**A National Conversation to inform a New Dementia Strategy for Scotland**

*As an individual with an interest in the lives of people living with dementia, and those providing care/support:*

1. What does dementia mean to you and those around you?

RCGP Scotland welcomes the opportunity to respond to this consultation. As the membership body for general practitioners in Scotland, we exist to promote and maintain the highest standards of patient care.

We recognise that dementia is a complex condition which impacts on patients, their carers and families in various ways, which can often be life changing. GPs have varied experiences dependent upon the demographics of their patient list. As our population ages, caring for those with dementia and the frail elderly represents an expanding workload for GPs. According to the Alzheimer’s Society the number of people dementia is estimated to be 90,000, with approximately 3,000 below the age of 60. As Scotland's population ages, dementia will have an increasing impact on the community, the care sector as well as general practice. Services including mental health support for the elderly, dementia diagnosis and treatment are already facing sustained pressure which is likely to continue.

Many patients fear the diagnosis of dementia and can be too frightened to see their GP, and the GP experience is that it may be family or carers who flag their concern:. Initial conversations are often complex and sensitive, balancing the patients’ wishes and perceptions with those of their family and supporters. GPs are aware that diagnosis can be difficult if the patient is experiencing other mental and physical co-morbidity, and reaching a correct diagnosis usually requires a careful, structured holistic assessment, which requires time and expertise. Knowing the patient and the family makes a huge difference in this situation. Some patients would rather not be diagnosed at all, or decline referral

There are particularly high caring burdens for those looking after or living with those with dementia, not least the distress of seeing someone lose their memory, and other cognitive functions. It can be particularly difficult for those with severe dementia, who might not be capable of recognising the partner or family member caring for them. People’s personalities may change and patients may become hostile or even violent, causing tremendous distress. Relatives caring for those with dementia also have higher risks of depression. Continuity of care means GPs about are aware of family connections and can recognise that family members may need help too: relational and family care is central in helping those with this condition

Care home workload in this space is expanding, and so we see it as a specialist area of generalist care requiring an expanded and specific resource and workforce. In the later stages of dementia, it can be hugely stressful for families, care home staff and GPs to look after these people who will often have physical deterioration and behavioural challenges. Whilst progression is variable and unpredictable, it is inevitable and those with advanced dementia universally lose physical as well as cognitive ability. The GP will be involved in palliative and end of life care, working closely with family, carers, community nursing colleagues and often Care Home staff. The majority of people in care homes have dementia and are in the last 1-2 years of life.

It's important to note that the pandemic has had a huge impact on those with dementia and the people looking after them. In 2020, 28% of deaths in Scotland due to Covid also had dementia listed as a co-condition[[1]](#footnote-1): three quarters of those deaths were in care homes. This has left a legacy of bereaved families who had the added burden of grief of not being able to see, care for, or say goodbye to their loved ones at the end of their lives. We recognise that care home staff, too, were often working in the most difficult of circumstances, trying to maintain a home for patients with dementia, whilst following strict infection control procedures and looking after those ill or dying. Many staff, as well as families, will suffer an emotional legacy from those times and we need to remain mindful of that.

We also know that the health of many with dementia worsened when

isolated from friends and families. Established relationships and interactions are central to wellbeing and this is especially true for those with dementia.

1. What supports work well for you?

Continuity of care improves outcomes for those with dementia, but can also assist with the early detection of symptoms and the difficult discussions that might subsequently be needed. In patients with dementia who have high GP continuity of care, there are reductions in rates of delirium, better prescribing, less incontinence and fewer adverse events and emergency hospital admissions[[2]](#footnote-2).

For those with memory difficulty and those supporting them, an ongoing relationship with a GP can make a huge difference. Those with dementia can often have other chronic conditions and so compassionate and realistic care can be hugely helpful. As dementia progresses, there is often complex shared decision-making round deprescribing, optimising long term condition care but also withdrawing from interventions when they are no longer appropriate or helpful. Close and good working relationships are key.

Community Link Workers can also contribute to care, supporting people with their personal, social, emotional and financial issues, particularly early on in the condition. Often, they can help support families too. Carer’s organisations such are invaluable, VOCAL serving Edinburgh and Midlothian being one example.[[3]](#footnote-3) Many of our patients have very positive experiences of the post-diagnostic support now available to all those with a new diagnosis: this is a time of adaptation and often trauma for the patient and their families and this support is invaluable[[4]](#footnote-4).

