Understanding dementia better

Resource Pack
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At Dementia Adventure, we think differently about dementia. Our Understanding Dementia Better training supports your current level of knowledge and helps you to consider the importance of seeing the individual rather than the condition. We work with people who are living with dementia, and their family and friends to support the value of choice and control through nature-based experiences, activities and adventures.

What is dementia?

Dementia is an umbrella term for over a hundred different degenerative illnesses and diseases of the brain, of which the most commonly known is Alzheimer’s Disease. Dementia is characterised by a set of symptoms associated with the higher mental functions, which may include difficulties with memory, attention, concentration, perception, senses, language and communication. Dementia is a progressive condition which will result in an increasing loss of function. There is no set timeline or pathway and each individual’s needs and progression will be different.
Dementia is a major concern for Government and policy-makers, as reflected in a range of initiatives and strategies including the ‘Prime Minister’s Challenge on Dementia 2020’, Dementia Friends (Public Health England & The Alzheimer’s Society), Dementia Friendly Communities and the National Dementia Declaration (Dementia Action Alliance 2015).

UK dementia statistics

- Over 900,000 people living with dementia
- Over 700,000 family carers of people living with dementia
- One in six people over 80 have dementia
- 45,000+ people have dementia under the age of 65
- 70% of people in care homes have dementia or severe memory problems
- More than 25,000 people from black, Asian and minority ethnic groups are affected
- 2/3 people with dementia live in the community
- 1/3 live in a care home
- The financial cost of dementia to the UK is £26 billion per annum

Source: The Alzheimer’s Society
How to live well with dementia

“When you’ve met one person with dementia you’ve met one person with dementia”

Dementia Reconsidered Tom Kitwood

Whilst we wait and hope for a cure, there is much that can be done right now to care for and enable the 900,000 people living with dementia in the UK to live healthier, more active and enjoyable lives with meaning and purpose to everyday.

The late Tom Kitwood highlighted in ‘Dementia Reconsidered’ (1997) that:

‘When you’ve met one person with dementia, you’ve met one person with dementia’

recognising that we should see the person first before we see dementia and support people’s unique life interests, to continue to be active and live well.

Being out in nature and sharing activity outside is something which brings immediate benefit to people living with dementia and, we believe, is a crucial part of ‘living well,’ as highlighted by our ABC approach:

A. Active lifestyle
B. Brain stimulation
C. Connection with people and places outdoor
There are four categories of activities that fill our lives: They are work, self-care, leisure, and rest. Maintaining a healthy balance among these activities helps us manage stress levels and optimize our positive sense of self.

Work - Living with dementia does not eliminate the need to be needed, to be seen by others as a productive, and a vital member of the community. It can become more difficult for the person to perform certain task. Encouraging the person you support to help with a task, such as making lunch together can help provide an opportunity to take part in a work activity.

Self-care a person with a dementia diagnosis might start to experience issues completing self care tasks, as an example the cleaning of teeth. By passing them the toothbrush, the feel of it in their hand might be the prompt that they need to complete the task unaided. Can we find ways to encourage a person to do as much for themselves as possible? This may help a person to retain independence, dignity and a sense of self for longer.

Leisure - These are activities we do because we enjoy them and get pleasure from them. Activities such as walking, reading, gardening, singing, social groups.

Rest - These are activities that promote re-energizing and revitalization. Although sleep provides the majority of needed rest, it is not the only way to recharge. Reading a book or sitting quietly outside are great ways to rest and give our bodies a break.
Different types of dementia

For further information about the different types of dementia visit:
https://www.alzheimers.org.uk/about-dementia/types-dementia
https://www.raredementiasupport.org/
The brain is incredibly complex and is responsible for every aspect of our actions and behaviour, from the smallest movement to the most complex reasoning, planning and carrying out of an activity.

There are so many mysteries yet to be discovered about the brain’s function and disease processes. But it does help us to understand the dementia disease process better if we are informed about which part of the brain is affected. A CT or MRI scan may help identify this.

(CT) Computerised Tomography Scan — detailed image of the inside of the brain

(MRI) Magnetic Resonance Imaging — can produce clearer images than a CT scan
About the brain:

- Weighs three pounds.
- Made up of 100 billion nerve cells.
- The largest part of the brain is called the cerebral cortex - divided into four lobes which have different functions.

