

Lived Experience Advisory Panel (LEAP) Report for April 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 April 2022

Panel members were asked to share their lived experiences of the Long Term Care (LTC) scheme including; the information available about this scheme, seeking professionals' advice, and also the financial aspect of this, the assessment process, and their on-going experiences of the scheme once active for them.

The experiences of Panel members are summarised below, followed by a section with the Panel's recommendations.

A total of 33 people attended the LEAP meetings in April, 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 April 2022

The outcomes of the discussions have been summarised below.

1. **Public Awareness:** All Panel members said that they were totally unaware of any details of the LTC scheme before they needed to make use of it, although some who paid tax knew of the scheme's existence.
2. **In-person visits to Customer and Local Services:** All Panel members agreed that because of the complexities of the LTC scheme, being able to speak in person to an advisor was preferable to speaking on the phone or by email. Many also commented that the staff they spoke to were helpful and that although the scheme was complicated speaking in person about their own circumstances was most helpful, one member adding that they, *"Had a good passage through the system"*.
3. **Provision of information:** Most Panel members said that they were not given any information about the LTC scheme from health care professionals until it had come to their attention independently by others who advised them to ask for an assessment. One Panel member said, *"Even then, I didn't know who to ask or how to start this whole thing. How does anyone know?"*.

Another Panel member said *"I was paying out to a private agency for a whole year before anyone told me about the LTC scheme. Not even the agency mentioned this."*

4. **Information about types of 'care' included within the LTC scheme:** Most Panel members said that they initially thought that care packages would only be for personal or nursing care, so they therefore did not access the scheme as early as they might have done had they been aware that 'care' also included social care for a person with dementia. Most Panel members said they benefitted from this provision.
5. **Long Term Care scheme brochures/leaflets/information:** All Panel members said that they had struggled to understand the details of the LTC scheme, one member describing feeling *"Swamped and overwhelmed by the complexities of it all"*, and another saying, *"Because the figures and charts looked so complicated, I just closed up the leaflet and didn't look at it again"*. Many members commented about the information concerning the 'care cap' and the 'co-payment', which they said was very unclear, and only later realised was a vital part of the scheme.
6. **Delays in assessments:** Some Panel members said that they had waited several months from initially asking for an assessment of a person's care needs to this being carried out, submitting their financial statements and then hearing from the LTC office about the payments they would receive, or contributions they would need to make towards the costs of care. This delay caused stress and financial hardship for many.
7. **Assessors' assessments:** Some Panel members commented that the person carrying out the assessments of care needs for the LTC scheme appeared to be unfamiliar with the LTC assessment procedure and that some of the information they had been given about the scheme was inaccurate. Further to this, some Panel members believed that the assessors had assessed the person with dementia at a lower level than they expected, which they felt was because the assessors did not appreciate the complex needs of a person with dementia that were not as visible as with some other disabilities.
8. **Activities and care not included within the LTC scheme** Panel members said they and others they cared for derived huge benefit from attending the Meeting Place Project (MPP) and other day care services and were surprised that the LTC scheme did not support such group activities financially to provide such essential service.
9. **Availability of appropriate care:** Most Panel members expressed concern that, although they or the people they cared for qualified for care at an assessed level, they found it almost impossible to source the amount of care they needed at the times they needed this, which they understood to be due to the care providers having insufficient staff.
10. **Training and experience of care staff:** Further to the above, many Panel members commented that, not only did they have trouble accessing the care they needed, but that the care they received did not always meet the standards they expected. They commented that care staff often appeared to have little or no dementia specific training, and some had very little experience of working with people with dementia. Some Panel members commented that because care agencies received significant funding from the LTC scheme there was a duty to provide excellence in the care they delivered, and particularly so because as one Panel member said, *"We're not the customers and can't shop around to find the quality products we want"*. Other members did however want to acknowledge that some care from individual carers had been excellent and that they had been able to source the care that they needed, though added that this was now 4-5 years ago.
11. **Turnover of care staff:** Another concern related to the above was that many Panel members were disappointed that there was often discontinuity of care for the person with dementia due to high staff turnover and that this meant the person being cared for faced extra distress. They expressed concern that *"Tax-payers are financing a scheme in which the quality of care is often not of the standard that it should be"*.

