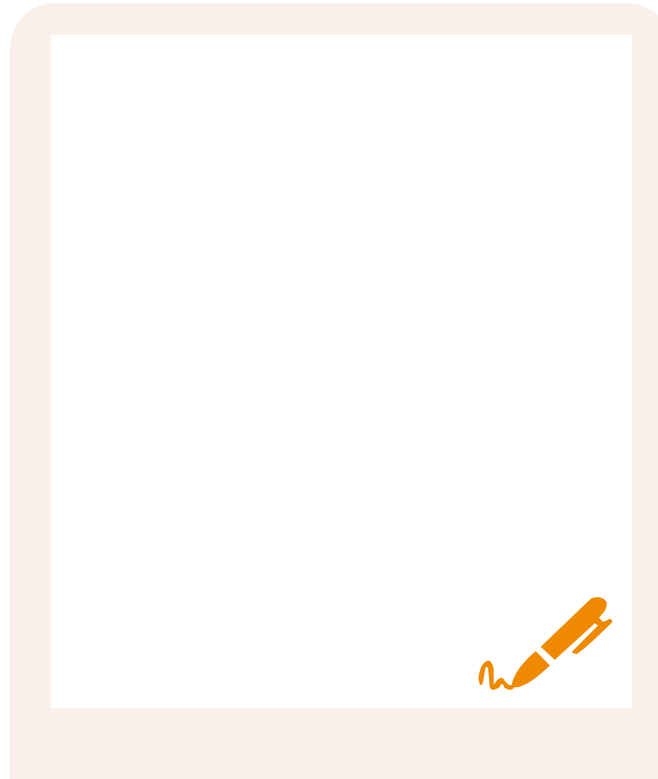
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studies have shown that it may be less than two minutes in total and, if they also have distressed behaviour, many of those interactions may be negative. If you find that one or more residents are in this position, what could you do about it?



- 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 many years.



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### Activity 3c): Self assessment quick quiz



**Check whether you have understood the main points so far**

**Answer true or false to the following questions:**

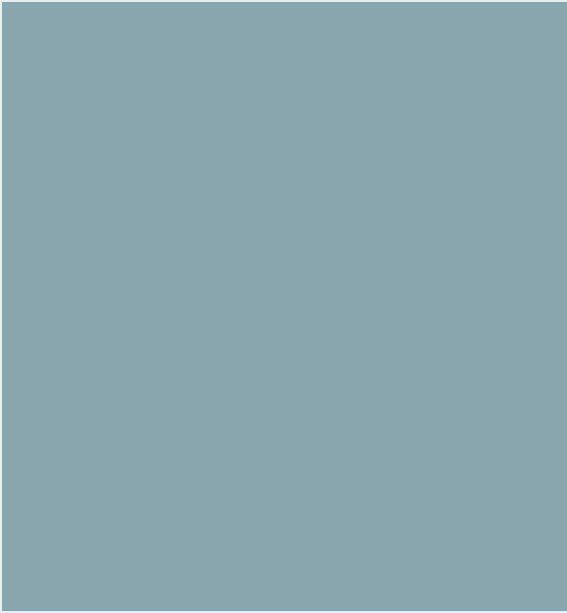
1. Everyone with dementia will appreciate a touch on the hand to let them know you are there for them. **T/F**
2. It is often best to validate the person's feelings and meaning of their words, rather than trying to repeatedly correct them. **T/F**
3. It is always best to correct the person when they make mistakes. **T/F**
4. If someone has a language impairment they will be unable to understand what words mean and unable to express themselves clearly. **T/F**

1. Correct answer is: FALSE  
2. Correct answer is: TRUE  
3. Correct answer is: FALSE  
4. Correct answer is: FALSE

### 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 living 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 4: Evidence-based psychological interventions in dementia care



### Learning objectives

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

1. Explore and evaluate evidence underpinning interventions for people with dementia.
2. Determine effective interventions in response to assessment and identification of need with the person with dementia.
3. Utilise a range of psychological approaches and techniques in supporting the person with dementia.
4. Utilise support and supervisory mechanisms to continuously improve practice.



## Section 4

### Evidence-based Psychological Approaches

In recent years a range of psychological interventions for people living 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 person you are working with. A helpful starting point can be to talk to the person living 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.

As you see from this example, creating opportunities for people to engage in meaningful activity does not have to involve special event 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 living 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.

### 4a. Cognitive Stimulation Therapy (CST)

CST is currently recommended by SIGN 86 and NICE (2018) 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 four or five 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

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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 living with dementia whose distress 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.

CST can reduce excess disability, by tapping into the strengths of the person living 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.

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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 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 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:*

- NHS Education for Scotland (NES) regularly deliver free CST workshops across Scotland. For more information on these workshops, please contact: [Psychology@nes.scot.nhs.uk](mailto:Psychology@nes.scot.nhs.uk)
- Manuals available from Hawker Publications. Training DVD included. For more information click on this link to the CST website <http://www.cstdementia.com/>

### 4b. 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.

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- Reminiscence groups – typically involve five or six people with dementia and one or two 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 to touch, items to smell and taste, 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.
- Football reminiscence groups are growing in popularity and are evidencing good outcomes for those that attend such groups. Research seems to be suggesting that male only groups tend to be more effective than mixed gender groups. This would be something important to consider when organising your own reminiscence groups.
- 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 living 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

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reduce excess disability. Some positive results have been reported for reminiscence groups in relation to 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](#)



### **4c. 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, by-pass, 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.

Cognitive Rehabilitation is an individualised approach, in which the therapist works with the person living 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.

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 required. and should be in place before engaging with a cognitive rehabilitation approach.

#### **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

## Section 4

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: a learning resource for staff.** This resource is for staff working at the Enhanced and/ or Expertise level as stipulated within the Promoting Excellence framework and staff should have experience of using cognitive rehabilitation strategies in their clinical practice.



Have you used or set up any of the suggested activities or groups suggested here in your work place?

If you have, what has the response been like from people living with dementia?



### 4d. 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 living 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 living with dementia from a sensory deprived environment directly into a multi-sensory 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?