The parietal lobe:

Functions:
Remembers sequences of actions, such as:
- Body sense (‘pro-prioception’) - sensing where one limb is in relation to the rest of the body
- Sentence construction
- Calculation
- Interpreting visual information received from the occipital lobe
- Locating objects

Damage to the parietal lobe can cause:
- Problems in processing visual information, which can cause difficulty in recognising faces
- Difficulty in carrying out learnt sequences
- Problems processing visual information, making it difficult for people to recognise objects even when they can see the object perfectly well
- Changes to body sense (knowing which part of your body is where (pro-prioception)), and also people’s ability to know where objects are relative to their own body

The frontal lobe:

Functions:
- Planning and organising actions
- Learning tasks
- Initiating and stopping
- Regulating behaviour
- Abstract thought
- Logic
- Language
- Personality
Damage to the frontal lobe can cause:
- Lack of inhibition
- Difficulty initiating actions
- Difficulty with planning, decision-making and abstract thought
- Difficulty making choices about something that isn’t physically present
- Problems with reasoning

The occipital lobe:

Functions:
Processing information received from the eyes about:
- Colour
- Shape
- Movement

The temporal lobe:

Functions:
- Learning new information
- Recording and storage of verbal memory (such as names)
- Visual memory (such as faces)

Damage to the temporal lobe can cause:
- Difficulties in understanding and producing speech
- Problems with remembering recent events (past-memory can remain)
- Individuals to have a short attention span

Source: Social Care Institute for Excellence - The Open Dementia Programme
Hippocampus:

Sometimes referred to as a ‘seahorse’ because of its shape, amongst many other functions, it is thought to play an important role in converting short-term to long-term factual memories. It is also thought to be responsible for spatial navigation. It is one of the first regions to be affected in Alzheimer’s Disease, hence symptoms of memory loss and disorientation.

Amygdala:

Sometimes referred to as an ‘almond’ because of its shape, consists of two almond lobes located within the centre of the brain. Each lobe is responsible for how we perceive, process and store emotional memories. It is believed that the amygdala remains unaffected and therefore we should try to connect with the emotional intelligence of people living with dementia, because it is often a strength.
Dementia and the brain:

This is a magnified view of a healthy brain.

The oval objects are neurons - neurons store memories and skills that we build up throughout our lifetime. Every time we need to do something - like pick up a drink and drink it, there is a chemical reaction (message) firing in the brain (the lights that you can see) and they travel through the interconnected network until the chemical reaction locates the neuron that holds the answer.

This is the magnified view of the brain of someone who is living with dementia.

These plaques and tangles start to build up between the neurons and they block the previously clear connections. The message does not necessarily get lost, but it will need to find a clear pathway to the neuron that holds the answer. This will take more time. Are we able to give the person we support the time they need to find that clear pathway?
Communication and dementia

People living with dementia may experience difficulties with word-finding and forming sentences (Aphasia). One theory (Albert Mehrabian) suggests that 7% of how we communicate is verbal (words), 38% is tone of voice and 55% is body language.

We shouldn’t make assumptions about people’s ability to communicate because of dementia. It may be our inability to interpret what somebody with dementia may try to communicate, which may lead to frustration or withdrawal. We should, therefore, move from a reliance on factual word connections and move towards a greater emotional intelligence in the way we interact and communicate. This is supported by the area of the brain, which is still working well - the Amygdala (emotional intelligence).

Each person is an individual who may or may not require specific support. However, there are some simple steps you can take to make sure that you communicate effectively.
Steps to try:

1. Make sure you communicate with the person with dementia and not just the carer/family member. Don’t talk about people as if they are not there.
2. Ask for the person’s opinion rather than asking them to search for factual information.
3. Use simple visual aids to help communicate (photos, simple route maps).
4. Use clear and short sentences and speak slowly with pauses between sentences, but avoid speaking as though you are addressing a child.
5. Being patient and remaining calm can help the person communicate more easily.
7. Give the person the time they need to understand and answer questions - chunking topics into sub-topics and ensuring people understand ‘A’ before moving onto ‘B’
8. Be prepared to repeat things several times, if asked.
9. Use humour.
10. Try to include the person in conversations with other people.
11. Don’t stand too close to the person as this can be intimidating.
12. Place yourself at the same level or lower than they are – this is less intimidating.
13. Refrain from correcting a person if what they are saying isn’t factually correct.
14. Avoid using phases such as ‘don’t you remember?’

