

## A National Conversation to Inform a New Dementia Strategy Royal College of Psychiatrists in Scotland Response

5 December 2022

### Context

This response is informed by the views of members of the Faculty of Old Age Psychiatry of the Royal College of Psychiatrists in Scotland (RCPsychiS).

As the professional medical body for psychiatry in Scotland, the RCPsychiS set standards and promote excellence in psychiatry and mental healthcare.

We lead, represent and support psychiatrists nationally to government and other agencies, aiming to improve the outcomes of people with mental illness, and the mental health of individuals, their families, and communities. We have over 1,400 Members, Fellows, Affiliates and Pre-Membership Trainees in Scotland.

To utilise the experience and expertise of our membership, we conducted a survey which has informed the following response. Those taking part included Consultant, Trainee and Research Psychiatrists working in Old Age Psychiatry, from across the Scottish Health Boards.

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

- **Dementia as a journey** – Many of our members described dementia as a 'journey' which can be complex and difficult. People living with dementia require holistic support throughout this journey, which takes into account their physical health, mental health and social care needs.
- **More than memory problems** – To our membership, dementia can mean many things. It is a 'cruel' condition that can cause confusion, distress, fear and isolation.

Symptoms extend beyond memory problems alone. They can change and fluctuate over time and affect everyone differently, requiring different approaches in terms of support.

It should also be remembered that dementia is not always an illness associated with old age. It can affect younger people, sometimes as part of a more general neurological condition.

- **Impact on carers of people living with dementia** – Dementia, as an illness, has a profound effect on individuals. However, it also affects those around them, including loved ones and carers. As a result, the mental health of the carer should be taken into account alongside the mental health of the person living with dementia.

## 2. What supports work well for you?

- **Person-centred care** – Most commonly, our members highlighted that the best support for people living with dementia is flexible and person-centred. This means considering people as individuals, taking into account the stage of their dementia, any other long term conditions they may have and whether they live in an urban or rural community, for example.
- **Home support** – Our members strongly recommended that people living with dementia be supported in their own homes for as long as is possible. One member told us that ‘allowing people to remain part of their community is key.’ As outlined above, this home support should be tailored to the individual and include social opportunities which provide stimulation.
- **Support for carers** – Support for carers is vital if they are to continue their important roles. Our members identified Carers Centres such as Angus Carers as vital sources of support and information. Clear information around financial entitlements is particularly important at the moment, too, in the midst of the current cost of living crisis.

As well as this, respite also provides ‘a lifeline for carers and loved ones which allows them the opportunity to continue to support their loved one at home for longer.’

- **Health and social care staff** – Health and social care staff also play a vital role supporting people living with dementia and should be supported to fulfil this role. Our members highlighted NHS staff, social care staff, specialist mental health nurses, dementia care nurses and social workers for praise. However, it was argued that these professions require increased resources from the Scottish Government to continue this good work.

Social workers in particular are able to provide support for carers, meals on wheels, community alarms and tracking devices, for example. One of our members noted that for social workers, the most effective support often comes when they work ‘outside their narrow remit to support isolated elderly people.’

It was also stressed that a cohesive, multidisciplinary approach benefits both health and social care staff and the people they support.

- **Crisis models** – It was noted that dementia crisis teams had delivered benefits to patients' access to immediate interventions.
- **Post-diagnostic support** – It was shared that post-diagnostic support, when available, can be very effective.

### 3. What challenges need to be addressed?

- **Impact of COVID-19** – COVID-19 had a significant impact on services across Scotland. Diagnosis and presentation for conditions like dementia to our services have increased as we have emerged from the pandemic. Due to lack of early engagement opportunities, many of these presentations are now at a more advanced stage, meaning greater and more specialist intervention is required.

When asking our membership for their views on the new Health and Social Care Strategy for Older People earlier this year, it was suggested that the Scottish Government should commission research to explore the impact of the pandemic on dementia diagnosis. This should include the impact of a loss of interactions with services on late diagnosis and whether it had led to greater progression in a person's condition.

One member shared with us that the 'removal of all but the most basic of community supports during COVID-19 proved catastrophic' for people living with dementia. They said that they have witnessed 'more rapid deterioration in their general wellbeing, increased levels of frailty and poorer mental health.' Whilst there are other contributing factors, it is felt that services which had provided vital social and cognitive stimulation had been removed during the pandemic.

Furthermore, recent Scottish Government secondary analysis of National Records of Scotland deaths data showed a marked increase in deaths with dementia as the underlying cause in the early stages of the COVID-19 pandemic. This analysis also established that dementia was the most common pre-existing medical condition amongst those whose deaths involved COVID-19.