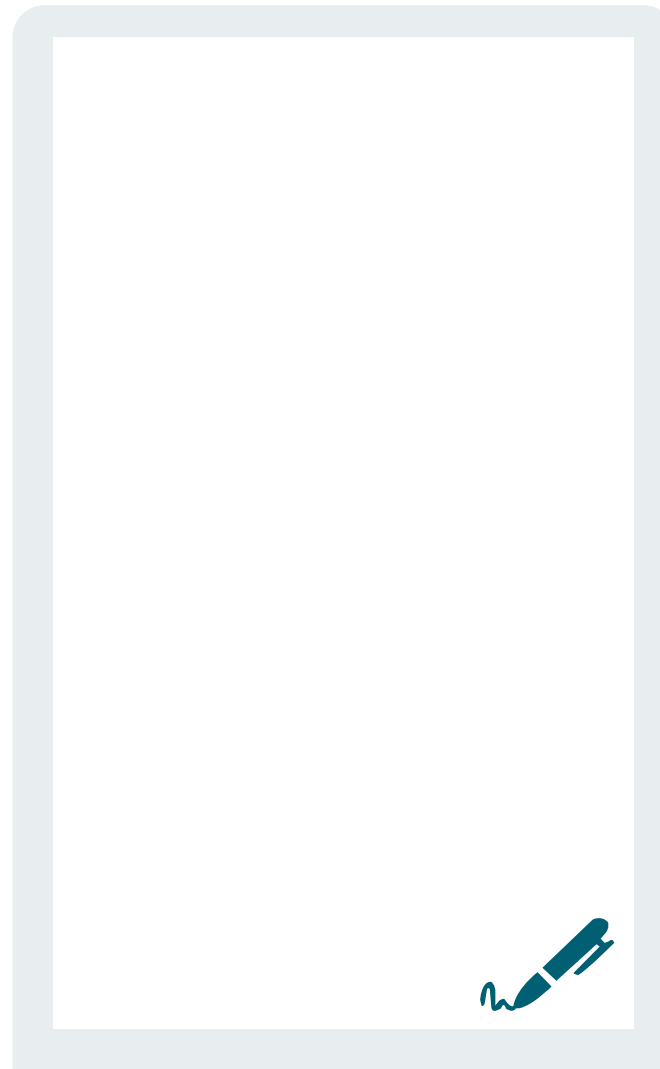
### Activity 4d): Overstimulation



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 a 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 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 living with dementia. We have explored who these approaches are suitable for. We have reviewed the appropriate and inappropriate use of these techniques.



# SECTION 5: Psychologically informed practice to guide proactive and preventative strategies in dementia care

### Learning objectives

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

- 1. Better understand the underlying causes of distressed behaviours in dementia.**
- 2. Explore the evidence-based proactive and preventative strategies within dementia care.**
- 3. Reflect on the benefits of engaging in proactive strategies to prevent distressed behaviours from arising.**

For an introduction to meeting the needs of a person living with dementia who may be at risk of escalating distressed behaviour, please see module four of the NHS Education for Scotland (NES) Dementia Skilled Improving Practice resource which can be found on the NES Dementia webpage.

## Section 5

We would also recommend you to access a NES training programme titled: **‘Essentials in Psychological Care – Dementia’**. This is a one day face to face training programme for those working at the Skilled Level of practice or above within the Promoting Excellence framework. This training programme builds on the information within this section of the resource.

For more information about Essentials in Psychological Care - Dementia, please visit the NES Psychology of Dementia webpage or contact the Psychology of Dementia team via [Psychology@nes.scot.nhs.uk](mailto:Psychology@nes.scot.nhs.uk).



### Psychologically informed practice in dementia care

#### What is it?

Understanding dementia from a social and psychological perspective can have a significant impact on how dementia is understood and how those experiencing it are viewed. Maintaining a sense of control, identity and connection is a key focus of psychologically informed practice in the context of dementia. A number of psychological models and frameworks can enable us to keep this focus at the core of our working practice. As dementia progresses, it may become harder for the person to remember and communicate important information or to access familiar and personally-meaningful experiences. There is a risk that, as a result of this, the person may experience a sense of isolation at a time when the emotional resources to protect against this threat are lacking. It is important to support the person living with dementia to maintain links with key aspects of their social and cultural identity, including personal preferences, wishes, memories and experiences. This support helps to build and maintain trust, to establish a sense of security and comfort, and to provide a sense of social connection. This can go some way to maintain and promote wellbeing and self-esteem. (BPS, 2016).

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 living with dementia may become distressed but, equally, there are many reasons why carers and staff can become distressed by certain behaviours.

## Section 5

Throughout this resource, there has been a clear emphasis that each person is different and an individual in their own right, whether or not they have dementia. Each person's experience of dementia is unique. This means that each person will have their own specific underlying factors that may be triggering, maintaining or exacerbating distress, if it were to present. No two people will be the exact same, even if they have the same type of dementia. To be able to work in a psychologically informed, proactive way, we must be able to embed the use psychological models and frameworks into our working practice to help us better understand the person living with dementia and to know who they are as a person. This will then guide how we engage and make links with each person in a truly person-centred way.

When we think about distress in the context of dementia, 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, however for approximately 80% of people who have been prescribed them, this is not the best 'treatment'. They do not address the underlying causes and may inadvertently cause negative side effects.

Each person living with dementia will have abilities to perceive, understand and communicate which are unique to them. The underlying causes, triggers, maintaining factors of distress and their ability to reduce and manage their distress can differ significantly. In order to maximise the effectiveness of any approach we use, we need to first understand this complexity.

A recurrent theme and recommendation in the dementia literature relating to distressed behaviours, is the importance of individualised treatment approaches (Bird et al, 1995; Cohen-Mansfield, 2001). [The Standards of Care for Dementia](#) (2011) state that individuals with dementia and their carers, have the right to access a range of treatment and care options that is likely to be of benefit, including psychosocial, proactive approaches. Of course, it is essential that for any proactive strategy or approach to be as effective as it can be, contributing physical factors must first be excluded or addressed. Let's look at excluding physical factors first:



### 5a. Exclusion of medical/physical factors

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

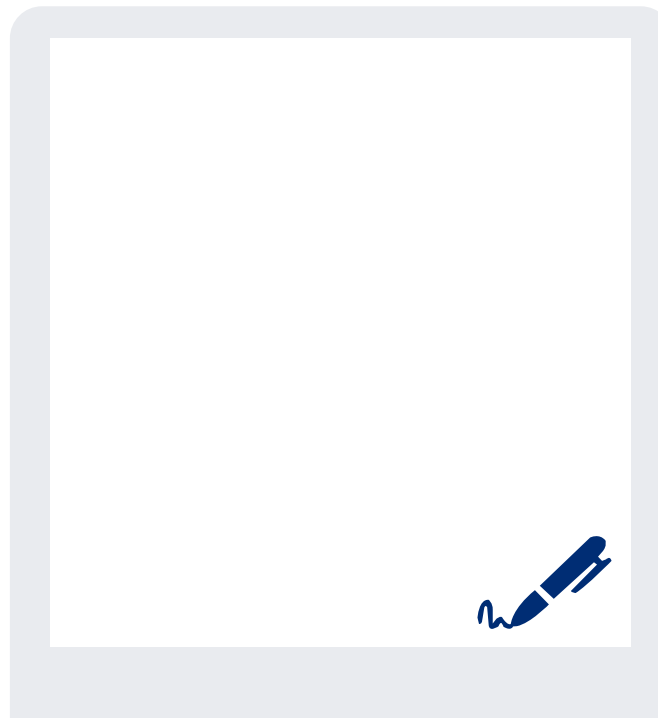
- delirium caused by infections (chest, urine, skin for example)
- constipation
- dehydration
- respiratory problems
- pain
- skin irritations
- medication interactions (many people with dementia are on a large number of medications, some of which may have adverse effects)
- general discomfort (e.g.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

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 distressed behaviour. 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?



