How can you encourage medicines optimisation to improve the lives of people living with dementia?

In this article, Dr Jane Brown complements the information in the medicines optimisation briefing on dementia.

These briefings have been developed for pharmacists and pharmacy teams working in England, Scotland and Wales.

Medicines optimisation is all about supporting patients so that they get the best possible outcomes from their medicines. It means using effective consultation skills (see: www.consultationskillsforpharmacy.com) in talking and engaging with individuals to understand their beliefs and concerns about their medicines and what they would like their medicine to achieve. It also involves ensuring that the medicine chosen for the patient is clinically appropriate, safe, effective and will help them to achieve their goals. It is about supporting the patient to continue to use their medicines in a way that fits with their lifestyle.

The medicines optimisation briefings we have produced are for pharmacy professionals working in all sectors of healthcare. We believe that, as experts in medicines and their use, pharmacy professionals are well placed to support patients to get the best outcomes from their medicines.

Dementia
Dementia is a growing challenge. As the population ages and people live for longer, it has become one of the most important health and care issues facing the world. In England, it is estimated that around 676,000 people have dementia. In the whole of the UK, the number of people with dementia is estimated to be 850,000. Dementia mainly affects older people, and after the age of 65, the likelihood of developing dementia roughly doubles every five years. However, for some dementia can develop earlier, presenting different issues for the person affected, their carer and their family.¹

There are around 540,000 carers of people with dementia in England. It is estimated that one in three people will care for a person with dementia in their lifetime. Half of them are employed and it’s thought that some 66,000 people have already cut their working hours to care for a family member, while 50,000 people have left work altogether.¹

There is a considerable economic cost associated with the disease, estimated at £23 billion a year, which is predicted to triple by 2040. This is more than the cost of cancer, heart disease and stroke.¹

When a person with dementia feels that their mental abilities are declining, they often feel vulnerable and in need of reassurance and support. This will also impact on the people closest to them – carers, friends and family – who will want to do everything they can to help the person retain their sense of identity and feelings of self-worth. The Dementia Friends initiative was launched by Alzheimer’s Society to raise awareness of dementia and how people can be supported to live well with dementia. Dementia is one of the ten priorities in NHS England’s Five year forward view.

The briefing distributed with this issue of The Pharmaceutical Journal focuses on how pharmacy professionals can work with patients and carers to improve the lives of people living with dementia. This is one of a series of briefings that complement and build on each other. The content is not intended to be exhaustive; the aim is to improve your understanding and approach to helping people living with dementia.
How can pharmacy teams support people living with dementia to improve their outcomes?
People diagnosed with different types of dementia experience a different range of symptoms, all of which may lead to different challenges. Find out more about the different types of dementia and the symptoms people may experience at the Dementia UK and Alzheimer’s Society websites.

Here are some ideas for how pharmacy teams can help patients living with dementia to support medicines optimisation, in addition to those in the briefing. As you will see, even if you do not specialise in this topic there are still plenty of opportunities to make a difference.