[Dementia Advisors](https://www.alzscot.org/living-with-dementia/getting-support/dementia-advisors) are invaluable and can especially help people with a new diagnosis - a process which is often a traumatic and life-changing moment and for which support is needed. The concept of [dementia-friendly communities](https://www.alzscot.org/our-work/dementia-friendly-communities) is one that merits further exploration, and greater knowledge of the disease from the multi-disciplinary team (MDT) can help achieve a better experience for patients and carers.

1. What challenges need to be addressed?

GPs are the primary medical carers for those with dementia from diagnosis to end of life. Many such patients are in care homes; others may be reliant on house visits for care. As outlined above, diagnosis requires time and attention and once diagnosed, there are multiple workload challenges. GPs embark on empathetic discussions around realistic medicine principles for deprescribing, and adjusting chronic disease management. Patients may present with new and concerning symptoms, unrelated to dementia, and those will need to be addressed appropriately. Compassionate and time consuming discussions will also take place round the decision-making capacity, end of life care and – where indicated - do not attempt cardiopulmonary resuscitation (DNACPR) certification. Other aspects of care, which take time and resources, are the sensitive discussions and liaison needed where indicated for power of attorney and guardianship. Anticipatory care planning –and adding those plans to the Key Information Summary - can only be done in the GP record.

Once a diagnosis has been made, usually by a specialist team, there are several medications available which slow the progression of the disease. These are usually initiated by specialists and once established, ongoing prescribing is undertaken by GPs, usually with a Shared Care Agreement. Staff shortages in specialist sectors can lead to challenges in initiating medication, and GPs can feel pressurised to prescribe without full input, although national guidance is that treatment should only be started by a specialist or a healthcare professional with additional specialist expertise[[5]](#footnote-5). As the number of patients with dementia increases it is crucial to have adequate staff to ensure high quality and safe care across the interface.

People with dementia may be agitated, cause disturbance or even be violent: as outlined via the Biological and Psychological Symptoms of Dementia (BPSD). The emphasis now is not on using medication (and particularly anti-psychotics) in this scenario[[6]](#footnote-6), but rather adopting supportive behavioural and environmental strategies instead. This course of treatment may require advice from specialists, and that can be difficult in areas where there are shortages of Community Psychiatric Nurses (CPNs) and psychiatric staff. It also requires co-ordination with care staff who will take on the demanding care such treatment recommendations often require. Sometimes BPSD can cause acute severe disturbances in home or care home settings, posing very significant challenges to all those involved. There is a severe shortage of inpatient mental health beds for the elderly and most have to be managed in the community.

The progression of dementia is highly variable, though care needs tend to be universally high at the end of life. include of the variance, the introduction of palliative care discussions and approaches can be a difficult decision for practitioners.

Often patients need adaptations to care as their condition progresses, and we see the role of Allied Health Professionals as including physiotherapy and occupational therapy (OT) as crucial. We know that some with dementia have other unaddressed needs such as vision and hearing issues. There are often long waiting times for these services, although their involvement can significantly help with adaptations which can be challenging. We align with the vision for AHPs outlined by Alzheimer Scotland[[7]](#footnote-7).

Hospitalisation can be deeply harmful for those with dementia, and there is clear evidence that prolonged admissions are especially damaging. Adequate care staffing and expanded care home provision is needed if we are to mitigate for this and allow prompt discharge, or admission avoidance where possible.

Furthermore, expanded number of GPs, their extended teams including district nurses, and CPNs for the elderly are imperative in order to maintain and keep people at home for as long as possible and allow for earlier discharge. We now have profound, and growing shortages in of all these sectors: WTE GP numbers have dropped since 2019[[8]](#footnote-8), despite a rising workload. The lack of GP capacity must be seen as a hugely significant challenge in this area of care

1. How would addressing these challenges change lives?

Enabling those with dementia to have active, meaningful lives would be the single most impactful outcome for people living with dementia. This might include, for example, allowing people to live where they would like to in the surroundings and people they are comfortable with. To achieve this would generally mean giving adequate carer support to those at home and enhanced staffing and access to support for care homes.

RCGP supports the Scottish Government’s healthcare framework for adults living in care homes, and especially its vision of a nurturing environment with the person at the centre of the 'wheel of wellbeing', supported by health and social care staff. Holistic care is essential for those requiring dementia care and aligns with the GP vision. However, the framework does not outline how workforce shortages will be addressed, nor how this work will be resourced if GPs (or others) are to undertake it. We would strongly support addressing these challenges as the means to affording people with dementia the lives and care they would hope for.

