

Lived Experience Advisory Panel (LEAP) – Report for December 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 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 December 2021

Panel members were asked to share their lived experiences of day care centres and were then asked to describe what they considered excellence in day care centre provision would be like. This is summarised in the 'recommendations' section below.

A total of 25 people attended the LEAP meetings in December 2021, including people with a diagnosis of dementia and supporters or carers of people with dementia. Because of the amount of interest shown in this subject, a fourth meeting date was added to our scheduled Panel meetings.

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

Outcomes of the LEAP meetings held in December 2021

Included in the broad definition of Day Care Centres discussed below are: The Hollies, The Willows, Sandybrook, Dementia Jersey's Saturday Club (now closed) and Dementia Jersey's Meeting Place Project.

The outcomes of the discussions have been summarised with the following recurring themes.

1. **States of Jersey and Dementia Jersey's day care services:** Apart from 3, all other Panel members who had some experience of attending, or of a relative attending The Hollies, The Willows and Sandybrook Day Care Centres reported mostly negative experiences of these. In contrast, all Panel members with experience of The Saturday Club and The Meeting Place Project reported positively about their experiences of these.

2. **Design of the buildings/space used:** Members commented that all the buildings in which day care services were located were suitable for the purpose, though all Panel members were in agreement that there was not enough accessible outside space for people to choose to access as and when they wished. This related to the general agreement between Panel members that there were not enough outside activities included in day care schedules, such as gardening or small DIY/shed projects.
3. **Choice of activities:** Further discussions related to the general provision of activities with most Panel members agreeing that there was little choice offered at The Willows, The Hollies or Sandybrook, summarised by one Panel member with dementia saying that, "It's join in, or nothing". There were significantly more positive comments about the range of activities offered at Saturday Club and The Meeting Place Project. Comments about these included, "It's really good with things you always look forward to doing" and "If it were a lot of tosh I would not come. I do come so it's not tosh." Another said, "It's good. It feels like a ladies/gentleman's club".
4. **Communication between staff and family members:** There was considerable attention given in the Panel's discussion concerning the lack of communication with family members, including: not being given any leaflets to explain the aims and objectives of the day care centre, the agendas or plans for a person's day, staffing including ratios, and the names, roles and qualifications of staff. In some cases information concerning the procedures for advising about absences, emergency procedures, and details of other care provisions were not provided. Further to this, many reported that they were not given any of the information they expected about the person with dementia's day (particularly because people with dementia may not be able to remember what they have done) or what they'd had to eat and drink.
5. **Criticism of the management and leadership:** Point 4 above led the Panel members to then levy some criticism on what they experienced as the poor management and leadership at the day care centres. Some said managers were uninspiring for their staff, were not good role models and showed little of the flexibility needed to accommodate the wide range of symptoms that people with dementia often experience.
6. **Allocation of places:** Many Panel members said that there appeared to be no clear criteria to assess a person's suitability for a place at a day care centre, nor how many days/sessions a person was allocated. Some said that they believed that the staff were making unfair and inaccurate assumptions about a person's wealth and seemed to allocate places to those they considered less able to afford one-to-one care at home with an agency.
7. **Carer's need for respite:** Many Panel members drew attention to the fact that they considered day care services to be essential respite, without which they would not survive. They appreciated being able to be in their own homes by themselves for the time their relative was out at a day centre. For many, even though they were not entirely happy with the quality of the provision, they nevertheless would like further days to be offered to them to meet their needs for respite.

Panel members' recommendations for improvements to day care centres

Panel members offered many recommendations for possible improvements as detailed below.

1. **Aims and objectives:** First and foremost, Panel members said that there should be clear aims and objectives for the provision of day care centres.

2. **Jersey Care Model:** Secondly and related to the above, Panel members agreed that such provision should be written into the new Jersey Care Model in which, at present, they do not appear to be included.
3. **Costs associated with care and the reduced need for professional care at home and for care home provision:** And again, very much related to this, Panel members were in full agreement that if there was greater provision of excellent quality day centres for people with dementia, this would significantly reduce their dependence on professional care agency care and reduce the costs of this for both themselves and ultimately for all tax payers. They also stressed this would enable people to stay living at home for much longer before a move to a care home, again reducing the overall costs of care for Jersey tax payers. Panel members wanted to draw attention to their belief in the clear economics of such extended and improved day centre provision.
4. **Respite for carers:** All carers said how essential respite was to them and that the respite offered by day centres was essential for their ability to cope and to continue in their caring roles. They therefore recommend that such provision should be available to everyone with flexible options in the choice of days and hours, over 7 days a week and from 08.00 to 18.00, as appropriate, to make sure this could be structured around the carer's and people with dementia's needs, being especially important for carers who needed to continue in their employment.
5. **Transport:** The Panel recommends transport to and from the centres should be provided as required.
6. **Buildings and locations:** The Panel recommends that such centres should be available in each parish, that they should have flexible spaces for various use and group sizes, that they should be accessible for people with all disabilities and have secure gardens for all to enjoy.
7. **Staff:** The Panel was insistent that all staff should be well trained and experienced, friendly, warm and kind. They should be able to give medications and include a trained nurse. They recommend that both male and female carers should be on the staff of each centre and that there should be a range of supplementary staff to provide: hairdressing, barbers, chiropodists, exercise specialists, dentists, dieticians, counsellors, audiologists and chiropodists etc. The Panel members also recommend that staff should be trained and experienced so that they are able to deal with all the many expressions of dementia, enabling these to be places of welcome and accessible to all.
8. **Activities:** The Panel recommend that such centres should be open to other visitors including: school groups, musicians, dancers, amateur dramatic clubs, pet therapists etc. They also recommend these should offer the opportunity for people to develop new skills including; leaning a new language, learning a musical instrument, singing in a choir, gardening, art lessons, petanque, and have a small cinema etc. They also recommend that these centres should have resident pets, including fish, rabbits or chickens etc. All this they believed would be a way of replacing what some described as being, 'the unacceptable baby-sitting model' to being centres where people could continue to learn, experience new things in their lives and thrive.
9. **Communication:** The Panel recommend that communication between staff and attendees' families/carers would be improved if there were notice boards and leaflets available explaining the aims and objectives of the centres, a 'who's who' of the staff, an agenda for the day's activities, an explanation of the policies and procedures, and a hand-over summary note of helpful information concerning the attendee's day.
10. **Charges and costs:** The Panel recommended a range of options for funding these centres and for any charges levied. They were unanimous in believing these should be States/H&CS

run and not be private businesses. They believed that these should be seen as essential health care provisions and funding should be made available for these, as for people being cared for and treated for any other progressive, terminal condition. Panel members recommended that these should not be means tested but that, like the model for pre-school nursery age children, there should be a certain number of free care hours available each week, with the option for further hours, at a small cost, as required, and being incorporated within the Long Term Care Scheme. Others suggested a model more like that of the Day Hospice.

11. Finally in the words of 3 Panel members who attend The Meeting Place Project:

“I feel normal when I go there and not out of place at all.”

“It’s good to meet other people with the same problem as otherwise you would feel all on your own.”

“That place really stretches your brain!”

These comments we believe speak loudly and clearly about the value of such centres and are a recommendation for more day centres of such quality.