

20 February 2015

Kellie Boydens
Scrutiny Officer
Morier House
Halkett Place
St Helier
Jersey
JE1 1DD

Dear Ms Boydens,

The Health and Social Security Scrutiny Panel Review of Adult Respite Care

I am writing in order to provide comments on behalf of Jersey Alzheimer's Association regarding the current provision of Adult Respite Care for people aged under sixty-five who are living with dementia and their carers.

We have recently exchanged emails as you had requested statistics as to the number of people with early onset dementia in Jersey. I recommended that the Scrutiny Panel contacts Ian Dyer at Health and Social Services to obtain a copy of the 'Older People Community Based Mental Health Services Implementation Document - Version 9' which contains the most up to date statistics of which we are aware. The Panel should also consult with the specialist staff at the Memory Clinic based at The Poplars, Overdale Hospital.

The vast majority of people living with dementia in Jersey are aged over sixty-five. Given the nature of our work, we are aware of several diagnoses of early onset dementia in the Island. It should be borne in mind that probably only half of those people with dementia will have obtained a formal diagnosis from either their GP or the Memory Clinic.

More accurate statistics concerning the incidence of early onset dementia are needed in Jersey. In addition there needs to be significant and ongoing investment to tackle stigma and encourage timely diagnosis and reduce waiting lists for appointments at the Memory Clinic. White Paper funds have still not been released for many dementia services. Our charity considers that more diagnoses of early onset dementia will be made in the future given global dementia trends.

The availability of and access to Respite Care are some of the most important issues affecting those to whom our charity offers help and support. In our experience Respite Care is rarely if ever offered – instead it has to be sought out by individuals and/or their families.

In practice the amount of Respite Care available does not meet the needs of the increasing number of people with early onset dementia who are living at home. The planning and promotion of Respite Care must be improved if care in the community is to be sustainable in every sense. The most suitable - and cost-effective - form of Respite Care will in all probability be quite different for a person aged under sixty-five compared with the needs of a person aged over sixty-five. It is important to remember that each person's experience of dementia is unique.

In the last year or so there was discussion about bringing Respite Care closer to people with dementia. The aim of this initiative was to engage the voluntary sector in determining who was most in need and to ensure that the most effective form of Respite Care was provided in each case. This scheme, however, was not implemented.

Finally, Respite beds for people with dementia aged under sixty-five are only available in Old People's Homes/Hospital Wards. These are not appropriate settings for younger people with dementia, especially those with Down's syndrome.

Please do not hesitate to contact me if you require any clarification or further information.