

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

Panel members were asked to share their lived experiences of attending the hospital, including the A&E department, out-patients and as in-patients.

The experiences of Panel members are summarised below, followed by a section with the Panel's recommendations. A total of 23 people attended the LEAP meetings in February, 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 February 2022

The outcomes of the discussions have been summarised in separate sections for the ambulance service, out-patient, in-patient, and for general comments.

- 1. Panel member's experiences of the ambulance service:** Although we did not specifically include reference to the ambulance service, Panel members wished to comment on this. Most members shared the opinion that those who attended them from the ambulance service were kind and confident in their approach which they found reassuring. However, one Panel member was very unhappy with the service following their relative's series of falls. On each occasion the person with dementia had banged their head yet were not taken to hospital as they thought they should be. They were further troubled because they had to sign a form stating the paramedic had explained this to them, and asked them to monitor

the person at home. This member said, *"I was just so hugely burdened by the responsibility that fell on me and it just felt like I was battling with them"*. The Panel member appreciated that the service was under pressure and that taking someone to hospital would put pressure on the hospital too. Others were worried by long delays in ambulances arriving. Another's experience was of being asked to call back 4 times and then when a paramedic arrived in a car there was no option of taking them to hospital. They said, *"It was all a disaster"*. Another reported that they too had to wait for an ambulance for 2 hours after a person with dementia had fallen down the stairs.

2. **Accident and Emergency Department - parking:** It was reported that this was always difficult and that getting a parking space even some distance away could not be guaranteed. Panel members reported that this always added extra stress to an already stressful event for a person with dementia and that there was always the need to leave extra time to find a space, which was an added extra problem.
3. **Accident and Emergency – conversations about patients not being resuscitated:** Two Panel members said they were asked to discuss details about not resuscitating their relatives in the A&E department. They considered this to be inappropriate because this had not previously been discussed and that A&E was not the time or place to make such decisions. They were further aggrieved because this was discussed in the presence of their relatives who were both conscious at the time yet not included in these discussions.
4. **Accident and Emergency – other disruptive patients:** Several of our Panel members expressed their disappointment that their relative with dementia had found the whole experience of being in A&E distressing because of the disruption caused by other patients who were loud, aggressive and frightening. No alternative quieter spaces had been offered to the person with dementia.
5. **Accident and Emergency – dementia not triaged:** Some of the Panel members said that they were unhappy that their relative's dementia did not appear to affect the triage system in place in A&E. They said that they had told staff that their relatives would be distressed if they had to wait in unfamiliar surroundings and this would likely make any diagnosis and treatment harder for the staff. Panel members said that this made them feel that medical staff did not value their suggestions and they felt powerless to help.
6. **Accident and Emergency – patient support:** During covid restrictions, relatives have not been able to attend A&E with the patient. One Panel member said it had taken them 30 minutes to try and persuade the staff that their relative would need them nearby as otherwise they would be anxious and disruptive. They remained outside the department and liaised with staff via a mobile phone. The member said that they thought the staff were all very stressed. All members understood the covid measures but felt there should have been exceptions for people with dementia and others with learning difficulties.
7. **Out-patient experience – care:** Most Panel members reported that the care given by all staff within the out-patients department was kind, courteous and professional. One member said, *"The team in clinical investigations were fantastic and the service was fabulous"*.
8. **Out-patient experience – navigating through the hospital:** All Panel members had experienced some difficulty themselves with navigating through the hospital to get to the departments they needed to access.
9. **Out-patient experience – communication:** Some carers of people with dementia reported that staff had spoken to them, ignoring the person with dementia, and others said that staff had spoken only to the person with dementia excluding them when they said it would have been obvious that the person with dementia would not understand or remember any details of the conversations.

