



Understanding & caring for **someone with dementia**

An introduction



Dementia is a condition that causes significant loss of a person's ability to carry on with their usual day-to-day life. There are many different types of dementia and each has its own symptoms and associated issues.

Whichever type of dementia a person has, it is likely to have a huge emotional and psychological impact on them as well as on their family and friends.

This booklet provides an insight into what to expect and how to support someone with it.

What is dementia?

Dementia is a progressive neurological degeneration and an over-arching term that describes a series of symptoms. As dementia is better understood as a collection of symptoms, it is more accurately described as a syndrome. Neurologically, the brain physically and biologically changes with dementia, which can lead to changes in an individual's cognitions, behaviours and emotions. This can result in psychological distress.

There are over 400 different types of dementia, each affecting the brain in different ways and with different associated psychological difficulties. Over time, an individual with dementia may have difficulties managing their daily functional and psychological needs, including cooking, self-care and hygiene; managing their personal safety including medications, finances, and socialising; as well as having difficulty understanding their experiences and making sense of their environment and emotional responses. People with dementia therefore are considered vulnerable adults and often rely on others for support and management of their needs. Over time, as dementia progresses and the brain continues to degenerate, the person is likely to become increasingly physically and psychologically debilitated by their symptoms.

“There are over 400 different types of dementia, each affecting the brain in different ways and with different associated difficulties.”

What causes dementia?

The causes of dementia are not fully understood. Dementia is not a disease. However, we do know there are different diseases and conditions that can lead to dementia.

Alzheimer's dementia

Alzheimer's dementia is the most common type of dementia. It accounts for 60-80% of dementia cases and is caused by a build-up of protein and amyloid-b deposits (plaques), which grow around brain cells. Brain cells and nerves therefore become damaged and chemicals that transmit messages between cells, decrease.

The brain size of a person with Alzheimer's dementia decreases and is smaller than that of a person of the same age without Alzheimer's dementia. The condition progresses slowly to start with and due to this, it often progresses for many years before diagnosis. Typically, Alzheimer's dementia initially affects an individual's short-term memory. Gradually, everyday tasks become more difficult for them.

Picks disease

Picks disease is a condition that can lead to ‘fronto-temporal’ dementia. It affects the cortical regions which are associated with personality changes, emotional regulation and executive functioning (associated with the ability to plan, make decisions and behavioural inhibition). For example, a person might say or act in ways that they did not used to and may not be consistent with social or cultural norms.

Vascular dementia

Vascular dementia accounts for about 10% of dementia cases and is associated with strokes, high blood pressure, cholesterol and diabetes. The condition is linked to either a thickening of blood vessel walls in the brain, which become damaged, or a reduction in the blood flow to the brain. Both of which result in brain cells dying. The symptoms experienced are dependent on the area of brain that has been affected. They progress in stages – initially symptoms appear suddenly and then the individual might remain stable for some time, before a further ‘sudden’ decline.

“As we know that dementia is a syndrome which affects the brain, we can expect individuals with dementia to experience noticeable changes in their cognitive abilities.”

Cognitive impact of dementia

As we know that dementia is a syndrome which affects the brain, we can expect individuals with dementia to experience noticeable changes in their cognitive abilities. Some of the cognitive difficulties that individuals with dementia may experience are listed below:

Attention

- An inability to focus or sustain their attention on certain tasks.

Executive-function

- Difficulty with behavioural inhibition, planning and making decisions
- Difficulty with emotional regulation
- Loved ones may experience the person as having ‘personality’ changes or a change in their emotional expressions and regulation, for example, they might appear more angry, aggressive or upset.

Learning and memory

- Forgetfulness – forgetting where they are, who you are, why they are at a particular place, at a particular time
- Confusion and fear as a result of forgetfulness, which is at times expressed as agitation and anger

Reassurance seeking

- Repeating themselves in conversations and asking the same questions multiple times.