12. **Continuing contact with a Social Worker:** Panel members' experience was that, after the initial assessment of a person's care needs, they felt *"On my (their) own"* and did not know when and how to make any changes to the care plan. Those of the Panel who had some on-going support from the same health care professional said that this was very important.
13. **Invoicing for care costs:** One Panel member said, *"It was so hairy when the bills started to come through and then being chased to pay these when we were not expecting the huge sums involved and expecting the scheme to be in place in time to cover most of the costs"*. Some other Panel members then spoke of similar distress, but most then agreed with the member who said that *"In the end things were resolved"* and *"The system then seems to work well"*.
14. **Costs of care:** While most Panel members said they appreciated the contribution from the scheme towards the cost of care, others commented that the amounts were insufficient to cover the costs of full-time or live-in care at home, which at level 4 was well in excess of £1160 a week. Others who were not yet needing such high levels of care were then concerned about future care costs that would not be covered above the level 4 payments received from the scheme. Most Panel members agreed that making decisions about care was a heavy weight of responsibility because of the huge costs involved. One Panel member commented, *"When else would I have ever been responsible for spending such huge sums of money, never! And someone else's money too."*
15. **Potential for conflicts of interest given excessive costs for care:** Panel members were eager to draw attention to the difficulties they faced in making decisions related care and the costs of this, particularly if they were also known to be beneficiaries in the cared for person's will. The possibility of there being seen to be possible compromises in the amount of care sourced troubled some Panel members. They commented that such decisions regarding care, particularly when the costs were so high, was a considerable burden to them which they felt could be lessened with an alternative scheme for the financing of essential care.
16. **Property loans:** While many Panel members were pleased that the scheme safeguards some of the value of a family home, others who were less well versed in the details of this part of the scheme were concerned that if they accessed the LTC scheme they would lose control over what happened to their family home, and for this reason alone were hesitant in accessing the other benefits of the scheme.
17. **Respite care:** All Panel members said that the system for accessing and paying for respite care was extremely complicated and not understood by most. Some said that they believed they would be entitled to some respite care within the LTC scheme but when they needed this they found there to be no budget available for respite. Others found there were no care options available either in care homes or for respite at home. The collective experience of respite for the Panel was summarised as being, *"Virtually non-existent, so useless"*. Further to this, some Panel members whose relatives now live in care homes commented that they would have benefitted from a break while the person still lived at home and that if there had been better provision for respite they may have been able to care for the person at home for longer. Panel members commented that there appeared to be no supporting information about respite in any of the LTC brochures or leaflets.
18. **Reductions in assessed care levels following a move to a care home:** Some Panel members said that they had been extremely anxious when, following a move to a care home, their relatives assessed care level had been reduced from care level 4 to 3, when the move was needed because of the person's increased needs for care. This was particularly worrying for people who still needed to meet their care cap/date as they would be paying for care for longer than they expected. Further to this, Panel members commented that when they asked for this to be explained, no clear explanation was given. They could not understand how the person's assessed care needs had decreased, when the necessary move to the care home was because of the person's increasing needs for care.

19. **Asset disregard/exemption:** Panel members noted that the asset exemption figure of £419,000 had not increased since 2014, which they believed should be increased because when this was initially set in 2014, it protected the value of a modest 2 bedroom home, which now it did not.
20. **Costs for the government and the individual:** Most Panel members shared the opinion that, with the annual cost for living in a care home being approximately £80,000 for a person with level 4 care needs, private businesses were benefitting to the disadvantage of the Jersey taxpayer and individuals needing to contribute towards care and co-payment costs. The Panel believe that home and residential care should therefore be incorporated within Jersey's health services, and would in so doing save millions each year. The Panel are also of the opinion that care would then be of the high standards they experienced from other government health services in Jersey.

