



Wellbeing for Life Treatments



Learning Outcomes

- To know what medical treatments are available.
- To know what non-medical treatments are available.
- To understand how to support a person with making choices of treatments.



Treating Dementia

- If a person you support is diagnosed with Alzheimer's Disease, the most common type of dementia, they may be offered some medicine, sometimes referred to as anti-dementia medicine. This is a pharmacological intervention.
- Alongside, or instead of, medicine, a person with Alzheimer's Disease, or any other type of dementia, may want to try alternative therapies, otherwise known as non-pharmacological interventions.
- Whatever treatment(s) a person chooses, these may need to change as their type of dementia progresses and should always be regularly reviewed.
- No new medicines have been licensed in the UK for Alzheimer's Disease since 2002. However, there is a lot of research into new medicine treatments. These aim either to give better relief from symptoms or - if possible - to slow down or stop the underlying disease in the brain.

Remember: There is currently no cure for any type of dementia.



Pharmacological Interventions

There are two types of medicine used to treat Alzheimer's Disease:

- acetylcholinesterase inhibitors (often shortened to just 'cholinesterase inhibitors'), and
- NMDA receptor antagonists.

The two types work in different ways.

The generic names for the cholinesterase inhibitors are donepezil, rivastigmine and galantamine:

- Donepezil was originally patented as the brand name Aricept, but is more widely available now as just generic donepezil.
- Rivastigmine was patented as Exelon and is now also available as other brands, as well as generic rivastigmine.
- Galantamine was patented as Reminyl and is now also available as generic galantamine and the brands Reminyl XL, Acumor XL, Galsya XL and Gatalin XL.
- **The NMDA receptor antagonist is memantine. It was originally patented as Ebixa and is now also available as generic memantine. Other UK brand names for memantine include Maruxa and Nemdatine.**



How Pharmacological Interventions Work

Cholinesterase inhibitors (donepezil, rivastigmine and galantamine)

- In the brain of a person with Alzheimer's Disease, there are lower levels of a chemical called acetylcholine. Acetylcholine helps to send messages between certain nerve cells. In Alzheimer's Disease there is also a loss of the nerve cells that use acetylcholine. Falling acetylcholine levels and progressive loss of these nerve cells are linked to worsening symptoms.
- Donepezil, rivastigmine and galantamine all prevent an enzyme called acetylcholinesterase from breaking down acetylcholine in the brain. As a result, an increased concentration of acetylcholine leads to increased communication between nerve cells. This may temporarily alleviate or stabilise some symptoms of Alzheimer's Disease.
- All three cholinesterase inhibitors work in a similar way, but one might suit a certain individual better than another, particularly in terms of side-effects experienced.



Memantine

The action of memantine is different from that of donepezil, rivastigmine and galantamine. Glutamate is another chemical that helps to send messages between nerve cells. Glutamate is released in excessive amounts when brain cells are damaged by Alzheimer's Disease. This causes the brain cells to be damaged further. Memantine protects brain cells by blocking the effects of excess glutamate.

The NICE guidance (2011) recommends use of memantine as part of NHS care for severe Alzheimer's Disease. NICE also recommends memantine for people with moderate Alzheimer's Disease who cannot take the cholinesterase inhibitor drugs (this is usually because of side effects).

Memantine is licensed for the treatment of moderate-to-severe Alzheimer's Disease. In people in the middle and later stages of the disease, it can slow down the progression of symptoms, including disorientation and difficulties carrying out daily activities. There is some evidence that memantine may also help with symptoms such as delusions, aggression and agitation.



Is it only people with Alzheimer's Disease who are offered medication?

- NICE (National Institute for Health and Care Excellence), the government body responsible for recommending which drugs should be available on the NHS, recommends four drugs for the treatment of Alzheimer's Disease in the UK.
- The cholinesterase inhibitors were developed specifically to treat Alzheimer's Disease. There has been relatively little research into whether they (or memantine) are helpful for people with other types of dementia.
- There is evidence that the cholinesterase inhibitors are effective in people with dementia with Lewy Bodies and dementia due to Parkinson's Disease. Rivastigmine is licensed for Parkinson's Disease dementia. Acetylcholine levels are often even lower in people with dementia with Lewy bodies than in those with Alzheimer's Disease.





Is it only people with Alzheimer's Disease who are offered medication?

- NICE guidelines recommend that a cholinesterase inhibitor is offered to a person with dementia with Lewy bodies or Parkinson's Disease dementia if they have distressing symptoms (eg hallucinations) or behavioural symptoms like agitation or aggression. For memantine, one trial showed benefits for people with dementia with Lewy bodies and Parkinson's Disease dementia, but there is not enough evidence to draw any firm conclusions.
- Several trials have looked at the treatment of vascular dementia with a cholinesterase inhibitor or memantine. The benefits for either are very small (if any), and seen mainly for mental abilities of people with a combination of both Alzheimer's Disease and vascular dementia (known as mixed dementia). NICE guidelines recommend cholinesterase inhibitors for treatment of mixed dementia when Alzheimer's is the main cause, but not for the treatment of pure vascular dementia.
- From the few trials carried out, there is no good evidence that the cholinesterase inhibitors or memantine are of benefit for people with frontotemporal dementia, including Pick's disease. In some people they may make symptoms worse. These drugs are not licensed for frontotemporal dementia and will not generally be prescribed for it.