Active listening:

- Use eye contact to look at the person and encourage them to look at you when either of you are talking.
- Give them your full attention.
- Try not to interrupt and finish their sentences — silence often helps.
- If you are not sure what’s being said, repeat what you heard back to the person and ask if it is accurate. Check with them to see whether you’ve understood them correctly.
- Show your understanding — smile and nod to encourage more communication.
Bookcase of memories analogy:

- The bookcase of factual memories may collapse as the Hippocampus is affected by the dementia disease process.

- Over time it may become increasingly difficult to locate factual memories.

- The longer, firmly-established memories of the first few decades may remain in place but other books representing different factual memories from other decades are randomly dispersed and hard to find.

- Therefore, when somebody with dementia reaches out for a memory, the book (factual memory) they retrieve may be from one of the firmly-established memories of their early decades or by plucking at the nearest random book which may relate to a factual memory from their 50s or 60s for example.

- We need to enter into their world — their subjective reality. Expecting people to be in your reality or in your own subjective memory of an event, may lead to distress for you both and stifle effective engagement and communication.
‘Working Memory Notice Board’

Short-term memory has limited capacity and can normally store about seven pieces of information at once (G. Miller 1956) and the duration of short-term memory is 15 - 30 seconds (R.C. Atkinson & R.M. Shiffrin 1971). Short-term memories are converted into long-term memories by repeated use.

People with dementia may not be able to attend to more than one or two facts at a time. We can consider how we may respond when we have multiple tasks or things to remember which are being added to but we cannot process or contain that information - we may become stressed, angry, overwhelmed and increase our chances of forgetting the information on our memory/attention board.

As we get older our memory and/or attention board may become smaller and we are often able to cope with far less. For somebody with dementia we need to consider the number of facts and information they are able to process. We need to slow down and not overload people with too much detail - which may only serve to overwhelm, stress and result in a fight (become agitated) or flight (withdrawal) response.

Where possible, if we can reduce the amount of information needed to be processed by the brain, this can support someone living with dementia from becoming overwhelmed. Offering a quiet space and time can help reduce those feelings of being overwhelmed.
The ‘five senses’

- Sight
- Hearing
- Smell
- Taste
- Touch
- Proprioception
The 6th Sense - ‘Proprioception’

Even with our eyes closed we have a sense of body position — where our arms and legs are and that we are moving them. Muscles, tendons, joints and the inner ear contain proprioceptors, also known as stretch receptors, which relay positional information to our brain. Our brain then analyses this information and provides us with a sense of body orientation and movement.

The senses and dementia

Our senses help us construct a picture of our world, how it works, and how we function within it.

Common sensory losses associated with ageing:

**Hearing loss:** The most common form of sensory impairment in old age.

**Sight loss:** Including cataracts, glaucoma and macular degeneration.

**Altered taste buds:** Which may alter appetite and favoured foods. People frequently add extra salt or sugar to make flavours bolder and bigger against all health guidelines.

**Smell:** Much of what we perceive as taste is actually smell.

**Touch:** Experiencing the ‘Cutaneous sensation’ - ‘am I actually touching what I think I am touching?’).

Even in the most advanced stages of dementia, our senses enable a connection with the world which can bypass intellectual processes.

Impairment of the senses may mean that you may not be able to smell something burning on the cooker or you may experience a smell, e.g. burning rubber, that no-one else can smell. Smell often triggers strong emotional memories and is widely recognised as a memory stimulant. Smell can trigger memories even before our cognitive processes have recognised what that smell is (putting it in a factual context). Some smells, like almonds, are used to great effect to stimulate appetite.
It is important to recognise the social impact and isolation people experience when they are unable to participate in conversations because of difficulties with their hearing and vital to recognise that they may find translating what is being heard difficult.

As an example, if there is too much noise in a room, it may become difficult to process. The sound may feel amplified and overwhelming. This may lead to a person withdrawing from conversation or becoming anxious, frightened or agitated, a ‘fight or flight’ response.