### Delirium and Infections

Delirium is a serious medical condition which is common amongst older people. People living with dementia are at increased risk of developing a delirium and so it is something all staff should consider if a sudden change in behaviour is noted. In collaboration with the Scottish Delirium Association, NHS Education for Scotland (NES) and colleagues across NHSScotland, Healthcare Improvement Scotland (HIS) developed a range of tools and resources to support improvements in the identification and immediate management of delirium. This toolkit has been produced to provide easy access to all of these tools and resources. Please access this toolkit using the link below.

<https://ihub.scot/media/5955/20190312-delirium-toolkit-3-0-web.pdf>

In addition, NHS Education for Scotland (NES) have developed a number of helpful delirium learning resources. Please visit the NES website for further information on delirium.

SIGN recently published guidelines on risk reduction and the management of delirium: <https://www.sign.ac.uk/sign-157-delirium.html>. These guidelines can be helpful to refer to in addition to the resources available through NES and Healthcare Improvement Scotland (HIS)

## Section 5

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 are a good source of information in terms of best practice and treatment options. <https://www.sign.ac.uk/media/1051/sign88.pdf>

### Impaction

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 5a): Medical/physical factors



- Do you think about delirium if there has been a sudden change in the person's behaviour? How do you manage and treat delirium?
- Do you ask carers about bowel movements or potential constipation?
- If not, why not? Is this something you and your service could look at?



## Section 5

### 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 person 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 person, it may cause another to withdraw and become more confused. It is vital to know the person well, in order 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?”

A number of screening tools can be used to monitor pain in people with conditions likely to cause pain, such as osteoarthritis or other chronic long term conditions. Examples of such tools include the [DOLOPUS-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 people 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 5b): 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 dietitians are accessible in the NHS and it may be worthwhile identifying who the dietitian is for your client group and service.



### Activity 5c): Diet



- Do you know who your local dietitian is, or which Dietetics service you can refer your patients to?
- Do you ever refer patients to the dietitian?
- 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?



### **5b. Psychologically informed practice to guide proactive and preventative approaches to reduce escalation of distressed behaviour in dementia**

#### **Iceberg Model (James, 2011)**

When we think about someone's experience of distress we need to think about the underlying causes as well as the outward signs. A helpful model to enable us to get a better appreciation and understanding of underlying causes of distressed behaviour is the Iceberg Model (James, 2011).

The distressed behaviour can be seen as just the 'tip of the iceberg'. Part of the iceberg is under the water and represents what we don't immediately see or think about. This Iceberg Model reminds us not to just focus on and label a behaviour, but instead to think about what might be going on for the person and the underlying causes. It is important to remember that behaviours are often linked to beliefs.

John is used as a case example to highlight the different sections in the Iceberg Model. John believes he is 28 years old and works an early shift. This belief links to his need to get up early, leave the care home and get to work. He is worried and anxious about being late. In addition to John's beliefs, other factors are shown in the deeper levels of the iceberg. He may be experiencing side effects from medications, his eyesight may be poor as he does not always wear his glasses. For personality, John views himself as hard working and dedicated. Cognitive changes may mean he forgets where he is and acts without thinking. Physical difficulties such as arthritis and pain mean he becomes uncomfortable and sore if he lies in bed too long. This increase in pain can impact on his tolerance levels of uncertainty or confusion and make John more likely to respond negatively to heightened levels of anxiety. This last part referring to physical difficulties is particularly important to consider as proactive strategies will be less effective or not effective at all if physical causes or medical factors have not been ruled out in the first instance. For example, it would be helpful to provide regular pain relief for John's arthritis.





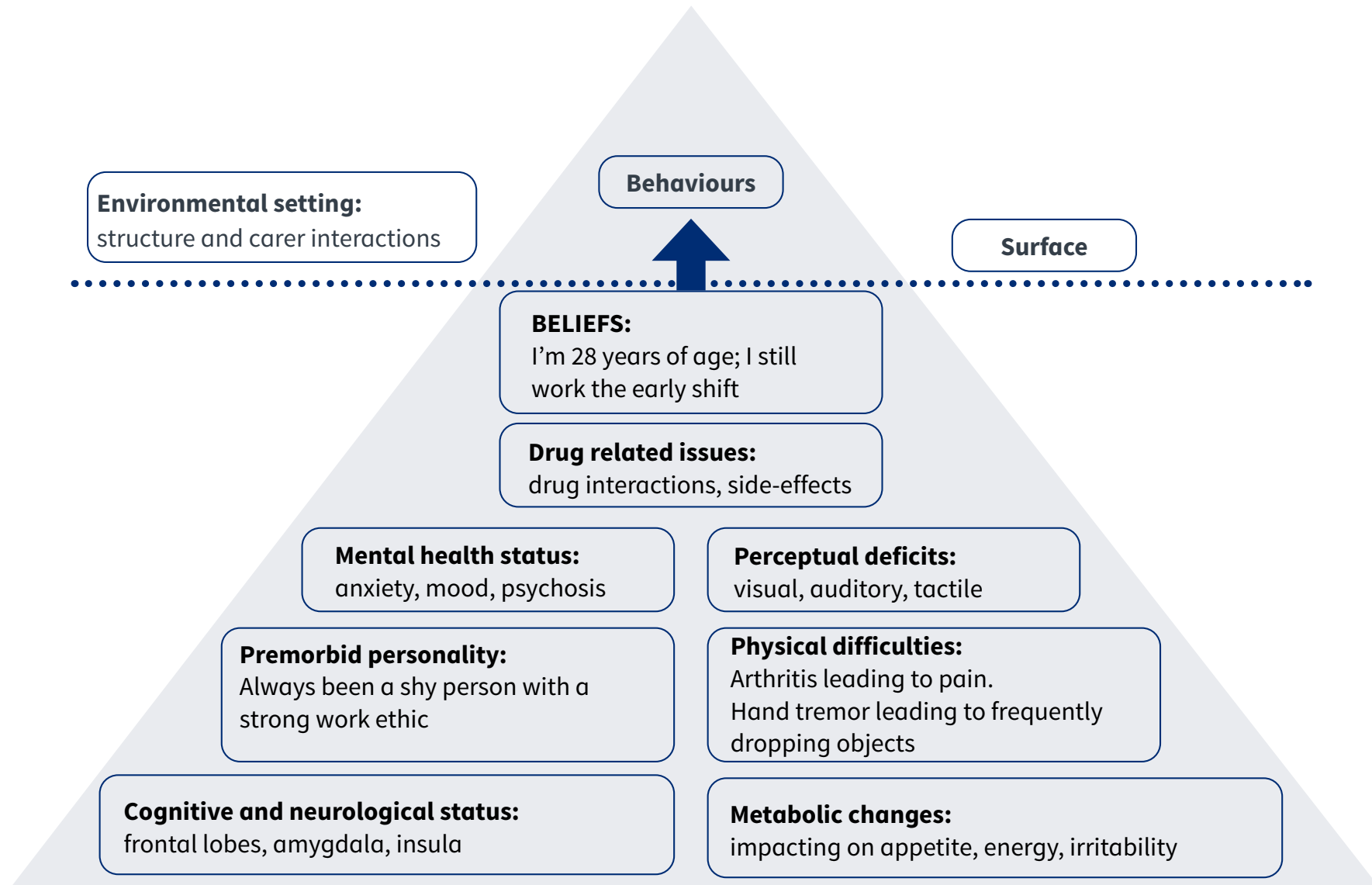


Figure 1: A diagram of the Iceberg Model

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### Biopsychosocial Model

Another useful way of understanding underlying causes of distressed behaviour is the Biopsychosocial Model.