Language

- Difficulties with language understanding, processing and communication
- Difficulties communicating their emotional needs as well as physical needs
- Loved ones might struggle to understand what the person is saying or might understand but find it difficult to respond effectively

Perceptual motor

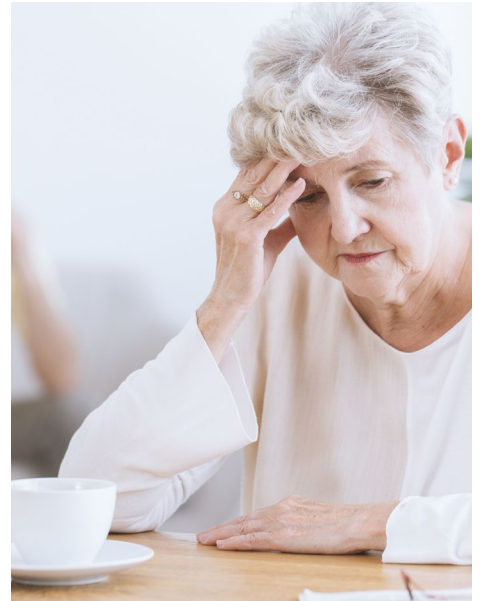
- Difficulties interacting appropriately with their environment, for example they might mistake an object's function or attempt to grasp an object that is not necessarily in the place they perceive it to be.

Hallucination

- Some people with certain types of dementia for example 'Lewy Bodies' may experience hallucinations and tremors.

Social cognition

- Some may have difficulties reading and processing interpersonal skills such as understanding body language, implicit social signals, or making sense of abstract information such as irony or repartee.



The behavioural and emotional impact of dementia

In addition to affecting cognitive abilities, dementia can significantly affect an individual's behaviours and emotions. These non-cognitive symptoms are generally considered to be one of the most difficult aspects of caring for someone with dementia.

For example, the limbic system is often affected by dementia and is associated with emotional experiencing and processing. This is likely to change the way your loved one feels and would normally react to things, such as appearing to be more afraid, angry or upset than before. They might feel unsafe and you may experience them as acting suspicious, accusing you or mistaking you for another person.

Some of the most common behavioural and emotional difficulties experienced by individuals with dementia are listed below:

- Feelings of anxiety
- Feelings of depression
- Difficulty with wayfinding (finding their way from one place to another)
- Hoarding
- Disinhibition
- Experiencing a different reality
- Increased agitation and irritability
- Increased aggression
- Repetition
- Asking to go home/ forgetfulness

The psychological impact of dementia

Outside of the physical changes to the brain that can impact an individual's behaviours, emotions, and cognitive abilities, being diagnosed with dementia can have a significant impact on an individual's psychological wellbeing and mental health.

Loss of identity

Individuals with dementia often report feeling that their identity has been threatened, stolen or attacked. Many have reported* feeling 'empty', disconnected from themselves, others and the world; feeling lost, drifting or absent; and struggling to find meaning in their lives. For some, their identity becomes defined by disability, loss of capabilities and loss of their family, social and professional roles.

"A nearly complete dismantling of the self I once knew"

"Helplessness to control this insidious thief who was little by little taking away my most valued possession, my mind"

Fear of stigma

Some people experiencing dementia feel they are seen by others as worthless or feel criticised and negatively labelled in light of their diagnosis. Many individuals have reported feeling afraid of being judged as "mad, stupid, childish, a liar, or dangerous".

"...the feeling of being excluded by others and society"

"I feel that I'm not much use to anybody"

"The fear of becoming a nuisance or burden"

Fear of the future

Many individuals with dementia are distressed thinking about the future, what they will lose as their dementia progresses. Some described their responses to their diagnosis as:

"I thought that was the end of my life"

"downward spiral of hopelessness"

"fear of losing control of the mind"

"foreboding of what's in front of me"

Re-living past experiences

Some people experiencing dementia become distressed when something in their present experience triggers unpleasant experiences from their

*All quotes from: Petty, S., Harvey, K., Griffiths, A., Coleston, D. M., & Dening, T. (2018). Emotional distress with dementia: A systematic review using corpus-based analysis and meta-ethnography. *International Journal of Geriatric Psychiatry*, 33(5), 679–687. <https://doi.org/10.1002/gps.4870>

past, such as experiences of wars, or other traumas. At times people with dementia might 're-live' their past experiencing as if it is happening in the present; experience hallucinations such as seeing objects that are not present; or feel as though the room is swaying or moving in some way.

Loss of autonomy

Some individuals with dementia have reported fears of being a burden or being taken advantage of. For example, not being understood by others, not being able to ask for what they want, not being informed or consulted in decision making, not being able to look after their own basic needs, or feeling like they are a burden to others.

Loneliness

It has been found that some people with dementia feel forgotten about, abandoned, betrayed and alone when in need. At times this is the actual absence of others, but it can also be a perceived absence of others due to memory loss, or a feeling of being alone despite being surrounded by lots of people.

"I fear being alone with a stranger who I don't know, maybe won't like..."

