

## Lived Experience Advisory Panel (LEAP) – Report for November 2021

### Dementia Jersey's Lived Experience Advisory Panel

This Panel brings together people with dementia and others with lived experience of supporting or caring for a person with dementia, to discuss issues of significance related to living with a diagnosis of dementia.

The Panel meets monthly, proceeds with a formal agenda, and because of its advisory purpose, the outcomes of discussions are documented and disseminated to inform, as appropriate; government departments, health and community service providers, businesses and other charities.

Subjects of discussion will be broad and will be submitted by panel members.

LEAP is headed up by our Dementia Advisor Team.

Please contact Dementia Jersey if you would like more information about our LEAP.

Email: [info@dementia.je](mailto:info@dementia.je)

Call: 723519

### Overview of the LEAP meetings held in November 2021

Panel members were asked to share their experiences of receiving a diagnosis of dementia, which all but one panel member received in Jersey via the Memory Assessment Service (MAS).

A total of 21 people attended the LEAP meetings in November 2021, including people with a diagnosis of dementia and supporters or carers of people with dementia.

The LEAP meetings were facilitated by Dementia Jersey's Dementia Advisors.

All information provided below is anonymised and non-specific gender pronouns have been used.

### Outcomes of the LEAP meetings held in November 2021

The outcomes of the discussions can be summarised with the following recurring themes.

1. **Dr Juan Melendez:** Firstly, there was considerable agreement that members' experience of Dr Juan Melendez (Associate Specialist Psychiatrist at the Memory Assessment Service) was positive, describing him as helpful, kind and compassionate.
2. **General criticism of the Memory Assessment Service:** However, there was considerable criticism of the Memory Assessment Service more generally for not providing the range of post-diagnostic support services that panel members wanted and felt they needed. The panel members then qualified this by saying that following the diagnosis they were referred

back to the care their GPs who many felt were not experienced in the care of people with dementia and did not understand and could not help with the complex needs of a person with dementia and their families.

3. **Information at the time of diagnosis:** At the time of diagnosis panel members also reported that not enough information was given to them, particularly concerning the likely progression of the condition including symptoms and how to manage these and the support services that might be needed and how to access these. While almost all panel members agreed with the above, one person however did indicate that there was too much information and said, "It was all a mass of confusing information".
4. **Emotions and feelings at the time of diagnosis:** Describing their emotions and feelings at the time of diagnosis, panel members said, "I was just left in the dark. It was awful." Another said, "I just hit the ground. Once the diagnosis was made it felt like we just had to deal with it on our own." Other commented, "I was absolutely gutted. We didn't understand the diagnosis and we felt we couldn't ask." And another added, "And then the fear set in." Another said, "The words I heard was that they had six years to live and that was it." Another just said "It was horrendous."
5. **Timing of the diagnosis:** Panel members also commented on the timing of the diagnosis. Three members said that they had been to their GP several times to raise concerns about their partner before it was followed up in any way by the GP. These comments led other panel members to say this has also been their experience pre-diagnosis.
6. **Support following the diagnosis:** Although not immediately concerning the time of diagnosis, panel members did want to comment upon other support following the diagnosis. More detail about this is recorded in the 'Recommendations' section below.
7. **Driving:** Although not all the following comments are relevant to the time of the diagnosis, they have been included as panel members wanted to speak about driving assessments. Some panel members said that the subject of driving was mentioned at the time of diagnosis. One person said "I believed this was absolutely the wrong time for such conversations". Another said that they were given information about driving but that "This was too complicated and too much to take in when so much else was changing." One person said they thought, "Dr Newton's assessment was unfair", another that it was "Not fair that some people had to pay for this" and another was said that "Dr Newton assessed X as being safe but I knew they were not". Another person said, "Dr Newton's tests were OK. I got 30/30 though I have problems coming up with the right words".

## **Panel members' recommendations for improvements when receiving a diagnosis**

Much of the conversation in this LEAP meeting focussed upon the negative emotions and experiences of panel members around the time of their own diagnosis, or their family member's diagnosis of dementia.

As part of LEAP's advisory role, members also wanted to comment upon what they believed could be improvements. These are summarised below.

1. **Dementia Jersey:** A very large majority of panel members wished to express their gratitude for the support they had received from Dementia Jersey (formerly Jersey Alzheimer's Association) describing this as, "Invaluable" and "Essential". Another said, "I don't know

what we would have done without this.” And another commented, “The only support we have had is from Dementia Jersey”.

The Panel’s recommendation is that Dementia Jersey should extend the promotion of their services further so that these are known about more widely for everyone for whom they are relevant. The Panel also recommends that GPs and the MAS are better informed about, and promote the services of Dementia Jersey more consistently.

2. **Care Co-ordination:** In response to two panel members’ experience of some early support received from a ‘Care Co-ordinator’, and the lack of support felt more generally, all panel members recommended that an essential improvement would be the appointment of a named Care Co-ordinator at the time of diagnosis. They recommended that this person should be an accessible first point of contact for them and that they should be knowledgeable about the complex issues related to dementia, and be able to sign-post people accurately, with up-to-date knowledge to other services and agencies that could offer support. One panel member summarised this by saying, “This would make all the difference in the world.”
3. **Driving:** While it was acknowledged by the panel that they understood there were legal requirements regarding driving and dementia, they recommend that a review of the way this issue is raised would be helpful together with a review of the procedures for assessing competence to drive. The panel also recommended that this subject should form the basis of a dedicated LEAP discussion. Dementia Jersey will schedule this.