Patient experience

- Pharmacy teams are well placed to notice early signs of dementia; early detection is important.
- Reassure people and encourage them to seek help early. Getting an assessment allows people and their families to navigate to the right care package and support for them.
- Keep a stock of up-to-date leaflets as these can help to reassure people that they will not be on their own and will raise awareness of dementia and the help that is available.
- Have up-to-date knowledge of local support services, memory clinics and services so you are ready to signpost people to the most appropriate support for them.
- Help to overcome the stigma associated with mental health problems by treating everyone equally.
- One consequence of stigma is that people and their families may not access help and support until the advanced stages of the disease. Accessing help and support early allows conversations around advance directives and lasting power of attorney to take place before it is too late for the person to be involved in decisions about their care.
- Include people living with dementia in decisions about their medicines and care for as long as possible. Although it is important to include their carers as well this should not be at the exclusion of the person with dementia; they should remain at the centre of consultations and decision-making.
- Think about alternative systems for checking proof of identify if a person with dementia cannot remember their address when they collect their medicines.
- People living dementia may ask, “What can I still do?” Pharmacy teams need to be prepared to respond to these types of questions. By the whole team becoming Dementia Friends or Champions and engaging with your local Dementia Action Alliance (DAA) you will be in a much better position to help. Your local DAA will be able to put you in touch with others who are committed to helping people with dementia live well.
- The Quality Payments Scheme within the Community Pharmacy Contractual Framework contains a workforce target: 80 percent of all pharmacy staff working in patient-facing roles are Dementia Friends. Remember this includes delivery drivers; they may be the only member of your team who sees people in their own homes so it is important to include them.
- Some people living with dementia experience difficulties in perception. This may mean that they become disorientated or anxious, even in familiar places. Small adjustments to pharmacies can help to make them more accessible for people with dementia. Review your pharmacy environment against the DAA dementia-friendly environments checklist. You may be able to change some aspects of the pharmacy environment immediately, such as improving signage; other things can be addressed when a refurbishment is planned.
- Be aware of the DVLA advice regarding driving and dementia; do you know that people must tell the DVLA if they have dementia?
• Be aware of the five things everyone should know about dementia:
  o dementia is not a natural part of ageing
  o dementia is caused by diseases of the brain
  o it's not just about losing your memory
  o it's possible to live well with dementia
  o there's more to a person than the dementia.

Evidence – is the medicine appropriate?
• Encourage people living with dementia to consider alternative therapies, such as dancing, massage, music, memory books or relaxation, and encourage people to engage in social activities.
• Look out for any medicines or acute or long-term conditions that may be causing symptoms that can be mistaken for dementia or worsen existing dementia. Examples include changes to medicines or doses, dehydration, delirium infection, pain or sleep problems. Managing those may solve the deterioration, prevent the need for any further measures and improve the outcome for the person.

Safe and effective
• Seven in ten people living with dementia are also living with another medical condition; the severity of someone's dementia can have consequences on their ability to manage their other conditions, presenting a considerable problem for the professionals and family members who provide the medical and social care for them.2
• Carers are often responsible for managing and administering medicines, so involve them in conversations and medicines reviews, with the consent of the person with dementia.
• Polypharmacy is a significant issue and pharmacy professionals can help by supporting people living with dementia, their families, carers and other health professionals to consider which medicines are most important, which can be stopped (and how) and which could cause problems, such as anticholinergic drugs.
• Ensure medicines are monitored, reviewed regularly and stopped when they are no longer required. Provide advice on stopping medicines gradually (when necessary) to avoid discontinuation problems.

Medicines optimisation as part of routine practice
• Encourage everyone in your team to become a Dementia Friend or Champion and join your local DAA. DAAs can offer advice about providing a dementia-friendly space for people living with dementia and their carers.
• Find out if people living with dementia have a care and support plan, and ask how you can help.
• Learn how each person living with dementia can or prefers to communicate. People living with dementia may experience 'a feeling' but not be able to explain or express why; by being patient and demonstrating an understanding you will build a trusting relationship.
• People with dementia may experience communication problems; this includes finding the right word or repeating words or phrases. Pharmacy teams should consider how they can improve their communication skills when caring for people with dementia. The Alzheimer's Society has produced a useful guide for customer-facing staff about how to help people with dementia, which includes advice about communication with people who are living with dementia. You could also complete the CPPE Consulting with people living with dementia e-learning programme.
• Be aware that the person’s emotional memory of the consultation may be retained even if the factual content is not, affecting the quality of future interactions.
• Be a regular and easily accessible point of contact for dementia patients. Offer shorter appointments with regular follow-up.
• Look out for people living with dementia who change their routine, for example, not ordering or picking up their medicines, and check they are alright.
• Work with people with dementia, their families and carers to support people who may be trying to order their medicines more frequently than required to avoid accumulation of medicines in people’s homes and unnecessary waste.
• Help people to develop medicine reminder charts that work for them.
• Support people to maintain their level and slow the progression of their dementia by encouraging them to keep active and socially involved.
• Help people living with dementia to communicate what they expect from their medicines and help them to identify if they are working.
• Find out more about reasons medicines are being crushed before providing information; a Mental Capacity Act (MCA) assessment is required before covert administration can proceed. Avoid making assumptions about a person’s capacity to make a decision because they have a diagnosis of dementia.
• Be aware of your safeguarding responsibilities regarding people living with dementia who use your services.
• If the person living with dementia has swallowing difficulties consider which formulations of medicines may be best for the person and review these regularly.
• Pharmacy professionals providing services to people with dementia, including in care homes, should complete relevant training to increase their knowledge and confidence in providing medication reviews, advice on the MCA and advice on formulations and administering medicines.
• Offer to visit your local dementia cafes to talk to people about medicines and expectations around them and how to deal with concurrent long-term conditions.