"It is quiet and lonely, but the silence, I have never liked...I do feel very lonely, and when you go out...I never tell her I'm lonely.... If I feel lonely, it's at night when I miss my wife...painfully lonely...I'm so lonely here...the sense of loneliness can be so overpowering...feelings of loneliness and social isolation...feelings of guilt and loneliness overwhelmed me."

"Should you have difficulties communicating effectively with your loved one, look out for changes in their emotional expressions and behaviours."

Recognising emotional distress

It is common that over time, your loved one experiencing dementia might not be able to understand their distress or communicate this to you verbally and may have difficulties with emotional expressions as they attempt to cope. This means that caregivers may need to be vigilant of their loved one's emotional wellbeing and offer or seek support sooner rather than later. Checking in regularly and asking your loved one how they are feeling; whether they are happy and comfortable; whether their needs for social connection, achievement, feeling safe, loved, cared for and supported, for example, are being met? Should you have difficulties communicating effectively with your loved one, look out for changes in their emotional expressions and behaviours.

Your loved one might...

- Display aggression
- Shout
- Seem agitated
- "Way-find" - explore their environment without purpose.
- Accuse you or others
- Seem afraid
- Act withdrawn or be quieter than usual – more silent expressions of distress may be more difficult to recognise...

Supporting a loved one with dementia

Listen and empathise, for example, stop what you are doing, sit with the person, make eye contact, nod and repeat back what the person has said in your own words to demonstrate you understand their experiences

Validate emotions and emotional expressions, for example, you could say that you understand how difficult things are for them, and feeling sad, angry, afraid is an appropriate emotion given their experiences

Name emotions for your loved one if they are struggling to do so, for example, you could say ‘I wonder if you are feeling lonely/ cross/ worried just now? And I wonder what I can do to help you feel better?’ Give a choice if the person is having difficulties knowing what would help, for example, ‘would it be helpful if we look at some photographs together; go out to the park or meet up with a friend?’

Comfort your loved one. Your loved one for example might have a comforting object, song, film you could direct them to. They might benefit from you touching their hand or shoulder for example, or being embraced. If you are not sure, ask the person if that’s what they need at that time and ask their permission to do that.

Be patient. Often with dementia, individuals may repeat the same story or ask the same question multiple times. Caregivers often experience frustration and helplessness with this aspect of care. There are many reasons why your loved one might be repeating themselves. For example, they might be attempting to have an emotional need met (love, care, purpose, inclusion); they might be attempting to have their need for pleasure or social contact met; or they might be afraid and are seeking reassurance. Try to establish your loved one’s underlying emotion and need and seek to support them to have this need met.

Facilitate a safe environment. Make sure your loved one is surrounded by familiar items such as furnishings, pictures, objects; and familiar smells and sounds. Try to ensure that the environment is not too loud, busy, hot, cold, dark, bright or overwhelming. At times, putting up signage can be helpful, such as ‘bathroom’, ‘bedroom’ and a display with the day, date and time, that can be seen. This supports orientation.

Practice self-care, stay calm and grounded. Make sure you seek respite and time for yourself to do the things you need. Yoga, mindfulness, and meditation are some ways to support good mental health and to help you keep calm and regulate your emotions. If you find yourself getting stressed or frustrated, excuse yourself from the situation if it is safe to do so, engage in breathing techniques before returning to the situation feeling more calm. Seek therapy to learn more about managing your own mental health

“It is important not to over-stimulate or under-stimulate your loved one and to make plenty of time for relaxation and rest.”

Try not to:

- Blame and reprimand your loved one
- Raise your voice
- Argue
- Reason – reasoning might not be effective especially in the latter stages of dementia

Show that you love your loved one. For example, embrace them; tell them you love and care for them; and involve them in decision making, plans, and conversations

Be explicit in communication. Sometimes too much information can be complex and overwhelming and can lead to frustration. Give clear and concise instructions or information. To facilitate choice, present two or three options, and require a 'yes' or 'no' answer. Allow extra time for the person to make that choice.

Promote their strengths and promote their abilities in tasks, for example if your loved one is able to, facilitate them to continue carrying out the tasks they have always done and give them a sense of achievement and social connection. For example doing the dishes, peeling the potatoes, sweeping the floor, gardening, making sure to facilitate this in a safe and respectful way. Focus on what your loved one can do and support them to achieve things that are a bit more difficult.

Facilitate socialisation and recreation needs, for example, with them, look up local groups in their local area and things of interest to them.

