

Lived Experience Advisory Panel (LEAP) Report for March 2022

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 and the recommendations of the Panel are documented and disseminated to inform, as appropriate; government departments, health and community service providers, businesses, other charities and our team at Dementia Jersey.

Subjects of discussion are broad and are submitted either by Panel members or Dementia Jersey's staff.

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 March 2022

Panel members were asked to share their lived experiences of respite care, including all aspects of this from sourcing it, its availability and its benefits. In this instance we defined respite as 'care provided by a professional to replace support or care usually provided by family or friends of a person with dementia'.

The experiences of Panel members are summarised below, followed by a section with the Panel's recommendations. A total of 22 people attended the LEAP meetings in March, including people with a diagnosis of dementia and supporters or carers of people with dementia.

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

Outcomes of the LEAP meetings held in March 2022

The outcomes of the discussions have been summarised below.

While people with dementia always attend Panel meetings, none had any lived experience of respite. Therefore, comments in the outcomes section below are those exclusively of supporters and carers of people with dementia. The recommendations section however includes recommendations from both people with dementia and supporters and carers of people with dementia.

1. **Information about respite services available:** Most Panel members reported that respite had not been offered to them or even discussed as an option unless they had asked specifically about this. In all instances when it was mentioned, this term was used

interchangeably to mean the regular care packages available from home care agencies, mostly as a few hours a day or week, day care centre provision, and extra professional care to replace the care usually provided by family or friends.

2. **Financing of respite care:** All Panel members said they had struggled to understand the mechanisms for the payment of respite care and that this had not been adequately explained to them both at the time of joining the Long Term Care Scheme and when discussing this with health professionals when trying to organise respite.
3. **Lack of flexibility in length of respite:** Most Panel members said there were significant limitations in the length of available respite packages. For example, one member reported, *"I just needed (person's name) looked after for a couple of days while I went to a family wedding in England but the only option available was to book and pay for a minimum of 2 weeks care. I knew (person's name) would be OK for a few days without me and was equally certain (they) would not be happy at all about staying away from home for longer, but I had no choice"*.
4. **Availability:** All Panel members said that they had trouble sourcing suitable respite options, both for respite care at home and in care homes.
5. **Rolling respite:** Some Panel members had experience of rolling respite which they found very helpful. This enabled them to be flexible with their planning and to take appropriate care of themselves.
6. **Visiting during respite:** Some Panel members expressed concern about the policy some care homes had of discouraging relatives and friends from visiting during the first week of respite care, as this was considered to be unsettling for the person with dementia. Panel members said that while they felt this was not in the best interests of their family member, they had no option but to follow these directives. Their experience was that this added to their own burden of guilt, knowing that their family member was missing them and feeling unsettled, and not understanding their absence.
7. **Planning for respite and emergency situations:** While some Panel members' experiences were of respite that was un-foreseeable due to emergency situations, all Panel members said that their experiences were very much like *'going into the unknown'*, words used by one member. The Panel all said they were unclear about the procedures for and financing of emergency respite care, for example if a main carer needed emergency treatment in hospital.
8. **Preferences for respite – own home or care home:** While all Panel members with dementia stated that their preference was for respite care in their own homes rather than in a care home, supporters and carers were divided in this. They said that in some instances care at home would be preferable for continuity and because this was considered less disruptive for the person with dementia, while others said that because they did not want to feel the need to leave their own home to have a break from their caring roles, they would prefer care to be available for the person with dementia away from their home. Some preferring care at home also commented that this would enable people with dementia to stay at home with their pets which would offer further comfort during a family member's absence from home.
9. **Inappropriate care context:** Many Panel members said that one of the problems they experienced was that while the person needing to be cared for did not have advanced dementia, respite in a care home meant that they were in situations alongside people with more advanced dementia and often very complex needs. This was often distressing for the person needing respite and for the relative arranging this. One Panel member said that their relative had said on their return, *"Get me out of this stupid place it's all full of mad people"*.

The Panel also commented that uniformed staff and hospital style beds added to the sense of this being “*institutionalised care*” which they considered to be inappropriate for respite.