In the past, we thought about health and wellbeing as being purely physical or biological. Now, health and wellbeing is seen as being much wider and more complex than that. Biological and physical factors are still important, but so is our psychological and emotional wellbeing, and our relationships and social environment.

It can be helpful to first think about the biopsychosocial model in the context of someone breaking their leg.



**Biological:** I have broken my leg. I need to take painkillers and wear a cast.



**Psychological:** I miss my colleagues at work and feel lonely. I feel isolated as I'm not seeing my friends as often and so my mood has dipped a little. My usual way of managing how I'm feeling is not currently available to me as I'm not able to go for a run. My mood dips further.



**Social:** I can't do my job so I need to take sick leave and stay at home. I'm not able to drive and so do not see my friends as often as I would usually, and I am not able to engage in my love of running.

It is the interaction of these three factors, i.e. biological, psychological and social, which affects our wellbeing and sense of self.

We will now look at this model for a person living with dementia.



**Biological:** I have a neuro-degenerative condition, I am becoming older so may be experiencing more pain due to physical health conditions such as arthritis. I am more prone to infections.



**Psychological:** I miss my family and friends which can lead to sadness and loss so my mood may dip. I don't feel connected to my surroundings, which increases my sense of fear and worry.



**Social:** I no longer live in my own home which has led to a loss of privacy and change of routine due to living in a care home. I do not feel connected to my

community and I am not engaging in usual activities or hobbies.

This model is helpful for thinking how best to be proactive in preventing distress. Because it covers biological, psychological and social factors, this means the proactive and preventative strategies we use can be much broader and more person centred.

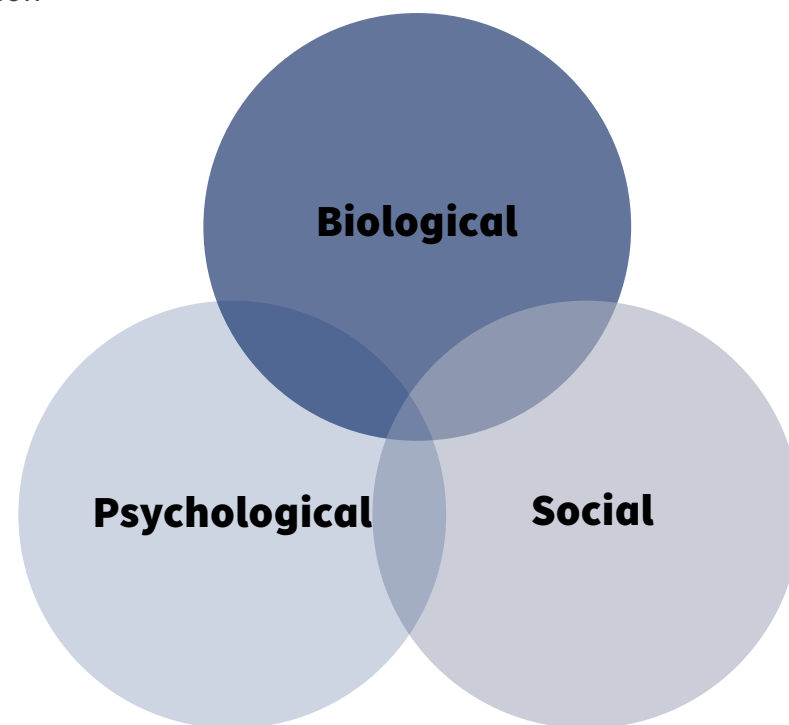


Figure 2: A diagram of the Biopsychosocial Model

## Section 5

Examples are given below for possible underlying causes for distressed behaviour in dementia. This list is not exhaustive but will give you some indication for possible triggers:



**Biological/Physical:** most common reason for distress in people with dementia. Examples: pain, constipation, dehydration, side-effects from medications, It is important to treat and rule out reversible biological/physical causes first, especially if the onset was sudden.



**Psychological:** missing family or pets, feeling lonely, or be worried about relatives because they can't remember where their family member is. This can cause feelings of low mood and anxiety. The person may feel threatened or confused, and be more likely to be nervous or scared and seek safety or the comfort of others. Changes in the brain due to dementia can lead to disinhibition: the person may not think before they act – hitting out when angry, stripping off clothes in the dining area.



**Social or Environmental factors:** not having a lot of stimulation or company can lead to feelings of apathy and sadness. Too much stimulation can cause sensory overload. The environment may be too noisy, too busy, too hot or too cold.

By breaking down all the contributing factors we can begin to see where we can be proactive and help prevent distress for the person living with dementia.

### Psychological Needs Model (Kitwood, 1997)

We have already looked at how medical factors, history, personality and beliefs influence behaviour. We will now look at how needs can also influence behaviour.

Tom Kitwood developed this model and defines five psychological needs based on clinical observations to establish the main focus for any given approach or intervention. The five psychological needs from his model are:



**Attachment:** we all need to feel we have a bond with someone or something. It is about feeling attached to objects and others, particularly at times of change or when we feel insecure or uncertain.



**Comfort:** is about the provision of warmth, soothing of pain and sadness and closeness to others. To take this further, it is a need to feel “thoroughly strong” (Kitwood, 1997, p.19), which in turn improves our sense of resilience and coping when faced with stressors.



**Identity:** is knowing who you are and how you feel about yourself. Your identity is a story about yourself including your history/past, values, interests, hobbies and relationships.



**Inclusion:** we need to feel accepted and part of a group (family or friend), part of a community and part of society.



**Occupation:** being involved in an activity that is personally meaningful and provides positive self-esteem. It is not just about work, but can be any activity or hobby.

We all have these psychological needs, and this doesn't change because a person has dementia. What does change is the person's ability to have their needs met and to communicate that their needs are going unmet.