- **Early-onset dementia** – It was also noted during our engagement for the new Health and Social Care Strategy for Older People that those with early-onset dementia struggled to access appropriate services that met their needs. In particular, age-specific requirements precluded them from many community supports. While recognising the limited capacity, no one who would benefit from 'older adult' services should be denied these if appropriate for their care.
- **A balanced medical and social approach** – It was suggested by one of our members that, whilst in some instances, medical intervention is the most effective approach, it should not be viewed as the only answer. Dementia is also a 'social condition' and supporting individuals with their daily activities

can help to avoid unnecessary hospital admissions for people living with dementia.

- **Dementia as a social condition** – It was argued by one of our members that we should ‘try and move away from the overly medicalised view of dementia.’ Instead, they suggested viewing dementia as a ‘social condition,’ focusing on supporting individuals with their daily activities rather than trying to treat their dementia with medicine. They claimed that it was the failure to provide the former that leads to most hospital admissions for people living with dementia.
- **Resources** – Many of our members feel that dementia services are not properly resourced. Those who responded to our survey called for the recruitment of more clinicians. Vacancies in medical and nursing staff have led to pressures within Community Mental Health Teams and crisis management rather than proactive work.

Our members also called for more resources to be made available for people living with dementia, such as local day centres. These should also become more flexible in terms of their role and opening times, providing more support in the evenings and over the weekend.

Inadequate care home accommodation for people living with dementia has also led to an increased number of hospital admissions, as well as delaying discharge for those in hospital.

Knowledge of the resources that are available is also key. Our members highlighted the need for greater awareness amongst health and social care staff of the range of services that are available. For example, the support that third sector organisations are able to provide in a locality.

#### 4. How would addressing these challenges change lives?

- **Quality of life** – Firstly, addressing these challenges will improve the quality of life of people living with dementia. With the correct support, people will be able to remain at home for a longer amount of time, avoiding unnecessary hospital admissions. And, with adequate care home accommodation, delayed discharges will be reduced. Increased resources for our members will also mean shorter waiting lists and better support for people living with dementia.
- **Carers’ mental health** – Addressing these challenges will also improve the mental health of carers. One member shared that, often, they ‘end up having to care for and treat the carer as well as the person living with dementia.’ Support should be given to carers to help them negotiate the health and social care system and access support, both for themselves and the person they are caring for.

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

- **National dementia strategy: 2017-2020** – We would recommend that, rather than starting from scratch, we continue to build on the achievements of the previous dementia strategy. The principles of the previous strategy should not be lost, and neither should its commitments
- We would recommend that the new strategy continue to build on the previous commitments where we have made good progress, so as not lose this positive momentum. We recommend retaining or refreshing the following commitments:
  - Commitment 1 (Person centred post diagnostic support),
  - Commitments 5 and 6 (End of life care),
  - Commitment 17 (Research and quality improvement work in relation to dementia care including qualitative studies),
  - Commitment 19 (Relating to Dementia diagnosis and prevalence to support future planning),
  - Commitment 20 (Dementia clinical guidelines).
- The current work on person-centred SIGN Dementia guidelines has occurred at an opportune time (related to commitment 20). The new strategy can help in shaping the implementation of these guidelines and good practice recommendations.

Our members shared with us that they believe the aims of the previous strategy are still relevant. It was suggested that, to support these aims going forward, more investment to support carers, greater coordination of third sector services and upskilling of care workers will be required. The latter should include ongoing support and education for general nurses to help them care for people living with dementia.

Post-diagnostic support was a key commitment in the previous dementia strategy and currently works very well, when it is available. We recommend building on the progress that has been made in this regard to ensure that accessing post-diagnostic support is consistent for all people living with dementia in Scotland.

- **Person-centred care** – Our members recommend continuing our progression towards increasingly person-centred care, with flexible services which fit around the individual needs of people living with dementia.
- **Research** – Our members also recommended more funding be devoted to dementia research, citing HIV and cancer as ‘recent examples of what can be done with conditions that were initially thought of as death sentences.’
- **Link workers** – The introduction of link workers has been welcomed by our members. They provide an excellent service for people living with dementia and invaluable support to teams which are often understaffed, allowing our members to ‘continue diagnosing and treating the next cohort of referrals which seem to be increasing.’

- **Mental health and incapacity legislation** – It was also suggested by our members that the recommendations of the Scott report be enacted to support people living with dementia and, in particular, that mental health and incapacity legislation be updated.

## 6. What else would you like to tell us?

- **Resources** – Some of our members shared that they currently feel unable to provide the best care for people living with dementia because of resource issues. Examples provided of resource issues included smaller teams and fewer doctors: 'Everywhere there is staff shortages, fewer medics and fewer nurses. Social work departments are stretched to the max which makes it very difficult to support patients and families in the community.'

Increased referral rates from GPs to Community Mental Health Teams have exacerbated these issues. One member shared the opinion that 'quality, efficiency and safety are linked. To improve quality, put resources in.'

- **Consistent support** – Our members shared that 'there is often less and less support as the illness progresses.' Support for people living with dementia should be consistent, supporting them throughout their lives. It was suggested, for example, that more time should be spent supporting people with severe dementia, who are often excluded from research studies.