10. **Reliance on other family and friends:** Because some Panel members were unaware of respite options and others found these almost impossible to access, and further because in some cases the person with dementia was not willing to accept help from professional carers, many relied on other family members or friends to cover for them when they felt they just needed a break from the person with dementia or when they needed to attend an essential appointment or meeting themselves. Many of these Panel members expressed guilt for leaving the person with dementia in unskilled or inexperienced care, and others felt guilt for asking family members or friends to help with care that they felt sure they would prefer not to have to do. One Panel member said, *“I felt so awful asking for help when I just needed to escape for a few hours, but I couldn’t say that could I”*.
11. **Carer ‘Recharger Day’:** While LEAP’s focus was not intended to include services and events provided by Dementia Jersey because they do not consider these to be ‘respite’, several members wished to draw attention to the value they found in attending these on-off, one-day events. One member said *“I could have 1001 other things to do if ever I could get a day off so the thought of spending a day supposedly relaxing and talking to other people in the same boat as me was far from appealing. But I was wrong. This day has stayed in my memory as one when I did feel alive again, for a while”*.
12. **Booking respite ahead:** All Panel members who wanted to book a holiday for themselves some time in advance said that it was impossible to find respite providers who would commit themselves to providing respite more than a few weeks ahead. This made booking holidays or other travel that needed advanced bookings almost impossible.
13. **Travel since diagnosis:** Some members reported that since their relative’s diagnosis of dementia they had not been on holiday or off the island. One member for whom holidays had been a major part of their life said *“I never took time to go on holiday again and now I doubt I ever will”*.
14. **Jersey Care Model:** The Panel reflected on how respite care might fit into the new Jersey Care Model. This was of particular interest because of the model’s increased emphasis on care in the community and their experience of this being currently so difficult to access. The Panel were of the opinion that, better respite options would certainly mean that there would be less need, or a delayed need for, in-patient hospital care or a permanent placement in a care home.

Panel members’ recommendations concerning respite

The following recommendations were made by the Panel, while appreciating that there may be circumstances in which a person with dementia could not be detained against their wishes in respite accommodation or be cared for by another person against their wishes.

1. **Recommendation - information regarding respite care:** All Panel members recommend that the subject of respite should be included in all initial conversations with H&CS staff at the point of diagnosis and subsequently at other meetings with H&CS staff. The Panel recommend this should include discussions with supporters and carers about the procedures and funding or any emergency respite.

2. **Recommendation – printed and online information regarding respite care:** All Panel members recommend that a document should be made available (both online and as a paper version) describing what options are available for respite care, which health professionals would assess a person for this and then help in organising it, who would be eligible for this, what limitations there might be concerning a person's capacity to consent to this, and clear details for how this can be financed via the Long Term Care Scheme or paid for independently.
3. **Recommendation – cost/financing of respite care:** While most Panel members recognised that a component of the Long Term Care budget is used for financing respite care, the Panel recommend a review of this method of accessing and financing respite because of the complexities of this process and because the available budgets are insufficient to cover usual care costs and the extra and higher costs of respite. They accept that this would involve some type of means testing.
4. **Recommendation – availability:** Because Panel members have often struggled to access the right type of respite care, they recommend that respite options should be increased so that family carers can take appropriate breaks from their caring roles when they need them, which they believe will in turn help them to continue in these roles for longer by maintaining their own health and wellbeing. They recommend that such flexible options and availability should be for both respite care at home and residential options.
5. **Recommendation – rolling respite:** Although not many Panel members had experience of rolling respite, all were in agreement that this would be helpful to them, particularly as it was difficult to commit to certain time frames for their own recovery from carer burden.
6. **Recommendation – flexible lengths of respite:** All Panel members agree that respite options should be available for any length of time from one day/night to a few weeks to meet the needs of the person with dementia and their supporters and carers.
7. **Recommendation – visiting during respite:** Panel members recommend that research evidence for the practice of restricting visiting during respite should be made available to confirm that this is best practice, or if such research evidence is not available, to have a more person-centred approach with care providers and supporters and carers being open to what might be best for each person regarding respite and visiting.
8. **Recommendation – planning for respite:** Panel members recommend that, people who may in the foreseeable future need to access respite care at some stage, should be encouraged to review all options and visit care homes in advance to enable them to make speedy decisions between any available options for care when needed.
9. **Recommendation – personal preferences and routine:** Panel members were in agreement that it was essential for all professional carers to get to know the person with dementia before any period of respite, so that their routines and preferences could be respected. This included people's preferences for meals and was a recommendation for care received at home and in other residential settings.
10. **Recommendation – expression of wishes/preferences:** Because some Panel members, including both people with dementia and supporters and carers, were unaware of the option to write, prior to any possible need for respite care, 'an expression of wishes' or 'Preferences' as part of a Lasting Power of Attorney, the Panel recommend that more information about this aspect of the Capacity and Self-Determination (Jersey) Law 2016, should be made available to all members of the public.
11. **Recommendation – hotel style respite care:** Because some people needing respite care away from their home were extremely distressed at being cared for alongside people with much more advanced dementia with complex needs and in secure facilities, the Panel

recommend that alternative provision should be made for care to be alongside others with less complex needs. They suggest that this should be available in hotel style accommodation, with access to a garden, varied activities and with appropriately trained staff to support and attend to people's varied needs as appropriate. The Maison des Landes hotel was suggested as possibly suitable for this but with the addition of care staff.

12. **Recommendation – carer 'Recharger Days':** Because all Panel members with experience of attending a 'Recharger Day' thoroughly enjoyed these and said they benefited from them, the Panel recommend 'Recharger Days' as essential annual events.
13. **Recommendation – respite care provision detailed in the Jersey Care Model:** The Panel recommend that those charged with designing and implementing the new Jersey Care Model review people's experiences of respite care, and consider the potential value of improvements to this, both in terms of the savings made from delayed moves to permanent care home placements and in the health and wellbeing of supporters and carers of people with dementia.