

## Executive Summary

The University of Stirling was commissioned by the Scottish Government to complete this review of dementia research, to inform the new Dementia Strategy for Scotland. The purpose of the review was to synthesise evidence on a series of specific issues identified by the Scottish Government during the development work for the new strategy.

This literature review focused on nine research questions:

1. How are people living with dementia and unpaid carers interacting with services or supports in the community?
2. What supports and empowers people to live a good life with a dementia diagnosis?
3. What are the health inequalities aspects and to what extent is the support offer responding to what the research tells us? Are there specific equalities aspects we could understand better? Do we do enough to tailor support for people with protected characteristics?
4. What other models or types of support exist that people living with dementia might access? What is working well and why?
5. What does the literature and research say on prevention? Is there practice working well and why?
6. What are the experiences of people living with dementia and unpaid carers interacting with NHS community, specialist and hospital-based services?
7. What supports people to remain living at home and connected to their communities?
8. How are people living with dementia being supported in care homes and what are their experiences?
9. How do we tackle stigma / tell a different story for people living with dementia and unpaid carers?

### **Methodology**

The literature review provides a 'rapid umbrella review' of research published since 1 January 2017. A rapid umbrella review aims to understand what is known and where there are research gaps. Four research literature databases were used to collect research papers for the review, which resulted in 264 items with an additional 25 documents added from grey literature resources.

### **Findings**

Eleven key themes were identified through the review, these addressed the nine research questions plus two additional topics that emerged as important with the review process: support for care partners and impact of COVID-19:

#### 1. Prevention of dementia

Identifying modifiable risk factors which will reduce an individual's lifetime risk of developing dementia has become a key research priority. Clinical, social and lifestyle factors are all thought to have preventative role. The evidence suggests that factors which have the greatest impact on increasing dementia risk are usually associated with an unhealthy lifestyle: poor diet, obesity, poor cardiovascular health, and smoking. However, there has also been evidence to suggest that there may be a connection between mental health conditions and higher dementia risk. Further evidence highlighted that social status, high education levels and higher social class can all impact on dementia risk, which may be as a

result of better physical and mental health, reduced acute or chronic life stressors, and engagement in stimulating activities.

## 2. Living well with dementia

Initial evidence suggests that a range of non-pharmacological interventions can have a positive impact for both the person with dementia and their care partners. A key factor in someone's ability to adapt to living with dementia is their ability to draw on a range of personal and environmental resources, for example: personal resilience, self-efficacy, and the social and physical environment. The relationships that a person with dementia builds with those around them can also play a key role in how they adapt to their condition.

Stigma, and misconceptions, can impact on the journey to receiving a diagnosis, in particular worries about the future which may lead to depression, resistance of a diagnosis, and potential reluctance to accept post-diagnostic support.

Empowerment for individuals with dementia and providing ongoing support and information is vital to a person's journey, while a person-centred, tailored approach is key to optimising support. Perceived loss of self and reduced status can have serious implications for a person with dementia and may limit their ability to cope with a diagnosis or seek support. Having a sense of purpose and opportunities to take part in meaningful activities and retain social value were also highlighted in research to play a positive role post diagnosis.

The review identified the vulnerability of people with young onset dementia and gaps in providing for their needs. Improvement in symptom recognition, reducing diagnostic errors, and identifying emotional needs are important to promote the diagnostic experience and the engagement with services.

## 3. Remain living at home and connected to the community

The domestic environment and neighbourhoods can play an essential role in keeping people at home and connected to the community. It provides opportunities for simple, low-cost strategies as well as a platform for reminiscence activities. Support at home needs to be adapted and tailored to suit individual needs. Supported housing, although meant to promote independence and autonomy, is not always able to achieve the goal for people with dementia in post-diagnosis journey as care needs increase. Lack of resources, staffing and limited training are all barriers for people to receive appropriate support. Further research is required to explore neighbourhoods and dementia on a larger scale.

A large number of interventions have been identified that were developed to help people living with dementia with independent living and daily activities. Assistive technology also provides a range of support that may enhance everyday life.

## 4. Dementia support models

Care models have the potential to support people with dementia at every stage of their journey, and benefit from considering the diversity within the population. In both care homes and hospitals, training was highlighted as being crucial to deliver effective care in addition to the presence of experienced staff. Person-centred approaches were also recognised to support quality of life. For those living at home, research suggests that care should focus on facilitating independence and providing support for care partners. These will

maintain quality of life and maximise time at home.

Research recognised that there are many complexities to supporting a range of people, including children of people with dementia, ethnic minority groups, and the LGBTI community. Including people from within these communities to advise and to delivery support is advisable but requires further work.