10. **Out-patient experience – appointment letters:** Some Panel members reported that their relative with dementia had received letters for appointments sent to them which they had either purposely or accidentally mislaid or forgotten about. Because of this some appointments had been missed.
11. **Out-patient experience – appointment times/length:** Panel members shared similar experiences related to the of the timing of appointments. Often this meant that the person with dementia’s routine had to be disturbed to attend at the given time and that because communication was often difficult the time allocated for the appointment then seemed rushed. The Panel’s experience was that if appointment times needed to be changed to a more convenient time of day, such changes incurred significant delays, often of many weeks.
12. **In-patient experience - care:** All Panel members reported that all staff were kind, courteous and professional, however almost all said that they felt that the care for people with dementia in hospital fell short of what they hoped for and expected. They also reported that the staff appeared to rely on family members and other patients to look after patients with dementia and *“keep an eye on them”*. They reported that they felt the staff were under pressure and knew they were not providing the services they seemed to want to provide. Some said that patients were not helped to eat or drink if they needed this nor helped with menu choices. Panel members felt that some of these problems seemed to be because the staff involved in the care did not understand the needs of a person with dementia or the associated symptoms that needed extra or different support, when they seemed relatively physically able to manage certain tasks. One member said that this issue caused their relative to lose 3 stone in weight during a stay in hospital. This person died in hospital. The Panel member said *“I was so saddened that this was the manner of their death. The whole experience was dreadful”*. Another Panel member however was pleased that they had been asked to return to the hospital to help settle their partner who was distressed. This Panel member said that this showed the staff to be flexible with visiting hours which to them showed they understood their partner’s needs.
13. **In-patient experience – personal property:** One Panel member reported that while their partner was in hospital both their false teeth and watch were lost. Others then reported similar situations. As these patients all had dementia, the Panel members believed it should not be the patients’ responsibility to care for such essential items. One of these members then said how distressing it was for their partner to have to revisit the dentist and that this was an extra expense they should not have had to afford.
14. **In-patient experience – communication with relatives:** Panel members unanimously agreed that there was not enough communication with all hospital staff regarding the welfare or treatment of their relative. Their experience was that in some cases the staff had given information to a person with dementia who would not understand this or who would forget it. Members did appreciate that a person with dementia had the right to information about themselves.
15. **In-patient experience – wards/bays:** All Panel members said that while there were some benefits of having 6 bed bays for the patients and staff, they also commented that people were troubled by others with dementia in the wards and their sleep was badly affected. Some also said that they were embarrassed by the amount of disruption their relative with dementia had caused for staff and other patients.
16. **In-patient experience – common rooms:** All Panel members agreed that they found it helpful to have the opportunity to chat with other patients’ relatives in common rooms and help initiate conversation between their relative and other patients.

17. **In-patient experience – signage and other navigation aids:** All Panel members said that they, or their relative with dementia found the spaces difficult to navigate. One Panel member said *“The whole place was so dementia unfriendly. I hope our new hospital, when we get it, pays attention to how extra difficult people with dementia find being in such a strange place and how difficult it is for them to get better when they are there”*. Everyone then agreed with this statement.
18. **In-patient experience – occupation:** While all Panel members said that they understood that the primary purpose of being in hospital was to help treat a significant medical problem, they felt that the hospital should provide something for people to do, *“Apart from watching the telly, if you could hear it, and if you could see it and if it was your choice of programme!”*
19. **In-patient experience – identifiers:** Some Panel members were aware of the dementia identifier scheme but most reported that this was not being used. They said they believed that if this was used and understood by all staff their relative would have had a better experience.
20. **In-patient experience - social work support:** Many Panel members reported delays in the social work team attending to set up care plans for discharge and that some social workers, particularly those who said they were relatively new in post, did not seem to have a thorough grasp of Health and Community Services in Jersey, care agency provision, care homes nor of the Long Term Care Scheme.
21. **General comment – Les Quennevais:** While the purpose of this Panel is to report on actual lived experiences, the subject of the relocation of some out-patient services and clinics to Les Quennevais was raised. Some Panel members reported that they were happy with this likely move as they lived near Les Quennevais and others said that they would be happy if this resulted in better parking.
22. **General comment – information:** Panel members were in general agreement that they felt they were *“Being kept in the dark”* about changes in the structure of our health services.
23. **General comment – confidence:** Most Panel members stated that they had little confidence in those charged with the maintenance of our present health care systems and also of the redesign of these for the future, and were concerned that staff employed within the health service felt similarly. They expressed concern that recruitment and retention of staff would remain a problem given the costs of living in Jersey.