1. What do we need to build on/learn from what has been done before?

Those with dementia can and must be supported all members of the Multi-Disciplinary Team (MDT). There is now a good body of evidence around what works; however, this can only be achieved through clinician time. Increasingly, members other than the GP are involved in prescribing, with practice-based pharmacotherapies taking on an increasing role. Community and practice nurses have a key role in maintaining health and optimising long term condition care, for example. There are innovations too: Advanced Nurse Practitioners are taking on new responsibilities too, particularly round acute intercurrent illness, long term planning and so on.

We have certainly learned that it is essential that the entire MDT has an understanding of dementia - for example, a GP receptionist will be the first port of call for those with dementia and their carers, and will be responding to people who can’t remember why they are calling, or may miss their appointments or will be calling in relation to a loved one. The receptionist will therefore require a sound understanding of how to work through this in an effective manner.

Protected Learning Time (PLT) is crucial in regard to complex conditions such as dementia - for extending the knowledge and understanding of staff, including around palliative care needs. People with dementia are a group who are particularly impacted by fragmented services and lack of social care, and the whole practice team has a role in co-ordinating care

Preventative care is also important. We know that diabetes, high blood pressure, smoking, some types of learning disability and multiple cardiovascular risk factors in middle age, lack of physical activity, and alcohol excess are risk factors for dementia. GPs and their teams, practice nurses in particular, have a crucial role to play in managing long term conditions and reducing such risks. We also recognise that public health factors are crucial including tackling risk factors for vascular disease, alcohol, physical inactivity, smoking, poverty and lower educational attainment. To address this requires societal change as well as effective programmes within GP practices..

We have a strong history in Scotland of developing frameworks, such as that of palliative care. However, for those who are elderly and especially those with dementia, what is needed is care close to home. It is crucial that we build our workforce to enable us to build on the experience we possess and enact the frameworks which have been developed.

6. What else would you like to tell us?

As noted above, the primary aim for this strategy should be enabling those with dementia to have active, meaningful lives, and ensure adequate support for those who care for them.

Again, we also believe it imperative to recognise the significant numbers of people with dementia, especially those in care homes, who lost their lives during pandemic. A high proportion of covid deaths in the community have been in care homes - since the start of the outbreak in Scotland:

* 13,157 deaths have been registered in Scotland where COVID-19 was mentioned on the death certificate up to 13 February 2022
* 29% of COVID-19 registered deaths related to deaths in care homes, 64% were in hospitals and 7% were at home or non-institutional settings (as of 13 February (2022))

 It is crucial that the experiences of these individuals and their loved ones is heard.

1. [Excess deaths from all causes and dementia by setting Scotland 2020-2021 - gov.scot (www.gov.scot)](https://www.gov.scot/publications/excess-deaths-causes-dementia-setting-scotland-2020-2021/pages/2/) [↑](#footnote-ref-1)
2. Delgado, J. *et al.* (2022) ‘Continuity of GP care for patients with dementia: impact on prescribing and the health of patients.’, The British journal of general practice. doi: 10.3399/BJGP.2021.0413. [↑](#footnote-ref-2)
3. [Support for carers in Edinburgh and Midlothian - VOCAL](https://www.vocal.org.uk/) [↑](#footnote-ref-3)
4. [Accessing post diagnostic support | Alzheimer Scotland (alzscot.org)](https://www.alzscot.org/pds) [↑](#footnote-ref-4)
5. [Recommendations | Dementia: assessment, management and support for people living with dementia and their carers | Guidance | NICE](https://www.nice.org.uk/guidance/ng97/chapter/Recommendations#pharmacological-interventions-for-dementia) [↑](#footnote-ref-5)
6. [Antipsychotics: initiative to reduce prescribing to older people with dementia - GOV.UK (www.gov.uk)](https://www.gov.uk/drug-safety-update/antipsychotics-initiative-to-reduce-prescribing-to-older-people-with-dementia) [↑](#footnote-ref-6)
7. [Allied Health Professionals and dementia | Alzheimer Scotland (alzscot.org)](https://www.alzscot.org/ahpdementia) [↑](#footnote-ref-7)
8. https://www.publichealthscotland.scot/publications/general-practice-workforce-survey/general-practice-workforce-survey-2022/ [↑](#footnote-ref-8)