Reminisce together, for example explore photographs, objects, smells, tastes from the past. Prompt conversations and ask questions about the past. It could be about films, holidays, music. As dementia progresses, use objects that encourage them to explore using their five senses: sight, touch, smell, taste and sound. An individual may not be responsive to stimulus via some of their senses, such as smell or sound and may not verbally communicate, however they may still enjoy a short spell of touch stimulation for example through different textures such as seen on Twiddle Muffs for example.

These are all suggestions and will not be suitable for all people at all times, therefore use what you know of your loved one to help guide you. Your loved one will also change over time and so what they enjoy, or need will not necessarily remain the same. Being flexible, and open to change will be helpful for you and them. It is also important not to over-stimulate or under-stimulate your loved one and to make plenty of time for relaxation and rest. Seek psychological support for you and your loved one if either of you are continuing to experience distressing emotions over time.



Reminiscing with your loved ones using photos, objects, smells and tastes can help prompt conversations about the past



Effects of caring for a person with dementia

Caregivers report feeling trapped, fatigued and burnt out. It's important for carers to find some time to relax each day.

There are approximately 670,000 unpaid/ non professional caregivers of people with dementia in the UK. As dementia progresses, caregivers provide further support with all aspects of their loved one's life, including tasks such as washing; dressing; continence; medication support; meal making, ensuring nutrition; and ensuring psychological, physical and financial safety. This can lead to round the clock care which is physically and emotionally demanding.

Caring for a loved one experiencing dementia brings changes to one's life and relationships and can be overwhelming. Caregivers often experience distress too and reportedly have a poorer quality of life than those who do not care for a person with dementia. Caregivers often report feeling 'burdened' by this, which can further lead to guilt, shame and low mood. Caregivers have often reported feeling 'trapped', 'fatigued' and 'burnt out'.

Common experiences for example are:

*"...I'm worried and I'm scared what's gonna happen to say my husband... I'm worried I won't be able to cope with it... I feel resentful, why is it us... why do I have to look after him, I feel guilty that I feel like that. How can we address the here and now? How can I accept that my husband or my wife's never gonna be my husband or wife again? How can I accept the change in the relationship?"***

**Source: Sass, C., A. W, Griffiths., Shoemith, E., Charura, D., & Nicholson, P. (2021). Delivering effective counselling for people with dementia and their families: Opportunities and challenges. *Counselling and Psychotherapy Research*, 22(1), 175-186. <https://doi.org/10.1002/capr.12421>

How psychology and psychotherapy can help

Engaging in psychotherapy can help you manage some of the thoughts and behaviours that might be exacerbating your distress as a caregiver. For example, caregivers who feel motivated by a sense of duty, guilt, or social and cultural norms, are more likely to feel greater psychological distress. On the other hand, caregivers who can identify more beneficial components of their role tend to experience fewer feelings of obligation, better mental health and relationships, and greater social support.

Speaking to a therapist can help you identify many of the unhelpful thinking traps that you can get stuck in which sustain your distress. Psychotherapy can also help you manage feelings of anxiety, stress, and depression by helping you understand what coping strategies might be maintaining your distress, and what alternative coping strategies might be able to help you. This is important for preventing burnout and practising self-care.

Psychologists can offer psychoeducation about your loved one with dementia and the nature of your distress, which has shown to improve caregiver knowledge and understanding, reduce feelings of caregiver obligation and depression, improve caregiver wellbeing, and increase caregiver perceptions of satisfaction in their caring role. This is most effective when coupled with skills development regarding relational and behavioural management. This involves teaching caregivers how to monitor and identify possible triggers of distress in their loved ones and supporting caregivers to support their loved one more effectively.

Support groups and social groups can be an important source of social support and are often effective in reducing caregivers' feelings of pressure and obligation. Online, telephone and email support for caregivers has also been proven to reduce anxiety and depression and can be more accessible if it is difficult to regularly attend in-person appointments. Caregivers who have sought therapy reported:

*"[I was surprised by] just how easy it was to talk. I didn't think I'd be as open as I have been. Cos I were keeping things to myself a lot ... but I'm sort of more open since I've been talking to Pat about things" (caregiver).***

*"There is a lot of stigma and people ... I've told, I've said oh you should go... "oh I don't need counselling!" they do, but they just don't think that they need it. I think that they would get a lot from it but that word... counselling, conjures up lots of not so good things really... and it's not, for me it's been an opportunity to talk and reinforce some of the things that I already knew" (caregiver).***

*"... the first couple of sessions, I talked to- I spoke, erm truthfully and honestly about the situation that I was in and the situation my husband's in the situation we're both in together. Erm... which isn't the best by any means, but... you know, erm... but talking to someone, that listens and understands is... far better than not talking" (caregiver).***