Benefits of Pharmacological Interventions

- The guidance from NICE (2011) recommends that donepezil, rivastigmine or galantamine is offered as part of NHS care for people with mild-to-moderate Alzheimer's Disease. There is good evidence (strongest for donepezil) that these cholinesterase inhibitors also help people with more severe Alzheimer's Disease.
- Between 40 and 70 per cent of people with Alzheimer's Disease benefit from taking a cholinesterase inhibitor. In cases where the treatment shows benefit, symptoms improve temporarily (for between six and 12 months in most cases) and then gradually worsen over the following months. People taking a cholinesterase inhibitor can experience: reduced anxiety; improvements in motivation, memory and concentration; and improved ability to continue daily activities.
- It is not clear whether the cholinesterase inhibitors also bring benefits for behavioural changes such as agitation or aggression.



Risks of Pharmacological Interventions

- Generally, cholinesterase inhibitors and memantine can be taken without too many side effects. Not everyone experiences the same side effects, or has them for the same length of time (if they have them at all).
- The most frequent side effects of donepezil, rivastigmine and galantamine are loss of appetite, nausea, vomiting and diarrhoea. Other side effects include muscle cramps, headaches, dizziness, fatigue and insomnia. Side effects can be less likely for people who start treatment by taking the lower prescribed dose for at least a month.
- The side effects of memantine are less common and less severe than for the cholinesterase inhibitors. They include dizziness, headaches, tiredness, raised blood pressure and constipation.
- None of these drugs are considered to be addictive.

Remember: It is important to discuss any side effects with the doctor and/or the pharmacist.



Poly pharmacy

- Poly pharmacy is the term used when four or more medicines are being taken by a person, and is common in older people. Around 21% of people with a learning disability are exposed to poly pharmacy.
- Many people with a learning disability will be taking medicine prior to be diagnosed with a type of dementia, and then being offered anti-dementia medicine.
- In addition, they may develop other conditions during the course of their dementia, like epilepsy, that require medicine.
- Medicine may also be offered for behavioral or psychological symptoms associated with their dementia, most notably anti-psychotics, anti-depressants and sleeping tablets.
- Concerns about poly pharmacy include increased adverse drug reactions (side effects) and interactions between drugs. Poly pharmacy is often associated with a decreased quality of life, decreased mobility and cognition.
- It is well accepted in pharmacology that it is impossible to accurately predict the side effects or clinical effects of a combination of drugs without studying that particular combination of drugs in test subjects.



Review, review, review!

- Because of the risks of poly pharmacy, and the increased difficulties a person with a learning disability and dementia may have in articulating their needs and wishes, it is vital that staff ensure all medicine is regularly reviewed.
- Medicine reviews should be conducted by the person's GP, a consultant (if they have one) or a pharmacist.
- To help inform the review process, staff should document any side effects or changes in the person.
- During the review process, staff need to ensure that they understand what each medicine is for, how it is likely to interact with any other medicine and what the potential side effects might be.
- Staff need to feel confident about asking questions during a medicine review, and challenge decisions where necessary to ensure that the person's best interests are served.
- If staff are unhappy with the review process, they should seek a second opinion.



Non-pharmacological Interventions

Examples of recognised non-drug interventions include:

Acupuncture is a treatment derived from ancient Chinese medicine. Fine needles are inserted at certain sites in the body for therapeutic or preventative purposes.

Animal/Pet Therapy is a guided interaction between a person and a trained animal. The purpose of animal/pet therapy is to help the person to cope with their symptoms.

Aromatherapy is the practice of using the natural oils extracted from flowers, bark, stems, leaves, roots or other parts of a plant to enhance psychological and physical well-being.

Art Therapy is a form of psychotherapy that uses art media as its primary mode of expression and communication.

Bright Light Therapy is thought to affect brain chemicals linked to mood and sleep by exposing the person to therapeutic artificial light.

Dance Therapy is the psychotherapeutic use of movement and dance to support intellectual, emotional, and motor functions of the body. It is a form of expressive therapy.



Non-pharmacological Interventions

Examples of recognised non-drug interventions include:

Herbal Medicines are those with active ingredients made from plant parts, such as leaves, roots or flowers.

Intensive Interaction is an approach for teaching communication skills to people with autism, severe learning difficulties and profound and multiple learning difficulties who are still at early stages of development.

Massage Therapy involves working and acting on the body with pressure manually or with mechanical aids, and is used to promote relaxation and well-being.