Lifestyle messages
It is important to be aware of lifestyle advice relating to dementia and to tailor this advice to each individual. Here are some of the main messages:
• Encourage patients to keep active and stay involved.
• Attend local Singing for the Brain sessions, tea dances or other support sessions.
• There are a number of modifiable risk factors for dementia that pharmacy teams are well placed to support in their public health role. This includes identifying and supporting people to reduce excessive alcohol consumption, smoking cessation, healthy eating and increasing physical activity. See www.alzheimers.org.uk/riskfactors and www.alzheimers.org.uk/info/20030/staying_independent/348/dealing_with_memory_problems/4 for further details.
Signposting patients
There is a wealth of information about dementia available for patients and their family and carers. There will also be local support so find out what is available in your locality. This may include dementia cafes and Singing for the Brain. You and your team could visit some of these groups to find out more and collect some leaflets to hand out from your pharmacy. Tailor your advice and signposting to the individual and their circumstances.

Here are some useful websites you may want to signpost people to:

- Age UK
- Alzheimer’s Society
- Dementia Action Alliance (DAA)
- Dementia UK
- Carers Trust
- Carers UK
- NHS Choices Dementia guide: About dementia
- NHS Choices Dementia guide: Dementia choices
- NHS Choices Dementia guide: Help and support for people with dementia
- Dementia Engagement and Empowerment Project (DEEP) guides

Signposting pharmacy professionals
There is a wealth of information on this topic and below is a summary of the main resources that were considered important during the development of this briefing and article.

- Alzheimer’s Society
- Aging Brain Care: Anticholinergic Cognitive Burden Scale
- Barbara’s story
- British Association for Psychopharmacology (BAP) consensus guidelines
- Choice and Medication: Dementia and Alzheimer’s disease
- Clinical knowledge summaries (CKS)
- College of Mental Health Pharmacy
- Dementia Action Alliance (DAA)
- Dementia Evidence Toolkit
- Dementia Friends
- Dementia Roadmap
- Dementia UK
- Greater Manchester and Eastern Cheshire Strategic Clinical Networks: Dementia interactive care pathway toolkit
- Greater Manchester Dementia friendly pharmacy framework
- Local trust guidelines
- Mental Health Act 2005 and capacity
- National Association of Primary Care: Primary care navigators (PCNs) for dementia
- NHS England: Dementia
- NHS England dementia toolkit primer
- NHS England: Medicines optimisation dashboard
- NICE guidance
- Royal College of Psychiatrists
- Royal Pharmaceutical Society
CPPE learning programmes

- Accessible Information Standard – making it work e-learning programme
- Antipsychotic reviews in dementia e-learning programme
- Care homes, medicines and older people workshop
- Care homes: supporting people, optimising medicines e-learning programme
- Consulting with older people workshop
- Consulting with people living with dementia e-learning programme
- Dementia focal point workshop
- Dementia friends and focal point workshop
- Mental health e-course
- Older people distance learning programme
- Polypharmacy distance learning programme
- Polypharmacy focal point workshop
- theLearningpharmacy.com Dementia floor
- theLearningpharmacy.com Supporting carers floor
- The Mental Capacity Act 2005 and covert administration of medicines workshop

Other learning programmes

College of Mental Health Pharmacy Psych 1 course
NHS Education for Scotland: The pharmaceutical care of people living with dementia distance learning programme
Social Care Institute for Excellence: Dementia e-learning programme

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Reference

2. Alzheimer’s Society. All-party parliamentary group on dementia web page.