



**DEMENTIA
AWARENESS
WEEK** 31 May
- 6 June

Hidden Voices Hidden Impact Hidden Cost

People with dementia and their families have been significantly impacted by the COVID-19 pandemic, and the subsequent measures put in place to mitigate the spread of the virus. Almost every component of what could, and should, be a good system of personalised care and support for people with dementia and their families has been shattered. For well over a year, with the exception of residential forms of care, almost all direct community support has been delivered exclusively by families themselves.

There is no doubt that there has been a good level of digital based support introduced, which was enabled by local authorities agreeing to the flexible use of their commissioned funds and registered services being allowed to adapt their support. This level of pragmatic partnership working, alongside the commitment of frontline staff to develop new skills and abilities in digital and online based care, has been invaluable in helping many people cope and get through this pandemic.

However it would be wrong not to recognise that, as a result of the pandemic, the fundamental foundations of high-quality person-centred care from the point of diagnosis to end of life that we have been promoting and advocating for many years, has been decimated.

The principles of a timely early diagnosis and high-quality post diagnostic support which builds on an individual's own natural support networks, their hopes, strengths and ambitions, have been the bedrock of practice which have enabled people to live well with dementia. Over the last year, this has simply not been able to be fully delivered. The Scottish Government estimated that around 20,000 people will be diagnosed in 2020 and we know that prior to the pandemic fewer than 50% of this group were offered post diagnostic support. There is a community of people waiting to be diagnosed, as well as those individuals newly diagnosed, who have not had the opportunity to properly come to terms with the illness, to build a strong level of resilience and any form of meaningful self- management. If we do not quickly respond to their needs we will simply be accelerating the level of crisis and need for formal care services, such as care homes, to a level that we have not seen for decades, and perhaps never seen before.

Add into this those individuals who were managing to live well, using their well developed self-management approaches, attending community groups for peer support, therapeutic activities and expert advice on how to live well with dementia. They have experienced immense levels of loss, isolation and a disconnection from vital support which kept them well. We know that many of their needs have dramatically increased and they now need high levels of formal support – support which is simply not available. Families are filling this void, not just for this group but also for those with more advanced illness. Families – and not just primary carers – are essentially holding all of our social care infrastructure together. We owe them a great debt.



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Worryingly, many extended family members which have helped fill this void might not be able to do this for much longer, many people will be returning to work soon, furlough will come to an end and this extra level of available care will more than likely sharply decline.

When we consider the well-documented effect of the pandemic on people with dementia living in care homes, the immense and quite unimaginable pain that they, and their families, have gone through, the number of Covid related deaths and the deeply concerning excess deaths which have been reported of people living with dementia, one can only fairly and reasonably conclude that there has been a disproportionate impact on our community.

We do not believe that these issues can be resolved without a major change in the way local services are delivered and commissioned by Integrated Joint Boards. We believe that given the impact on this community, it would be wrong to leave the responsibility for recovery solely to local areas, and now is the time for the Scottish Government to establish a dedicated Dementia Directorate. This Directorate should be resourced with an adequate budget and empowered to support local Integrated Joint Boards, compliment their existing services in key delivery areas such as post diagnostic support, community services such as specialised Day Services and personalised individual support, increased carer respite and much needed community based Advanced Care Services.

We believe that this Directorate should in future become a core component to the new National Care Service, although we see no reason why it cannot be set up in advance of this service being established as a direct response to the pandemic. There are over 90,000 people living with dementia in Scotland. For too long, we have toiled to transform high-quality, innovative and progressive national strategies and commitments to support them well into local practice and services. For too long, dementia has been hidden under a mental health banner, or perceived as an older person's care issue, seen as something we can deal with in a generic way. There is more than enough evidence of how unsuccessful this has been prior to the pandemic, and we can no longer rely on seeking to influence, support or help shape local implementation of this. It is time dementia is given an independent and core position within our national structures and government. People with dementia and their families need - and deserve - a national response to this, one that must be led by the Cabinet Secretary for Health with a new dedicated Dementia Directorate capable of meeting this community's needs in partnership with local areas.

Yours sincerely

Henry Simmons, Chief Executive