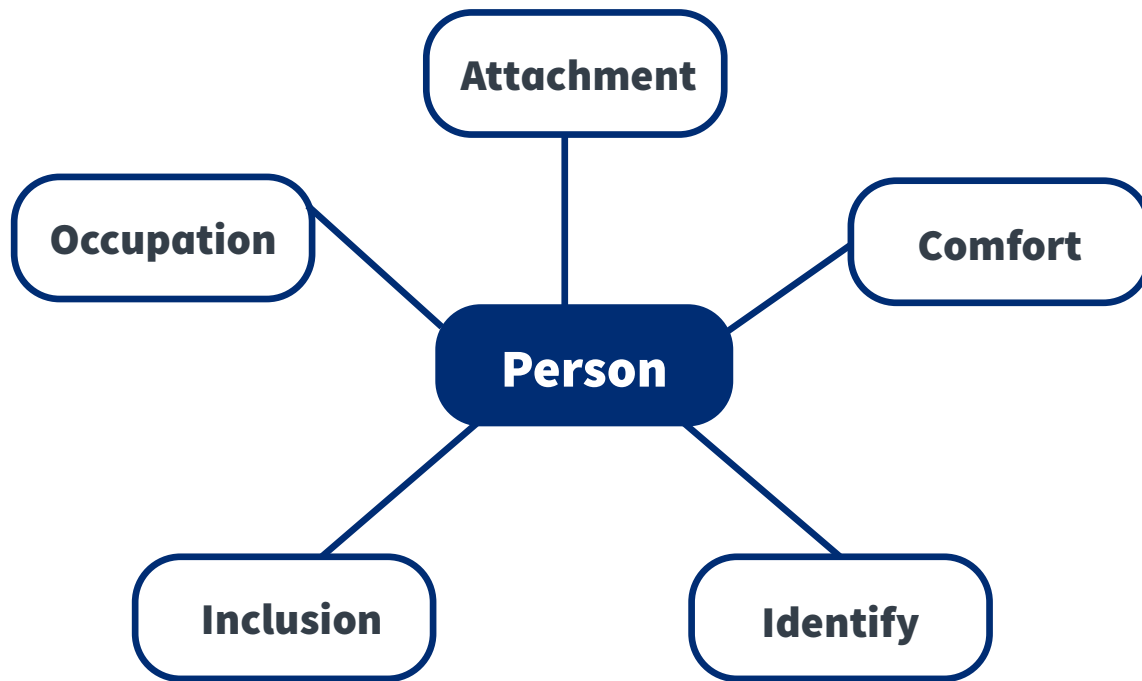


Figure 3: Diagram of the Psychological Needs Model



### Activity 5d:

Reflect on the concept that people living with dementia find it harder to get their psychological needs met by the nature of living with dementia, i.e. poor memory, lack of contact with family and friends, change in ability to speak/hold a conversation.

- What would you do to communicate your needs?
- How do you think this might differ if you had a diagnosis of dementia?
- How would you feel if your psychological needs continued to go unmet?
- What would you do?



### **5c. When Proactive strategies have not prevented the escalation of distressed behaviours**

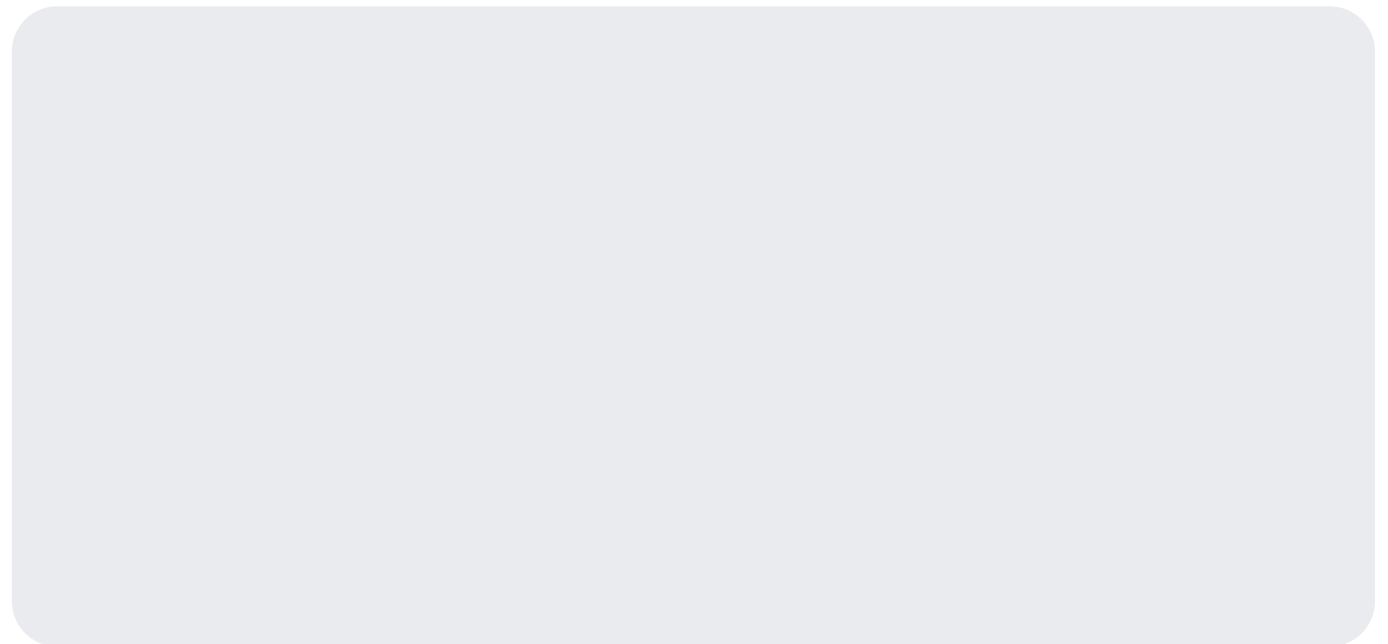
Using proactive strategies to reduce the likelihood of behaviours escalating and the person becoming distressed is something we encourage all staff to engage in. However, we recognise that behaviours can still escalate and the person living with dementia can become distressed despite using proactive and preventative strategies. When this happens, it is important to know what to do and how best to assess the behaviour. The following section looks at this in a little more detail. We recommend that if distressed behaviours are evident, a Stress and Distress practitioner, i.e. a clinician who has completed the NES Psychological Interventions in Response to Stress and Distress in Dementia, is contacted and that they support you in managing and reducing the distressed behaviour.