Panel members’ recommendations concerning hospital experiences

The following recommendations were made by the Panel.

1. **Ambulance service – speed of response:** Because of the extra distress experienced by many people with dementia and their supporters and carers the Panel recommends that in emergency situations such call outs, as far as possible, should be prioritised.
2. **Ambulance service – taking a person to hospital:** While the Panel members understood that hospital may not be the best place for a person with dementia, because communication of symptoms may be difficult or impossible, Panel members recommend that supporters or carers should not be left responsible for assessing someone’s condition or for making decisions regarding further call outs following an accident.
3. **Out-patient – appointment times/information sharing:** The Panel recommends that there should be an option to change appointment times for people with dementia to more suitable times in the day, without incurring any delay in attending the hospital for an out-

patient appointment. They also recommend that there should be, if necessary, extra time allocated for appointments for a patient with a known diagnosis of dementia. The opportunity for phoning or emailing potentially helpful information to hospital staff before appointments was also recommended.

4. **Out-patient - appointment letters:** While Panel members appreciated issues related to capacity and confidentiality were important, they recommend some mechanisms to be designed and implemented whereby letters for appointments could be sent to next of kin, with agreement of the patient, and to those with power of attorney to prevent essential appointments being missed.
5. **In-patient – assistance for people with dementia:** The Panel recommend that professional carers with specific training in dementia care should be allocated to attend to the complex and varied needs of people with dementia in hospital. This should include, but not be limited to, assisting to support nutrition and occupation.
6. **In-patient – patient with dementia identifiers:** Panel members' discussions revealed that the forget-me-not identifiers available for use in the above-bed panels were not in most cases being used. Where these had been used Panel members observed them to be helpful to raise awareness of a person's potential special needs while appreciating their discrete character. The Panel recommend that there is a renewed effort to roll-out the use of these in all wards and that all hospital staff should be trained to understand their significance.
7. **General recommendation – parking:** All Panel members agreed that the availability of a guaranteed, safe parking space near to the relevant hospital department was essential and was their first concern and recommendation.
8. **General recommendation - appropriate spaces for people with dementia:** While all Panel members acknowledged that hospitals were primarily places for emergency treatment and care and recovery from acute illness, they also stressed the importance of quieter rooms or spaces for people with dementia so that they would be *"less troubled by the regular hustle and bustle of hospital life."* The Panel also recommends that both ward and single rooms options should be made available for people with dementia and for lounges where visitors can meet with patients away from the ward environment.
9. **General recommendation – navigation signage:** All Panel members recommend that attention should be made to improving the signage in all areas of the hospital so that spaces are more clearly defined and pathways to them made clearer. They recommend floor pathways as appropriate, pictures to enhance text as appropriate, clearer fonts and consistent use of these and to discard any unnecessary signage or notices. The Panel recommend that new signage and way finders should be tested by people with a range of disabilities and illnesses before these are made permanent.
10. **General recommendation – dementia specific training:** The Panel recommend that all staff working in the hospital in any context should have compulsory dementia specific training appropriate to their roles and that this should be regularly updated.
11. **General recommendation – communication with next of kin, attorneys or delegates:** The Panel recommend that all staff treating or caring for a person with dementia should be aware of the possible need to involve others when sharing information with the patient, while bearing in mind and respecting patient confidentiality and their capacity.
12. **General recommendation – social work support/dementia navigator/care co-ordinator:** Because many Panel members reported not knowing how to access the help they needed and a general lack of social work support, and further that discharges from hospital were often delayed because of complications with care plans, they recommend that all people at the time of a diagnosis of dementia, are allocated a named dementia navigator or care co-

ordinator. This person would then be able to get to know a person over time and be able to follow through with any changes as necessary, particularly following a discharge from hospital.

13. **General recommendation – advice in writing:** Because people with dementia do not always remember the advice given to them by medical staff, and because relatives have reported that people with dementia occasionally find it difficult to accept information or guidance passed on by them, they recommend that any advice from medical staff is also available in writing for later reference.

Dementia Advisor Team – February 2022