One lady shared her experience of an auditory hallucination, which could be distressing. She could constantly hear a theme tune from a music hall favourite 24 hours a day (ear worm). We should, however, take into consideration the power of music and sound, which can trigger powerful memories through an emotional connection.

 Perception

People with dementia may have difficulties with how they experience and how they perceive their environment.

This image on the left shows how a black and white tiled floor pattern might be seen by somebody experiencing visual perceptual difficulties. The image may make you feel confused, disorientated, fuzzy, painful, challenging - therefore the response may be a reluctance to go into this room.

The image on the right illustrates how shadows which contrast with the pavement surface may be interpreted as holes, barriers or take on the shape of something strange and intimidating.
Difficulties with visual perception may include:

- Decreased sensitivity to differences in colour contrasts such as black and white, and contrasts between objects and background, for example, a white toilet in a white bathroom.
- Reduced ability to detect movement.
- Changes to visual field (how much you can see around the edge of your vision whilst looking straight ahead, or is patchy, or has holes in your visual field).
- Reduced ability to detect different colours (e.g. difference between blue and purple).
- Recognition of objects, faces and colours.
- Double vision.
- Problems with depth perception e.g. stairs, steps.
- Lack of ability to name what has been seen.
- Perceiving shadows or dark mats as holes or moving creatures.

Source: Alzheimer’s Society fact sheet -‘Sight, perception and hallucinations in dementia’.

Environmental Considerations:

Lighting:

We all generally need higher levels of light as we get older.

- Dimly-lit areas can cause confusion.
- Strong reflections can cause disorientation.
- Shadows can create distress. Some people experience visual hallucinations, experiencing shadows/patterns as crawling insects, for example.
- Pools of bright light and shade should be avoided.
- Try and make as much use of natural light as possible.
- Lamps and up-lighters can be very effective at breaking up what can be harsh lighting and create a softer, more relaxed feel whilst also raising the general level of light.
Floor Surfaces:

- Avoid highly reflective and/or slippery surfaces.
- Change in the colour of flooring, or even contrasting floor-strip can appear as a barrier or a change of depth.
- Patterned flooring can cause problems - plain or very lightly-mottled flooring is preferable.

Steps:

- Try adding a contrast strip on the edge of steps to distinguish individual steps - on both length and width.

Colours and Patterns:

- Patterns can cause problems - plain or very lightly-mottled is preferable
- Avoid bold, heavily-patterned carpets.

Toilets:

- Some people can’t see the toilet basin because it blends into the background.
- Contrasting toilet seats can make a huge difference.
Signage:

- Even in a familiar environment people with dementia may become disorientated.
- “What is behind that closed door?”
- Where possible, have see-through doors or cupboards.
- Use photographs on the doors of what is in the room or cupboard.
- Avoid stick-man images.
- Back up signs with words.

Reflective Surfaces:

- Mirrors and reflections can cause confusion. The image may be perceived as a stranger, or several badly-placed mirrors or pictures with reflective glass may create tunnel effect and multiple reflections.
- Cover up or remove mirrors and soften reflections with pictures or paintings.

Seating:

- Chairs should be of contrasting colour to floor surface
When you provide care and support

Looking after yourself!

“A diagnosis of dementia is not just given to one person - it is given to a spouse, a partner, a child, the extended family and friends...A carer may make the difference between a person living well with dementia or not.”

Dementia Action Alliance, The Carers Call to Action 2013

Alistair Burns, NHS England’s National Clinical Director for Dementia stated ‘a diagnosis of dementia is not just given to one person - it is given to a spouse, a partner, a child, the extended family and friends’ and also stressed that ‘a carer may make the difference between a person living well with dementia or not’ (Dementia Action Alliance The Carers’ Call to Action 2013).

There is mounting evidence, supporting what has been experienced by many family carers for many years, that there is a greater need to support the on-going levels of loss, grief, stress and distress experienced by living with someone diagnosed with dementia. Seeing the loss of a husband, wife, mother, father, or partner’s abilities in front of your eyes over what could be a short or extended period is more than life-changing. Frequently, carers’ views and needs have not been included in assessments, but the Care Act 2014 should ensure that the health and wellbeing needs of family carers should be assessed as well as the person for whom they care.