#### **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 opposite:



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### Activity 5e): 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	II	I		8
Wednesday				I	I	III	I		6
Thursday					II II	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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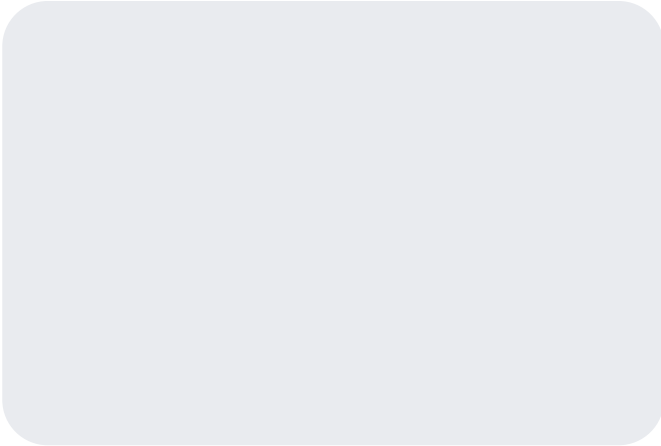
### Functional analysis

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 (“I don’t want to be left alone”, “how dare she speak to me like that”); 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 or trigger might not be as helpful as we would want it to be to help us understand the behaviour. 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 ABC charts and functional analysis. If you are interested in learning more about the use of ABC charts and functioning analysis, it is likely that you will be able to access training by contacting your local NES Dementia Specialist Improvement Lead (DSIL), an Essentials Trainer, or a Stress and Distress in Dementia Trainer. The ABC charts advocated within these training programmes have been developed by Ian James (2011). These charts differ from others in that they look at the emotions of the person before and after the event. This may give us some indication as to the thoughts and feelings the person may be experiencing.



Briefly, functional analysis includes the formal, scientific examination of what occurred, before, during and after the episode, observation or incident. A certain number of ABC charts need to be completed over a set period of time; this tends to be between 12-15 charts or over a 2 weeks period (whichever is reached first). ACB charts should never be completed indefinitely. The information collected from these charts forms the functional analysis. If more than one distressed behaviour is present, choose the one which is having the most impact on the person living with dementia; never try to assess and record more than one behaviour at a time.

### Summary

In this section, we have highlighted some of the key psychologically informed models which will support you working in a proactive, person centred way to prevent the likelihood of distressed behaviour arising. We have highlighted the crucial aspect of ruling out medical and physical causes for a sudden change in behaviour in the first instance, as without doing this, no proactive approaches will have the desired effect. It is also important to recognise that despite proactive approaches being used with people living with dementia, that person can still become distressed. If this happens, then it is important to take the appropriate steps in terms of assessing the behaviour and linking in with those who have been formally trained in functional analysis and the use of interventions to manage and address the distressed behaviour.



# SECTION 6: Looking after yourself

### Learning objectives

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

1. **Recognise your own feelings of stress and how best to respond.**
2. **Put a supportive plan in place to help respond and manage your own heightened levels of stress.**
3. **Identify when you need further support and know how to access this support.**

## Section 6

Looking after yourself as a carer is vitally important. This is equally as important for those working in a caring profession. In this section, we will be taking a closer look at how you can look after yourself in relation to recognising what your own needs are and how you have these needs met on a daily basis. In addition, recognise when your levels of stress might increase to a point that is impacting on your own wellbeing and quality of life and how best to respond. It is important to recognise that your own needs are just as important as the person you care for and that by looking after yourself, you are in a better position to care and support others.

### Signs and Causes of Stress

Stress is a word that we tend to use to describe how we feel when the demands of our life are becoming too much for us to cope with. Stress levels can be affected by a number of different factors and these will be different for different people to varying degrees. Not only this, but our ability to cope with stressful situations varies from one person to another. Mild feelings of stress are normal and can be motivating, for example, preparing for an interview. However, long term stress can be bad for our physical health as well as our mental health and overall well being. If we notice that stress is having an impact on aspects of our health this is when we need to think about what is impacting on our levels of stress and how can we best respond.

It may be helpful to initially think about the emotional aspects of caregiving, before identifying what impacts on our own stress levels. Caring for someone living with dementia can bring about challenges as well as many rewarding experiences. A person living with dementia may misidentify you which you may find unsettling or upsetting, there may be another person who may not want to be in your company, whilst on other occasions a person is wanting to be with you at all times and so this can be difficult to manage

on a daily or weekly basis. It can also be upsetting to see a person in continual distress, despite proactive strategies being put in place to reduce the person's distress. As a result of these situations, you may experience an array of differing emotions. Whatever the emotion may be, whether it's frustration, anger, resentment, or sadness, it is important to recognise these emotions are understandable, normal and more importantly, okay. A crucial factor to highlight, however, is the importance of being able to recognise when you are feeling a certain way, to understand why and to know how best to respond. This will ultimately help you manage how you are feeling and look after yourself, which in turn will improve the care you provide to those living with dementia.

## Section 6



Let's take a look at signs which may indicate that you are feeling stressed.

- Withdrawal from friends and social supports
- Refusing offers of support
- Neglecting your needs – not getting enough sleep, eating poorly, drinking or smoking too much
- Working even harder still to achieve your goals
- Frustration and annoyance with yourself – thinking “I’m still getting it wrong after all this time”
- Denial of any problem or stress
- Emotional blunting and/or depression – feeling like you do not have the energy to care about anything else
- Irritability – snapping at colleagues and/or family and friends, feeling on the verge of tears, fantasising about escaping from everything

It may be helpful to consider your own levels of stress in relation to a psychological model: The Biopsychosocial Model. This model helps us consider our symptoms of heightened stress in relation to biological, psychological and social factors. We thought it would be helpful to use

the same model we use to help us understand underlying factors and possible triggers for those living with dementia.

Please see table below for signs that you may be feeling heightened levels of stress.

Biological	Psychological	Social
Tense/Headaches	Anxious	Doing less with friends or family
Poor sleep	Frustrated	Arguing
Low energy	Feeling pressured/overwhelmed	Avoiding people/places
Exhausted	Moody	Drinking/eating/smoking too much
Frequent colds/infections	Unable to relax	Rushing around