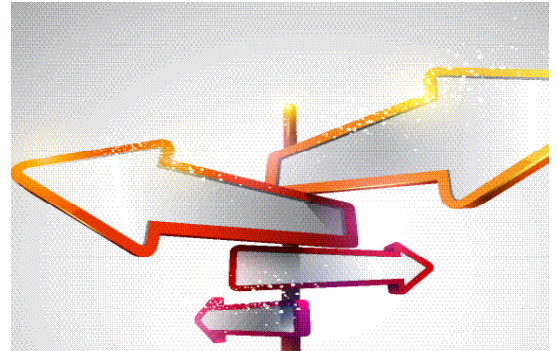
“Caregivers who feel motivated by a sense of duty, guilt, or social and cultural norms, are likely to feel greater psychological distress.”

****Source:** Sass, C., A. W, Griffiths., Shoesmith, E., Charura, D., & Nicholson, P. (2021). Delivering effective counselling for people with dementia and their families: Opportunities and challenges. *Counselling and Psychotherapy Research*, 22(1), 175-186. <https://doi.org/10.1002/capr.12421>

Additional resources

Further information and advice can be found at the following:

- Age UK <https://www.ageuk.org.uk/information-advice>
- Alzheimer's Scotland <https://www.alzscot.org>
- Alzheimer's research UK <https://www.alzheimersresearchuk.org>
- Care information Scotland <https://www.careinfoscotland.scot>
- Carer's Trust <https://carers.org>
- Dementia UK <https://www.dementiauk.org>
- NHS <https://www.nhs.uk/conditions/dementia>



First Psychology also has more information and advice in the form of free downloadable booklets. You may find the following titles particularly helpful.

- [Understanding grief](#)
- [Managing life transitions](#)
- [Accept, commit, act](#)

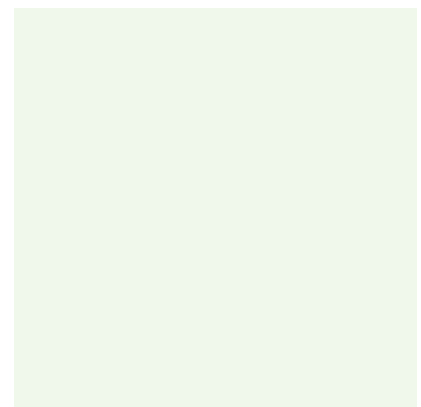
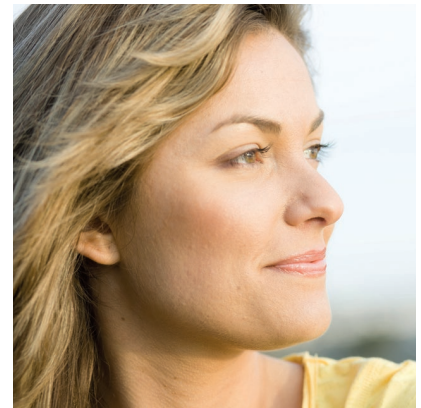
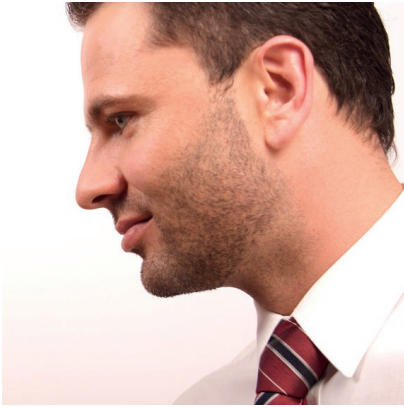


Our highly qualified and experienced team at First Psychology offers a variety of therapy services and works with people with a wide range of issues and problems.

We provide:

- Therapy and coaching services for individuals, couples, children, young people and families.
- Employee counselling, CBT & psychological therapies; wellbeing and personal performance coaching for employers; webinars, workshops, employee events and consultation.

All First Psychology practitioners have excellent qualifications and experience, so you can come to us knowing that you will see an experienced professional.



First Psychology offers:

Therapy & coaching services for individuals, couples, children, young people & families.

Employee counselling, CBT & psychological therapies; wellbeing and personal performance coaching for employers; webinars, workshops, employee events and consultation.

Aberdeen | Borders | Dundee | Edinburgh | Glasgow | Inverness
Newcastle | Perth | Online

Tel: 03330 344115
Email: info@firstpsychology.co.uk
Web: www.firstpsychology.co.uk