Sadly, we know that support infrastructure is often severely lacking for families living with dementia and people frequently struggle until a crisis point is reached. Barbara Pointon MBE (Dementia Carer Ambassador) highlighted her needs for on-going access to an expert in dementia care when she was a carer for her husband, Malcolm. She recognised that if only she had known then what she now knows, how different their lives would have been. There are many organisations offering specific support and guidance for family carers of people living with dementia including websites, helplines, forums and face-to-face carers groups. We would encourage you to share your concerns, look after and be kind to yourself.

Our extensive list of resources is there to enable you to find organisations that can support both the person living with dementia and carers.
The benefits of connecting to nature

Nature is intrinsic to our physical, emotional, and mental wellbeing. It has a unique ability to calm our stress, increase our creativity, empathy and our sense of wonder. Even small interactions with nature can help reduce feelings of loneliness, isolation and anxiety, and bring significant health benefits.

For people with dementia, research shows that meaningful outdoor activity and connection with the natural environment can have a positive effect and can slow down the progression of the symptoms.

Just 5 minutes outside can start to:

- Improve emotional well-being
- Increase a sense of social belonging
- Improve sleeping and eating patterns
- Reduce apathy and depression
- Improve verbal expression, memory and attention
- Reduce stress agitation and anger

National support organisations

Alzheimer's Society
Tel: Dementia Support: 0333 150 3456 / Customer Care: 0330 33 0804
www.alzheimers.org.uk

Dementia UK
www.dementiauk.org

Living with Dementia Toolkit
The Living with Dementia Toolkit is for people with dementia and their carers. This set of resources is based on research, and the expert experiences of people with dementia and their carers.

These resources are here to:
- give you hope for the future
- inspire you through examples of real-life experiences
- offer ideas to help you live your life as you choose

https://livingwithdementiatoolkit.org.uk/

Admiral Nurses from Dementia UK:
Tel: 0800 888 6678
Mon-Fri: 9am to 9pm / Saturday & Sunday: 9am to 5pm
www.dementiauk.org/get-support/admiral-nursing/

Community Transport Association
Directs you to local transport within your area.
https://ctauk.org/find-ct-provider/

Age UK
www.ageuk.org.uk

Carers UK
Tel: 0808 808 7777 Mon - Fri, 9am - 6pm
https://www.carersuk.org/
Carers Trust
Carers Trust is a major charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems. Our vision is that unpaid carers count and can access the help they need to live their lives. https://carers.org/

My Life, My Goals is a self-help guide designed to help people living with dementia, step by step, try to achieve their goals.

my-life-my-goals-workbook.pdf (alzheimers.org.uk)

Playlist for Life harnesses the powerful effects of personal music to help anyone who is affected by dementia, their families and carers. It helps you put together a meaningful playlist for the person you are supporting.

Playlist for Life - Personal music for dementia
Information and advice around sensory changes

Talking Sense By Agnes Houston

Talking-sense.pdf (dementiavoices.org.uk)

Dementia & Sensory Challenges - By Life Changes Trust

Leaflet.pdf (lifechangestrust.org.uk)

Talking Sense Online Course

Explores the effects of ageing and dementia on the senses. It’s informed by Agnes Houston’s research and book - Talking Sense: Living with sensory changes and dementia. Download the e-book at the end of the course.

Click to find out more
Information and support around diagnosis

Diagnosis checklist from Alzheimer’s Society

Click to download the symptoms checklist

Difficult conversations around receiving a diagnosis

Click to read about how to offer help to someone with dementia who may not want it.

Information to support diagnosis for the Asian community

Click to read the Race Equality Foundation toolkit on dementia awareness
LGBTQ+ Living With Dementia
Click to read the Alzheimer's Society LGBTQ+ Living with dementia booklet

Intercultural Care Guide
Click to read the NHS England Intercultural Care Guide.
Organisations run by people living with dementia

Dementia Tip Share
A treasure chest of tips to help you to keep living as well as you can.
From people with dementia, for people with dementia.
[https://dementiatip-share.org.uk/](https://dementiatip-share.org.uk/)

Dementia Diaries
People with dementia sharing their stories as blogs.
[https://dementiadiaries.org/diarists](https://dementiadiaries.org/diarists)

