

## Lived Experience Advisory Panel (LEAP) – Report for October 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.

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

Panel members were asked to share what, from their experience was most important to them when accessing care at home.

A total of 18 people attended the LEAP meetings in October 2021, including people with a diagnosis of dementia and supporters or carers of people with dementia.

The 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 October 2021

- 1. Involvement of the person with dementia in decisions and discussions:** One person with dementia summarised their experience by saying that, not being involved in the conversations with their own family and a home care agency about their care was, "Like an itch in my brain which needed to be scratched to make it go away". They then said that, "The itch only went away when I found the words to be able to have my say". This metaphor then seemed to open up further discussion for others concerning their inclusion in such decisions about their care.
- 2. Nature of the care received:** Most panel members were in agreement that such care should, as far as possible, replicate the care they received from their families, in that

they should be able to trust the carers implicitly, the care options and provisions should be flexible and suit the needs of the person with dementia and the family carer, and what was available should be of help both the person with dementia and the family carer.

3. **Timing of help for family carers and the person with dementia:** The Panel were in agreement that accessing care should be 'timely' and not before it was needed. Some carers developed this by saying that they as carers felt help was needed well before the person with dementia did. This meant that there was no help or support from any health care providers to support them and help them manage the difficulties they experienced looking after a person with dementia. Others agreed that such help would have been beneficial.
4. **Continuing engagement with hobbies and activities:** There was a consensus of opinion that care agencies should be able and willing to provide care that enabled the person with dementia to continue to engage with their usual preferred activities and hobbies (basic mechanics, decorating, gardening were mentioned) and some panel members with dementia felt that they were being prevented from doing the things they wanted to do because the carer "just wanted to keep them safe". Other similar comments followed on from this.
5. **Continuity of care:** The Panel highlighted the fact that continuity in the carers attending was essential as this facilitated a relationship "bond" to develop between the family, the person with dementia and the professional carer, which was considered essential. This might mean that only a small team of carers would be allocated to each client. Most Panel members said that in their experience, this was not what happened. Panel members said that they were often informed that the agency was short-staffed (pre-covid, during and post covid restrictions). Concerns were expressed that the person with dementia was more stressed when receiving care from someone unfamiliar to them.
6. **Training and experience of professional carers:** The apparent lack of training and experience of staff was a recurring theme, with all family carer panel members being concerned that this was lacking. Conversations around this subject continued with members' experiences being that professional carers did not seem to be aware of, or interested in, their client's 'history' and that more generally care did not seem to be person-centred. Some Panel members said they had chosen certain care agencies because they had described their services as person-centred. Some panel members said they were particularly concerned about the apparent lack of training in personal care and that some professional carers lacked experience and said they did not have any specific qualifications in working with people with dementia.
7. **Concerns about being discriminatory:** Panel members expressed their apprehension in being specific in their requests concerning the gender and nationality of the carer. Some felt it was extremely important that a carer should be of the same gender as the person with dementia, and others that it was essential a carer spoke excellent English without a strong accent because of their relative's difficulty with language caused by dementia and the dis-inhibition often associated with dementia. However they did not feel able to express this concern to agency staff. Panel members felt it would be helpful if care agencies welcomed such conversations and initiate them.

## Recommendations of the LEAP concerning home care

1. **Involvement of the person with dementia in all decisions:** All panel members were of the opinion that as far as possible people with dementia should be involved in the decisions regarding the care they received at home. This offered dignity and reflected what they understood to be person-centred care.
2. **Involvement of the family carers in the design and nature of a care package:** Panel members recommend that home care providers should seek the advice of the person with dementia and listen to the family carers concerning the most appropriate care to be given and the way in which this is offered, being flexible and open to a range of options.
3. **Timely help for both family carers and people with dementia:** The panel recommends that more practical and emotional help and support should be accessible particularly for the carers of people with dementia, independently of the support the person with dementia might request or require.
4. **Broader provision of care:** The panel were of the opinion that care should be more than 'keeping a person safe' or 'sitting' and providing 'personal care' and therefore recommends that carers should be more creative and initiate more varied activities for the person with dementia to include, as far as possible, helping the person access activities and hobbies that might otherwise not be accessible without assistance. The panel recommends further activities training for all carers.
5. **Continuity of care:** The panel strongly recommends a review into the provision of care and the services offered by agencies as part of the registration process. The panel recommends that some limit should be set to the number of different carers any person should be receiving care from.
6. **Training and experience:** The panel recommends a review into the minimum training and experience requirements for a carer to be considered qualified to work with people with dementia.
7. **Concerns about being discriminatory:** Panel members found this subject difficult to voice but recommend that, given the difficulties experienced by many people with dementia, and their wish not to be discriminatory, home care agencies should initiate a conversation about any possible problems a person with dementia might experience concerning a carer's strong accent or skin colour.