Music Therapy is an established psychological clinical intervention, delivered by registered music therapists, to support a person's psychological, emotional, cognitive, physical, communicative and social needs.

Reflexology is a system of massage used to relieve tension and treat illness, based on the theory that there are reflex points on the feet, hands and head linked to every part of the body.



Non-pharmacological Interventions

Examples of recognised non-drug interventions include:

Reminiscence Therapy is the use of life histories to improve psychological well-being.

Sensory Therapy and Sensory Stimulation can help reduce anxiety and depression, promote enjoyment, and increase a person's social interaction by helping them to connect to those around them.

Singing for the Brain is a service provided by Alzheimer's Society that uses singing to bring people together in a friendly and stimulating social environment.

Talking Therapy can help a person deal with negative thoughts and feelings and make positive changes.

TENS - Transcutaneous electrical nerve stimulation (TENS) is a method of pain relief involving the use of a mild electrical current.

Non-pharmacological Interventions

NICE recommend the following regarding non-pharmacological interventions for cognitive symptoms and maintaining function:

“People with mild to moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme. This should be commissioned and provided by a range of health and social care staff with appropriate training and supervision, and offered irrespective of any drug prescribed for the treatment of cognitive symptoms of dementia.”





Non-pharmacological Interventions: Important Considerations

- Most non-pharmacological interventions are not routinely offered on the NHS. Therefore, staff will need to seek private practitioners and funding would need to be in place to pay for treatment(s).
- The availability of non-pharmacological interventions will vary across the UK. Ask the Dementia Specialist, GP or CTALD to tell you what is available or you may need to research what is available in your local area.
- Choosing the 'right' non-pharmacological intervention may be difficult, particularly if the person you support doesn't have a specific preference.
- The better you know the person, the better you can advise them. Involve the person's circle of support for their ideas.
- Staff need to be open-minded about supporting a person with non-pharmacological interventions. Don't be pressurised into committing to one specific non-pharmacological intervention if you have the option of supporting a person to try a range of therapies – it is often by trial and error that the most suitable option(s) emerge.



Benefits of Non-pharmacological Interventions

Benefits largely depend upon the therapy that is chosen, but broadly speaking they can include:

- Enhancing the person's mood, concentration or memory
- Improving communication
- Alleviating behavioural symptoms like aggression, agitation and anxiety
- Reducing levels of stress and depression
- Relaxing the person
- Giving the person purpose, occupation and/or the chance to be creative
- Giving the person something to look forward to, and feelings of enjoyment, happiness and fun
- Pain relief
- Improving energy levels
- Regulating sleep patterns
- Improving appetite
- Introducing the person to something new that they enjoy



Risks of Non-pharmacological Interventions

- Whilst non-pharmacological interventions don't, on the face of it, carry the same risks as pharmacological interventions, if they are applied inappropriately, or by someone who is untrained or unqualified, they could put the person you support in danger.
- When considering non-pharmacological interventions, it is important for staff to seek professional practitioners who have experience in treating a person with a learning disability and dementia.
- It is vital at all times that all safeguarding procedures are followed and that any private practitioners that you engage have an Enhanced DBS (DBS??) check. Also check their registration details – ask for the information or check with the registering professional body.



Case Study Example – Meet Julie & Tom

Julie is trying to support Tom to find a non-pharmacological intervention for his dementia. There are lots of suggestions of potential interventions, but Julie isn't sure what's available locally.

Talk as a team: Where do you think Julie should start looking?

Good places to research might include: online searches, your local memory clinic, wellbeing centre, community hub, GP surgery, library, local halls or venues where groups are held, local notice boards, therapy centres and places where therapists work, local Alzheimer's Society or Age UK.

Making Choices

- Ultimately, the choice about treatment options rests with the person you support.
- In helping them to make decisions, you and your colleagues need to be informed by their GP or consultant about the options available to them. In addition, you need to research non-pharmacological interventions that are available in your local area, providing you have the funding to cover this.
- Remember to always ask questions if you are unsure of information regarding any intervention, be it pharmacological or non-pharmacological.
- Whatever option(s) the person you support chooses, ensure you monitor them carefully for any unwanted side effects, as well as documenting any improvements.





Contributing to Future Treatment Developments

- Because of the generally limited range of pharmacological treatments available for people with dementia, many people with an interest in this area are signing up to 'Join Dementia Research'.
- If staff members in your team want to find out more about this, they can visit:
<https://www.joindementiaresearch.nihr.ac.uk/>
- Remember: To enrol a person you support in research you would need their explicit consent.
- Even if you don't want to get involved with research, it's good practice to keep abreast of current developments in dementia treatments so that you are best placed to advise the person you support about new options as they become available.

Finally... to Recap



- Although there is currently no cure for any type of dementia, there are a range of treatment options, both pharmacological (anti-dementia medicine) and non-pharmacological (alternative therapies).
- Whatever treatment(s) a person chooses when they are diagnosed with dementia needs to be regularly reviewed, and may need to change as their dementia progresses.



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