Dementia Creatives
A website to share the creative ideas of people living with dementia to inspire others.
[https://dementiacreatives.org.uk/](https://dementiacreatives.org.uk/)

3 Nations Dementia Working Group
A friendly group of people diagnosed with dementia who want to make a difference whilst we still can.
[https://www.3ndementiawg.org/](https://www.3ndementiawg.org/)

Dementia Engagement and Empowerment Project (DEEP)
The UK network of dementia voices. DEEP consists of around 80 groups of people with dementia.
[https://www.dementiavoices.org.uk/](https://www.dementiavoices.org.uk/)
People living with dementia

Peter Berry
Click to follow Peter on Twitter
Click to follow Peter on Facebook

Wendy Mitchell
Click to read Wendy’s blog

Agnes Houston
Click to follow Agnes on Twitter

George Rook
Click to read George’s dementia diary
Tools to support independence

Radar Key
People who need to use accessible toilets will know that many of them in the UK are fitted with a RADAR Key Scheme lock, which can only be opened with a Royal Association for Disability and Rehabilitation (RADAR) key. These can now be purchased from Amazon.

The Herbert Protocol
The Herbert Protocol is a national scheme that encourages carers, family and friends to provide and put together useful information, which can then be used in the event of a vulnerable person going missing. Carers or relatives and friends can complete a form in advance, including important information about the missing individual such as the contact numbers, medication needed, locations the person was last seen and a photograph can be added.

Click to view the Herbert Protocol missing persons form

Sunflower Invisible Disability Products
Wearing the Hidden Disabilities Sunflower discreetly indicates to people around the wearer, including staff, colleagues and health professionals, that they need additional support, help or a little more time. Since its launch in 2016, it has been adopted globally by major airports and venues and in the UK, by many supermarkets, railway and coach stations, leisure facilities, the NHS, a number of police, fire and ambulance services, and an increasing number of small and large businesses and organisations.

Click to buy your Sunflower products

Please Be Patient - I Have Dementia Badges
Click to buy you ‘please be patient, I have dementia badge’
Help Cards

Help cards are for people with dementia to use and carry with them, to make it easier to get help or assistance when they’re out in the community. Help cards are a great tool to help a person with dementia maintain their independence.

They are the size of a credit card and are free to order.  

Click to find out more about Help Cards

Wearable Location Tracking Technology

A variety of items are available:

- Key ring
- Watch
- Belt
- Bracelet
- Necklace
Financial support and advice

https://carers.org/grants-and-discounts/introduction

https://www.carersuk.org/help-and-advice/financial-support

https://www.ageuk.org.uk/information-advice/care/helping-a-loved-one/financial-support/

https://www.citizensadvice.org.uk/
Activities and resource sheets

The Sensory Trust
Nature activities for people living with dementia & family carers.
www.sensorytrust.org.uk

The Woodland Trust
Seasonal activity ideas, crafts activity sheets.
www.woodlandtrust.org.uk

The Wildlife Trusts
Spotter sheets, seasonal activities.
www.wildlifetrusts.org

British Nature Guide e-magazines
A seasonal magazine full of articles, quizzes & activities.
www.britishnatureguide.com
Thriving with Nature - WWF/MIND 2020
Free download guide produced by WWF and Mental Health Foundation showing health & well being benefits from nature connection and practical ideas for each season - 100 page

Click here to download the guide

NAPA - National Activity Providers Association

http://napa-activities.co.uk/

Thrive
A collaboration between Thrive and Dementia Adventure. Advice on gardening and natural resources for people living with dementia.

Click for Thrive’s dementia and gardening advice

Alzheimer’s Society guide to becoming active

Click to download the guide
Dementia Adventure resources and publications

All our work is evidence based and we also undertake our own research and evaluate all our activities to add to this growing evidence base. Dementia Adventure has published various research and project resources which can all be found on our website, these include:

- The 2016 Social Impact Report - www.dementiaadventure.co.uk/research
- Clark P; Mapes N; Burt J; Preston S (2013) Greening Dementia - a literature review of the benefits and barriers facing individuals living with dementia in accessing the natural environment and local greenspace www.dementiaadventure.co.uk/research
- Mapes N (2011, Feb) Living with dementia and connecting with nature -exploring the benefits of green exercise with people living with dementia.