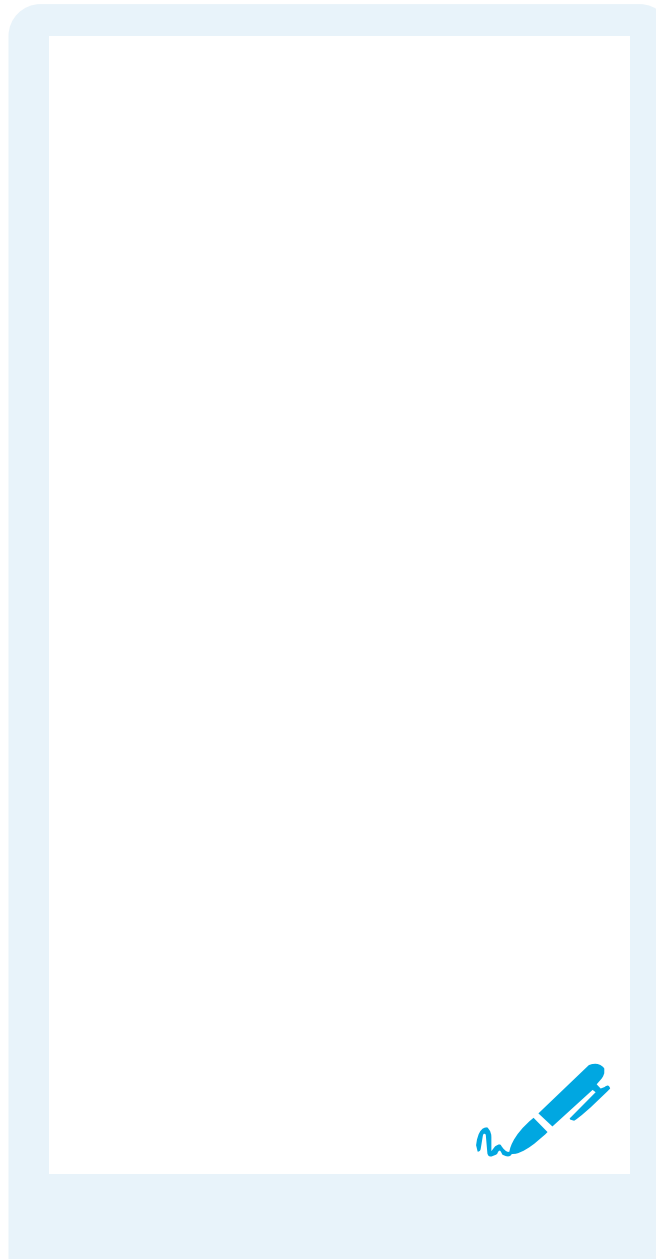
## Section 6

It is important to recognise and identify these signs as they may be an indication that you may be feeling or becoming stressed by the work you do and the role you have. If we ignore these signs, then the situation may escalate, ultimately having a more significant impact on you and the people you're caring for.



### Activity 6a) Causes of Stress

- What are your signs you are feeling stressed?
- Do you recognise any of your own signs of stress from the previous table?
- Are there particular triggers or events?
- How do you respond to feelings of stress?
- Is this a helpful way to respond?



### Maintaining a balance – managing stress at work and at home

The more time you spend in your working role without thinking about or recognising how you are feeling, the more likely it is you will develop high levels of stress. This is not helpful for you, your colleagues or for the people you care for.

No matter what we are doing throughout our lives, we all need time to ourselves to enjoy pleasurable activities and to take time out from our responsibilities. Whether this is having regular breaks throughout our working day or taking time to meet with friends, go for a swim or walk the dog when at home, it is important to still see ourselves as individuals with individual needs.

NES have developed an ABC Model of Self Care. It highlights the importance of Awareness, Balance and Connections as a way to support self care. The following illustration highlights some of the key components of good self care.

## Section 6

### AWARENESS



- + Awareness of your own responses
- + Acknowledge and accept feelings and thoughts
- + Activate self-compassion and calm coping strategies

### BALANCE



- + Breaks: regularly recharge at work
- + Boundaries: leave work at work
- + Basics: routine, eat well, hydrate, exercise, sleep

### CONNECTIONS



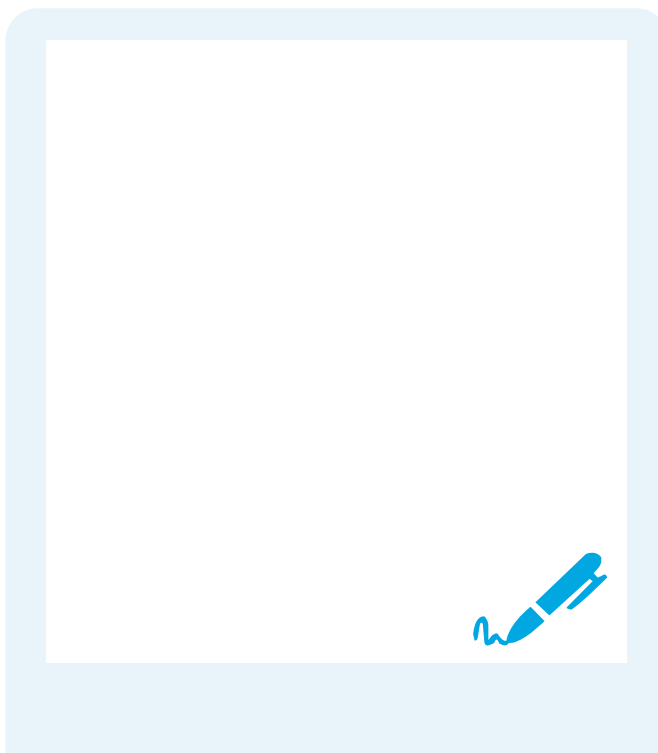
- + Colleagues: kindness to and from peers
- + Community: virtual and physical connection with family and friends
- + Cherish values: the meaning and importance of your work



### Activity 6b) Managing stress at work and at home

It may be helpful to reflect on the ABC Model of Self Care and ask yourself the following questions:

- Do I have time in the week that is set aside for me?
- If not, how can I arrange this?
- What are the things I would like to spend time doing?
- Who are the people I would like to spend time with?
- Who is in my network of support when at work?



Take some time to think about your answers to these questions and reflect on ways to address areas which have perhaps been neglected over recent time. It is important to ensure you have open discussions with colleagues and your manager if you are noticing that your stress levels are high and remain so over a prolonged period of time.

If you have noticed you are experiencing heightened levels of stress, it is important to identifying reasons for your stress. It may be that you are working with a person that reminds you of your own relative or a person may misidentify you as a loved one. If this is the case, consider minimising your contact with the person, where feasible. If you are distressed due to perceived threats to your own safety, discuss strategies to reduce risk with senior members of staff as it is vitally important that you feel safe and secure in your working environment. Ensure a risk assessment is completed and acted upon where there is a real threat to safety.

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In terms of managing heightened levels of stress, it is important to have a safe space for you to share your feelings and explore reasons for your distress. This can be done through formal channels such as supervision or informally through peer support – this could then form a supportive network for you when at work.

Some settings, for example, care homes have created ‘sanctuary’ rooms. These are places staff can go to to give them 5 minutes to themselves away from the frontline.

- Is this something you could consider to introduce to your work place?

Helpful discussions may identify that there are particular training needs and your line manager should be able to direct you to suitable training. It would also be helpful to make use of resources for managing stress such as those developed by NHS Health Scotland. One such helpful resource is ‘Steps for dealing with Stress’ which can be accessed via the link below:

<http://www.healthscotland.com/uploads/documents/5828-Steps%20to%20deal%20with%20stress-September2019-English.pdf>

## Section 6

The following table takes a look at ‘my non-negotiables’. This worksheet focuses on the importance of continuing to spend time doing the things which are important to our wellbeing and how we can overcome some of the barriers which often get in our way.

### Activity 6c) My Non-Negotiables: Looking after myself

Please complete as many rows of the table as you can. By completing the table, it may help you recognise what you have been neglecting in terms of looking after yourself.

