

**Mental Health Directorate – Consultation for stakeholders in relation to the inclusion of Mental Health Services, Services for People with Neurodiverse Conditions and Dementia in the National Care Service (NCS)**

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**About this response**

About Dementia is Age Scotland's Forum for Policy and Practice for people living with dementia and unpaid carers. Funded by Life Changes Trust, we bring together people affected by dementia, with professionals in the public and third sector to influence change around policy and practice in Scotland. We strive to create an environment in which people with lived experience lead the discussion and set the agenda on areas of change.

In recent years, our core activity has focused on both our lived experience Human Rights groups, creating a safe space for people living with dementia and unpaid carers respectively. Members work together to highlight the impacts to their human rights by sections of society. Both groups have been actively engaged with influencing our response to the National Care Service and our submission for the new National Dementia Strategy. Prior to the Covid-19 pandemic our activity focused around a number of thematic 'sub-groups'. The groups gathered evidence and proposed policy improvements around: Housing, Transport & Mobility, Human rights of Unpaid Carers, Prevention & Living Well, Technology, and Befriending & Peer Support.

**Questions this response relates to**

- **What are your immediate thoughts or concerns about the proposals and how community healthcare might change as a result?**
- **What other opportunities do you see for improving outcomes for our communities accessing support and services as part of the development of the NCS?**

**Our response**

We are broadly in favour of the inclusion of dementia under community health in the National Care Service. About Dementia adopt a social model approach to dementia, which sees the barriers facing people living with dementia and unpaid family carers as located primarily in the organisation of services, rather than in individual deficits. This approach has been validated by our membership, who highlight stigma and misconceptions of both dementia, and unpaid caring, as more detrimental to their ability to live well than medical symptoms.

While dementia is ultimately a terminal condition, many people if diagnosed early enough are able to live long and active lives with the right community based-support, and will likely not require clinical intervention until their condition is more progressed. At present this has led to a fragmented approach to the diagnosis, management and treatment of dementia which can be challenging for individuals to navigate. Diagnosis may be initiated through primary care, followed by a referral into community mental health.

However, it should be acknowledged that many people seeking support, either as an individual or concerned family supporter, often inquire first within local and community settings. This anecdotal evidence seems to point towards everyday people already inferring links between dementia and community health. Third sector and community-based initiatives can be the first port of call for many, as they provide a familiar and informal advice which may encourage people to seek a diagnosis through primary care. Community support can offer a soft introduction to more formal dementia support, and many third sector professionals have spoken about their role in 'coaching' people to pursue needed social services or clinical intervention when this becomes necessary. This type of is often invisible or unacknowledged in policy, so it must not be underestimated the level of which it is required and utilised as an integrated part of social care.

Depending on the trajectory of the disease the individual may then spend many years without requiring any clinical intervention. Often intervention, when it comes, is precipitated by a crisis, that leads to a period in hospital, followed by a move to residential care. We propose that redesignating dementia from the acute sector to community health will have a positive effect on streamlining the patient pathway and help to overcome the current fragmentation.

We believe that there are a number of other possible benefits of taking a community health perspective to dementia. There is a growing body of evidence to support the use of psycho-social and non-pharmacological interventions for managing dementia. This can include social prescribing services, Playlist For Life, and Cognitive Stimulation Therapy. Many of these services are already delivered in a community setting at Day Centres, Meeting Centres and Dementia Friendly Communities across Scotland. During the Covid 19 lockdown, when acute clinical services and primary care closed their doors, many of these community-based forms of support continued providing support and stimulation to people living with dementia. These were not only a vital lifeline to people during a stressful and isolating time, but for many prevented the acceleration of cognitive decline that was the pattern for many without access to these supports.

We are aware of existing good practice examples where community health approaches have been taken to diagnosis. Dementia Friendly East Lothian have worked in partnership with the Health Board and Health and Social Care Partnership to support memory clinics to be conducted within community buildings – bringing healthcare professionals to where people already are. This not only enables diagnosis to take place in a safe and familiar environment, but also allows newly diagnosed individuals to be signposted to community based forms of support. A similar model is in existence in NHS Orkney, where the Consultant Older Age Psychiatrist holds diagnostic clinics in the offices of Age Scotland Orkney in Kirkwall. Individuals and families are then referred immediately on to staff in the organisation for the provision of Post Diagnostic Support, and to join their meeting place for peer-to-peer support.

For many, when discussing the creation of a National Care Service, funding has never been far from the conversation. From a financial perspective, peer support groups and Meeting Centres are delivering a form of Post Diagnostic Support to many people simultaneously with few or no paid members of staff. An approach which places dementia under community health in the National Care Service may not only

save costs but could an additional benefit of reducing isolation and connecting people with peers facing similar problems and experiences. This is especially pertinent in the conversation around mental health, as we know that risks of suicide and depression are higher in the initial stages post-dementia diagnosis.

We are hopeful that the approach proposed for dementia under the National Care Service would enable good practice examples such as those shared above to proliferate, enabling individuals to get the best of partnerships between the third sector and clinical experts. This will reduce the fragmentation already outlined, and could also enable a preventative approach to ongoing care.