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Consultation Response from the Royal College of Physicians of Edinburgh to the Scottish Government's "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:

The Royal College of Physicians of Edinburgh (RCPE) is pleased to respond to this consultation and considers that it is extremely important that the views of clinicians are heard throughout the process of developing a new strategy. The RCPE is committed to working positively with the Scottish Government and all others involved in order to better support those with dementia.

Our response is based on the views of a number of Fellows, many of whom are geriatricians with significant direct experience working with patients with dementia. To ensure our response was as holistic as possible we also asked for, and received, input from members of our College's Lay Advisory Committee who advise the College on matters from a lay perspective.

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

Our Fellows referred, in variety of ways, to individuals developing cognitive impairment that affects memory, attention, orientation and higher executive function; it impacts on relationships and increases vulnerability and frailty.

It means the individual cannot rely on their own brain to allow them to perform all the actions that keep them safe, well and linked in to society and needs support from others.

It is a condition that has increased in prevalence over recent decades as the population ages.

For many people with dementia, admission to hospital is appropriate and necessary, but for others admission to hospital is either due to the community support services being insufficient, or due to patients developing Behavioural and Psychological Symptoms (BPSD) of dementia which are not managed in the community.

One Lay Adviser said for him it was about the start of another journey for an individual where, with the appropriate interventions, that individual can lead a rich and rewarding life, just in a different way.

2. What supports work well for you?

Fellows identified a number of specific support services that worked effectively including inpatient Distressed Older Adult teams, community teams and hospital meaningful activity teams but indicated these were not universal across the country.

The work of multidisciplinary teams- as long as those involved have adequate planned time for discussion and collaboration- and a cross-sectoral approach, including the third sector, in relation to advanced care planning and anticipating care and housing needs is considered highly positive and effective.

Rapid response mental health teams are effective: when such teams are in operation, and appropriately staffed, they can identify vulnerable patients in the community, intervene, and often prevent deterioration or admission.

The increasing recognition of dementia and earlier diagnosis is welcome and post-diagnostic support has been an excellent initiative where it has worked but there is significant variation in the availability and provision of services. The current post diagnostic support ends after 12 months – this needs to be extended or made easy for self re-referral so that help can be accessed timeously when needs change.

Community beds for people who need longer for delirium to settle or time for rehab or complex discharge planning are important but must be resourced. Too often patients get stuck in acute hospitals and deteriorate further with increasing care needs.

Local carer organisations such as VOCAL in Lothian were highlighted as good resources for unpaid carers.

3. What challenges need to be addressed?

The RCPE is aware of many challenges that require to be addressed to ensure the consistent provision of services that are truly integrated and seamlessly joined-up. Fundamentally, we need a properly funded workforce in health and social care with sustained investment across the sector. More services that include psychiatry, geriatricians and neurologists are needed, with clear triage to the most appropriate service and much shorter waiting times so that people can access therapy and information early. Workforce shortages across medicine, nursing, allied health professionals, social work and social care all impact on dementia care. One Fellow working in the North of Scotland highlighted the wide variation in the number of consultant geriatricians across the country with the North of Scotland having 1 geriatrician per 65,000 population compared to the national average of 1 per 36,000; they consider it is vital that geographical inequality in staffing and resources is addressed. They suggested that continuing consultant gaps contribute towards the loss of many recent trainees to other regions as they see the enormous strain current consultants work under. They also highlighted a significant loss of senior and experienced staff in nursing for older frail adults.

Fellows stated that there are insufficient non-acute specialist inpatient psychiatry beds for people with BPSD of dementia, so patients often linger in acute medical or geriatric medical beds rather than receiving specialist care.

Supporting individuals with cognitive frailty who require ongoing support and who may not have family members is a particular challenge when capacity in community support is under such great pressure. Enhancing the capacity of social care community support more broadly is a fundamental issue, including in relation to the provision of specialist care homes and elderly mentally infirm units that might be attached to other residential or nursing care settings. Much of the additional capacity required is in terms of staff in what is a people intensive sector. We should be aiming for a system where people with neurodegenerative conditions and their families should have proactive, timely, person-centred access to social care and should not have to wait for a crisis or breakdown of informal care before care options are offered. Patients and families also need a range of more flexible options than are often available now, including day care and links to voluntary and third sector resources.

Some Fellows identified improving engagement with local authorities was a continuing and important challenge, with some council colleagues unaware that geriatrics is a specialty. There was still potential for better collaboration and interface between consultants and local authority colleagues to anticipate and address together care and housing needs.