5. Experience of NHS community, specialist and hospital-based services  
Staff knowledge and education in dementia is fundamental to delivering high-quality healthcare for people with dementia. It can also protect staff against burnout and stress. For people with dementia, relationships both with the health care professionals and with their care partners can improve experiences and outcomes. Research also suggests that there may be a link between community-based healthcare and delaying / preventing admissions to hospital. Involving care partners, using psychosocial interventions and volunteer programmes can all have a positive impact too.
6. Experience of care homes and end of life services  
More research is required in this area, however the research that was available suggests that some psychosocial interventions, such as music therapy, physical activities, access to the natural environment, and animal assisted therapy have significant benefits for people with dementia and should be encouraged. Within residential care, lack of staff training and a high staff turnover were identified as challenges for the sector. Training needs in relation to end of life care, particularly around difficulties communicating pain or discomfort were also highlighted. Notably, research suggests that current approaches for palliative care may not be appropriate within the dementia care setting.
7. Stigma and stereotype in dementia  
Attitudes and perceptions amongst the public, healthcare professionals and structural prejudice within healthcare services can prevent people experiencing memory loss from accessing and benefiting from support. Some may fear discrimination, marginalisation and social exclusion. LGBTI people and ethnic minorities may also face challenges to receiving healthcare services, therefore staff training is highlighted as a requirement.
8. Inequality in dementia  
Various aspects were identified in relation to inequality in dementia and related care services, including the public's understanding, dementia-friendly society, cultural appropriateness and competence in service. Findings suggest measures to address the highlighted issues, e.g., improving public awareness of dementia and related health care approaches, establishing culturally appropriate services, promoting health services that seek to rectify the negative impacts of institutional racism, and ensuring equitable service provision, especially to ethnic minority groups, LGBTI groups, homeless people and those who do not receive unpaid care from family and friends.
9. Support for people with protected characteristics  
There are improvements to be made to promote the inclusion of diverse groups and provide appropriate services for them. This includes people from the LGBTI community and ethnic minorities. Currently, fear of discrimination from health providers may delay people from accessing support. There is a need to understand the requirements of different communities

in order to provide the most appropriate support and services. For example, research around deaf communities stresses the importance of life story work. For people with intellectual disabilities, a more complex approach to care and treatment is required. A lack of understanding and a culture of heterosexism within society can also negatively impact the LGBTI community

#### 10. Support for care partners

Care partners play a crucial role in providing care and support, which has warranted a significant amount of research in this area. Research has focused on education and training needs, information accessibility, emotion, wellbeing, and life experience. It was identified that care partners need education and support as they take on this role. Care partners themselves can be at risk of poor health outcomes, for a variety of reasons. Some research suggests more work needs to be done in developing intervention and training programmes to support care partners.

#### 11. Impact of the Covid-19 pandemic

There was some evidence available to recognise the impact the pandemic has had on people receiving a diagnosis, living with dementia, and their care partners. Research shows that the pandemic impacted negatively, for example through enforced isolation, withdrawal of key services, and challenges accessing vital healthcare. Some people with dementia experienced rapidly worsening symptoms and social isolation lead to loneliness, depression and anxiety. Care partners experienced higher levels of stress and exhaustion through an increase in caring responsibilities, compounded by loneliness. It is thought this may have had an impact on their sleep and increased risk of eating disorders.

### **Conclusions**

The review concluded that although there are a range of care models and interventions that show promise in supporting people living with dementia, and their care partners, to live well, there are also areas where significant improvements are still required.

Work is needed to improve the understanding of dementia among the general population, while challenging stigma and raising awareness of risk factors / prevention. Provision of additional staff training within healthcare settings is also highlighted as vital, not just in relation to dementia care but also challenging organisational stigma. Better working cross-organisation can provide better support and steps towards providing inclusive services.

Person-centred care and life story work can impact on a person's experience of dementia, and understanding the person is key to providing support. A variety of groups were identified as requiring better support including people with sensory impairments, people with early onset dementia, minority ethnic communities, and the LGBTI community. The significance of care partners has been raised during the review, including their contribution to supporting the person living with dementia, but care partners needs' also need to be addressed. There is also the necessity to provide better support for young carers and children of people with dementia.

Supporting people with dementia to make decisions, involving them in the decision making process, is crucial and should not be underestimated. Relationships with those providing care impact significantly on people's experiences, and so providing consistency of care and allowing relationships to develop is important. Innovation also has a role to play, whether through technology or innovative care models and methods of support.