Interests that give my life meaning	Reasons for maintaining these activities in my life	Negative thoughts that tell me I don't have time anymore	Arguments against these negative thoughts	People I'll ask to help me hold on to my interests
<i>e.g. Meeting with my friends</i>	<i>I gain support from my friends and I enjoy myself</i>	<i>I have too much to do in the day – I don't have time to have fun!</i>	<i>It's important to look after myself as this will help me manage how I am feeling</i>	<i>I'll ask my partner to look after the children on the occasions I plan to meet with friends</i>

## Section 6

If you would like more information on looking after yourself when in a caring role, there is a NES resource available which may give you some helpful ideas as to how we may look after ourselves if we notice we are experiencing heightened levels of stress. The resource is:

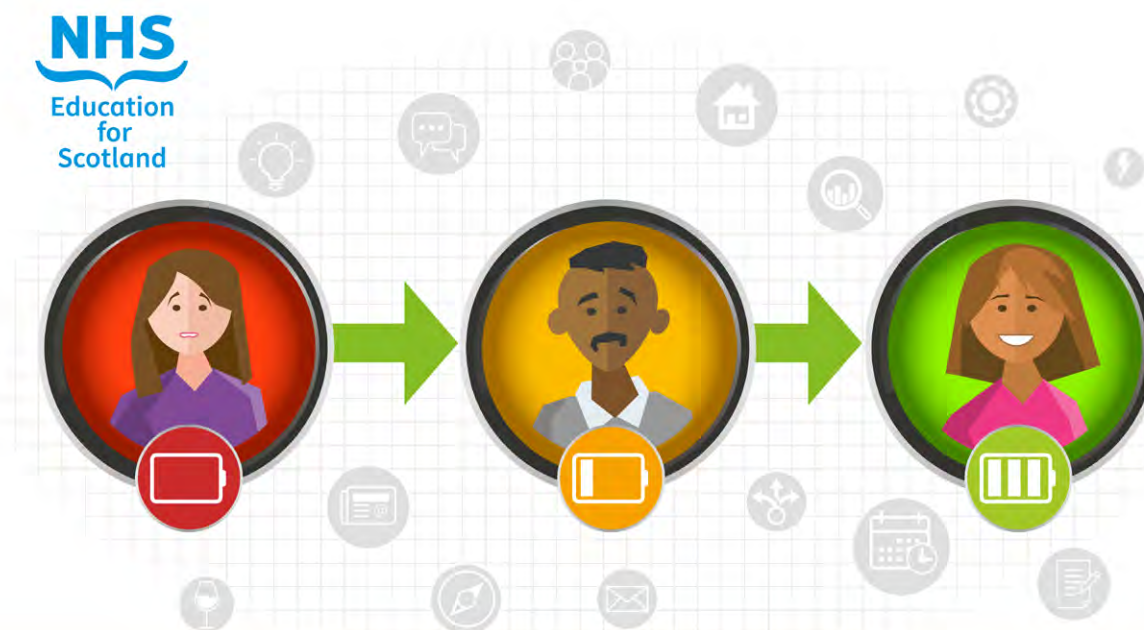
### “Responding to distress in dementia: a staff supported guide for carers”

As the title suggests, it is a staff supported guide to help carers recognise and understand distressed behaviours in the person living with dementia. However, there are sections in the resource which will be applicable and helpful for you as a professional working in dementia care. This resource can be requested from the NES Psychology of Dementia team via the email below:

[Psychology@nes.scot.nhs.uk](mailto:Psychology@nes.scot.nhs.uk)

Other NES resources which will be helpful in promoting good self care and looking after yourself, include the Wellbeing Planning Tool. This tool can be accessed via Turas Learn using the link below and searching ‘Wellbeing Planning Tool’: <https://learn.nes.nhs.scot>. The tool has been developed to help the workforce as well as the general population reflect on key steps to help look after and promote good psychological wellbeing.

We would also recommend you to access the NES e-learning module, titled: Psychological First Aid, which can also be accessed via Turas Learn: <https://learn.nes.nhs.scot>. Psychological First Aid involves offering a humane, supportive and flexible response to others when they are experiencing an emergency or crisis situation and focuses on providing practical help to enable people to utilise their own existing coping resources or to link them up to supporting resources where appropriate.



**Taking care of your wellbeing**



## Section 6

Information on promoting psychological wellbeing and Psychological First Aid have been developed into podcasts. There are 3 podcasts in total which provide practical guidance, suggestions and tips for staff, particularly those working in the care home sector. The focus of these podcasts is on promoting psychological wellbeing, including the use of Psychological First Aid (PFA) and practical strategies to protect managers and staff's psychological wellbeing when faced with heightened stresses when at work. The podcasts can also be accessed via Turas Learn in either film or audio formats using the link below: <https://learn.nes.nhs.scot/29715/psychosocial-mental-health-and-wellbeing-support/taking-care-of-your-staff>

Please speak to your line manager to enquire about any additional support which may be available within your team or support services within your organisation.

### Summary

In this section, we have highlighted the importance of looking after yourself and ways to recognise you may be experiencing heightened levels of stress. It is normal and understandable to experience an array of emotions when working with people living with dementia; it is never wrong to feel a certain way. However, it is important to notice and respond to these emotions in a helpful and healthy way so that you are looking after yourself in the best way possible.

# SECTION 7: Other resources



## Section 7

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](#)

[Standards of Care for Dementia in Scotland](#)

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

**Dementia Skilled - improving practice resource**

**Dementia Informed Practice DVD**

**Acute Care Dementia Learning Resource**

Cognitive Rehabilitation in Dementia:  
A learning resource for staff

Responding to distress in dementia: a staff supported guide for carers

Caring for a Person Living with FTD:  
a supportive series of resources for carers  
<https://learn.nes.nhs.scot/36726/dementia/frontotemporal-dementia-ftd>

Psychosocial mental health and wellbeing support <https://learn.nes.nhs.scot/28063/coronavirus-covid-19/psychosocial-mental-health-and-wellbeing-support>

### **Useful websites & sources of information**

[SIGN – guideline on the management of patients with dementia](#)

[Social Care Institute for Excellence](#)

NICE guideline  
[Guideline for dementia care \(2018\)](#)

Alzheimer's Scotland:  
[Action on Dementia - Alzheimer Scotland](#)

Alzheimer's Society:  
[Alzheimer's Society - Leading the fight against dementia](#)

## Section 7

### Dementia Design

[Dementia Services Development Centre](#)

[Enhancing the Healing Environment  
- The King's Fund](#)

### Miscellaneous

CST website:

[An Introduction to Cognitive Stimulation  
Therapy - CST](#)

[Dementia Activity Tool Kits](#)

[Lifestory Network](#)

[ARTZ is Artists for Alzheimer's](#)

[The interface between Mental Health  
and Dementia \(Mental Health Foundation\)](#)

[How to manage Stress  
\(Mental Health Foundation\)](#)

This document has been created as an interactive PDF so it can be both printed and used on screen, the main menu is clickable and there are navigation buttons throughout, the actions for these are shown here.

This resource may be made available, in full or summary form, in alternative formats and community languages. Please contact us on **0131 656 3200** or email **altformats@nes.scot.nhs.uk** to discuss how we can best meet your requirements.



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