Panel members' recommendations concerning the Long Term Care Scheme

1. **Recommendation – public awareness:** All Panel members agreed that it would have been helpful to have had some awareness of at least some details of the LTC scheme before they needed the assistance of it. They therefore recommend that the Government of Jersey consider promoting the scheme via a public awareness film and circulating an easy-to-read leaflet via Jersey Post. They recommend that this should include *“Some demystifying of the section concerning the protection of people's property and property loans”*.
2. **Recommendation – finance for other types of care/activities:** While panel members appreciated there would be some possible financial consequences of the LTC scheme financing the MPP and other such essential services provided by other charities, they recommend that the providers of these should receive some contribution from the LTC scheme to finance such important work. They believed that without government support these services were vulnerable and could not be guaranteed.
3. **Recommendation – availability of care staff:** The Panel recommends that *“Something should be done”* to increase the number of qualified and experienced dementia care staff working for care agencies as most were unable to source all the care that they had been assessed as needing.
4. **Recommendation – quality of care:** Because of the significant costs of care, both to individuals and the taxpayer, all Panel members recommend that the care paid for in this scheme, should be of the highest standard. The Panel wanted to draw attention to this because some had experienced care that they said fell short of what they expected for some of the island's most vulnerable residents and that this was further affected by the high turnover of staff which resulted in poor continuity of care. They emphasised their belief that quality care was vital to the success of the LTC scheme.
5. **Recommendation – timely provision of information:** All Panel members agreed that health care professionals should take the initiative and provide information about the LTC scheme to everyone at the point of diagnosis so that this could then be understood and accessed at the appropriate time. They also recommend that this should include information about support for social care.
6. **Recommendation – care co-ordination/service navigation:** All Panel members recommend that anyone meeting the criteria to access the LTC scheme, should be allocated a named Care Co-ordinator or Service Navigator for the duration of their illness to assist them to access further care as their dementia progresses.
7. **Recommendation – simplification of information:** While Panel members acknowledge that the LTC scheme is necessarily complex, they recommend that attention should be paid to changes to the supporting documentation so that it is less daunting and more *“User friendly”*.

8. **Recommendation – communication of information 1-1:** Because all Panel members said they needed a professional to explain the scheme to them, the Panel recommends that fully trained professionals, skilled in communicating complex details in an easy-to-understand way, should be available to assist patients/clients' understanding.
9. **Recommendation – time taken to access the LTC scheme:** All Panel members recommend the shortest possible time for a person's assessment and application to be processed. The Panel was of the opinion that if a person is being assessed because it is considered they are likely to meet the scheme's criteria of having high level care needs (of level 1 or above) then no delay should be acceptable.
10. **Recommendation – assessors:** Panel members recommend a review of the process used to assess health care professionals' understanding of the LTC scheme, that extensive training in this is provided for this, and that assessors are suitably trained and qualified to assess a person with dementia.
11. **Recommendation – review in care payments provided by the scheme:** Panel members recommend an increase in the payments towards the cost of care provided by the scheme at each level, particularly in the light of rising hourly rates charged by care providers.
12. **Recommendation – care decision makers:** While Panel members understood that people with Power of Attorney for health and welfare decisions would have been appointed by people with capacity to elect their Attorneys, there was some concern expressed that some people's care could be compromised by beneficiaries not wanting to access the appropriate care because of the significant costs of this. Some Panel members would like to propose the appointment of independent professionals to ensure that recommendations for care were actioned.
13. **Recommendation – respite:** The Panel recommend a much simpler system for respite, to be provided for under a separate section of the LTC scheme. They suggest a person would have a guaranteed, non means tested, entitlement to paid-for respite related to their assessed care level. They recommend an increasing annual allowance whereby a person at care level 1 should have a respite allocation of one week, to 4 weeks for care level 4. The Panel believe this system would be more helpful, equitable, and easier to understand and manage. They also recommend that H&CS have their own respite facilities so that the lack of available spaces in care homes did not hinder the provision of this essential respite, particularly in emergency situations. A further recommendation is that respite should be included in all discussions so that the current means of accessing and payment for this is clear.
14. **Recommendation – care level changes:** Panel members recommend that people's assessed care levels should not be reduced with a change to a care setting, if this resulted in a person needing to pay for care for longer than they expected and had budgeted for.
15. **Recommendation – asset exemption/disregard:** While home owners on the Panel recommend that the asset exemption/disregard should be increased in line with the value of a modest 2 bedroom home at 2022 prices, those who were not home owners and who had fewer assets felt the scheme did continue to provide a good deal of financial security. Therefore, the Panel jointly recommend a review of the £419,000 asset exemption.
16. **Recommendation – Health and Community Services as care providers not private businesses:** Most Panel members recommend that Health and Community Services should deliver home and residential care and not private businesses, which they believed would result in significant savings. They therefore recommend a review of this model of care provision.