Fellows consider there is a need for existing diagnostic and therapeutic services and memory clinics to take account of the changing demographics of people with dementia and to be able to meet the needs of relatively younger people who present with primarily cognitive complaints as well as often older people with complex co-morbidities.

The impact of new drug trials will need to be considered and the role of Cerebrospinal fluid sampling and Positron Emission Tomography scanning as part of decision making for new treatment options means these need to be widely available, along with infrastructure for IV therapies; all of these of course have additional resource implications. Technology innovations should continue to be explored with an aim to use these solutions to make navigating the complexity of care easier.

Improved public engagement and education in terms of helping families to support and anticipate ageing in relatives, for example in terms of housing adjustments, would be a positive step forward. Furthermore, improved education for families around the importance of a Power of Attorney is similarly important. The RCPE has previously highlighted the impact of guardianship delays leading to delayed discharge in wards; this guardianship process can often take many months.

There was a suggestion that a single point of contact or coordinator who links relevant trusted services across health and social care with advice and support in the patient's locality could make a massive difference.

Fellows consider that there is insufficient funding for dementia research. Fellows also stated that there was an ongoing need for high quality research that addresses the issues of most importance to people with dementia and their families and actively involves them.

Finally, Fellows stated that if there is a focus on brain health, there must be an equivalent focus to ensure that people who have a neurodegenerative condition do not feel blamed for developing this disease. A Lay Adviser stated further that as dementia is an illness and disease, dementia care should be free in all settings, as is the case with, for example, cancer or heart disease.

4. How would addressing these challenges change lives?

The RCPE considers that addressing the challenges outlined above would help improve patient care and enhance the care and support received by patients with dementia and their families.

Improving early support for and anticipating the needs of individuals with dementia and, crucially, their informal carers would reduce the need for or delay the need for institutional care.

Early diagnosis and access to support at diagnosis would allow people with dementia and their families to link into support services, avail of potential treatments, prepare for the future.

Early community intervention by rapid response psychiatry mental health teams and by social care would help avoid admission to acute hospitals

Increasing the number of specialist inpatient psychiatry beds for people with BPSD of dementia would ensure that such people with dementia would be cared for in an appropriate environment and be given optimal opportunity for improvement in symptoms.

Speeding up the Guardianship process would free acute hospital beds and allow the patient to move quickly into a more homely settled environment.

One Fellow emphasised the importance of efforts to maintain people’s independence and activity once in hospital with meaningful activity teams which will reduce length of stay from both cognitive and physical deconditioning.

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

The RCPE considers that it is important to build on good practice currently being achieved such as HIS’ Focus on Dementia and ensure that good practice is supported in any new strategy and can be replicated in all areas.

We consider that we must amplify the spread of the systems that work and remove the barriers to better outcomes.

Joining all services up is critical to making the pathway accessible at multiple points in an individual's timeline.

6. What else would you like to tell us?

One of the Lay Advisers highlighted the Butterfly Scheme (The Butterfly Scheme | Reaching out to people with dementia and to anyone needing memory support) as an effective approach for individuals with dementia in hospital.

Another, with significant experience of being involved in the development of Scottish Government strategies in other sectors, indicated that they were concerned that the new strategy should be completed timeously and that they were looking for clear assurances that the strategy would be implemented, have teeth and not simply be placed on a shelf. They suggested it might be appropriate for a government-led, Cabinet Minister-chaired taskforce involving relevant health organisations to be tasked with taking it forward, with the Minister keeping Parliament informed regularly on progress. They also questioned whether the previous strategy achieved its aims and how this was assessed.

With the National Care Service (Scotland) legislation currently going through Parliament and this being of major importance to people with dementia and their families, it is considered vital that the strategy sets out how it will relate to the National Care Service.

One Fellow concluded with the following:

We are only going to improve the lot for people with dementia by intervening as follows:

o Access to early diagnosis

o Access to support services at the time of diagnosis

o A national push to facilitate people with dementia to complete welfare and financial 'Power of Attorney' for trusted relatives or solicitors soon after diagnosis. This should be free for people with a new diagnosis of dementia.

- Increase the numbers of community mental health nurses and ensure that ‘rapid response’ teams for people with BPSD of dementia are funded and staffed
- Increase access to specialist psychiatry beds for people with worsening BPSD of dementia if they cannot be managed in the community. These patients should not have to come to an acute medical hospital
- Work with the Sheriffs’ Courts to speed up the guardianship process – one that leaves people with dementia lingering in acute hospitals