

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

Panel members were asked to share their lived experiences of medication, both at the time the medication was first being considered or prescribed and their continuing experiences taking medication. Discussions also included the medications' perceived efficacy for the management of any symptoms of dementia, and their experiences of any side effects.

The experiences of Panel members are summarised below, followed by a section with the Panel's recommendations. A total of 17 people attended the LEAP meetings in January, 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 January 2022

While our interest was predominantly concerning medications prescribed for use in relation to a diagnosis of dementia, the Panel's conversations also included their experiences of other medications. We have included these as it was clear from our discussions that people with dementia often have co-morbidities which require medication, with the impact of their dementia in some

cases affecting their ability to distinguish the different medications they take, difficulties in being able to differentiate possible side effects, and often needing assistance in taking these.

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

1. **Initial information provided:** Our conversations revealed that there was a clear difference of opinion in our Panel members concerning the appropriateness and amount of information provided by the prescriber. Panel members with dementia were generally content that they were given sufficient information about their medication/s while most supporters or carers stated that both the person with dementia and they themselves were not provided with the information they wanted. Many also said that they did not feel encouraged to ask questions or to voice any concerns. However, in relation to this, 3 Panel members said that they felt a diagram drawn by Dr Melendes concerning the probable progression of dementia with and without medication was very helpful. Another said, *“Although the doctor was explaining things to X, it clearly was all going over their head”*.
2. **Knowledge about medication taken:** 3 people with dementia said that they did not know anything about any of the medication they took but relied upon family members and the trust they had in them to take the medication with confidence. Conversations developed from this with Panel members voicing their concerns for people who did not have others in whom they could place their trust.
3. **On-going access to information:** There was agreement between Panel members that following a person’s discharge from the Memory Assessment Service (MAS) there was insufficient access to information concerning medication, particularly concerning reviews, and who would be responsible for these, and whether or not medication should be continued if symptoms changed. One person commented, *“I just feel in the dark, and so responsible for X’s welfare and I’m just not qualified for this. Years ago I was told that X would probably be on this medication for a few years but it’s about 6 years now, so they seem to have forgotten us.”* While some Panel members said they found their GPs to be good source of information and were comfortable having such discussions with them, others said they had not found their GPs happy to have such discussions.
4. **Alternatives to medication:** One Panel member said that they were told that attendance at the Cognitive Stimulation Therapy Group (CST) was ‘like medication’ and would help delay the progression of dementia. This comment stimulated considerable conversation amongst the Panel. Other members said they had not been told this and others said that they had not been offered this course and therefore felt they were missing out on possible sources of help for their relative with dementia, as an alternative or supplement to medication. The discussion progressed with members questioning why this therapy was not offered to everyone and for longer. Another member said that no other types of therapy had been offered but believed these should be available. Others who had not previously considered this were then in agreement.
5. **‘Pill boxes’:** These were discussed. All Panel members said they were very helpful, making it easier for the person with dementia to take their medication safely without supervision, and carers agreed that their use also helped them feel confident when giving medication to another person.
6. **Information leaflets:** There was general agreement that the font size of the information leaflets provided in the medication packs was far too small, and therefore, for some people this was inaccessible. Panel members were particularly concerned that they may not have access to necessary information concerning side-effects.

7. **Medication alert cards:** These were discussed in detail. One Panel member had made their own alert cards for themselves and their relative with dementia and carried these with them at all times. However, although such cards do exist, discussions revealed that their use had not been suggested to any other Panel members by any health professionals. Further to this there was some discussion about the Green Cross system which some Panel members used at home and believed would be helpful, but others were unaware of this. More information about this is presented in the 'Recommendations' section below.
8. **Effectiveness of medication:** While one Panel member with dementia said that they believed the medication they took 'for dementia' had helped them, all other Panel members said that they did not have real evidence that the medication was helping, but that they trusted that it did and were happy for this reason to continue taking it. One Panel member said that they were not given any information about how the medication worked and what benefits or changes to look out for or monitor. Others agreed that this was also their experience.
9. **Recognising medications:** The colour, size, shape and packing for medications was discussed and while Panel members knew that it was not right to rely upon these features to distinguish particular medications, most said that they did to some extent rely on this for themselves and when giving medication to others. One Panel member said "I was so *confused when the colours and shape changed I was not sure that this was the right medication for X*". Further comment about this is provided in the Recommendations section below.
10. **Use of antipsychotic medications:** Panel members were eager to initiate discussions about the use of antipsychotic medications with many being very unhappy about this. Their concerns included: the use of these without consultation with relatives or those with Power of Attorney; not understanding how these types of medications 'worked'; concerns about who determined their use in care homes if prescribed for PRN (pro re nata – when needed) use; and the length of time people were prescribed these medications, seemingly contrary to times recommended by NICE guidelines. Some Panel members also indicated that it was their observation that medication was being used as a first option before attempts were made to investigate any triggers leading to a person's changed behaviours and first addressing these. One Panel member said "*They were just like a complete zombie when they were given this*" and another described how they felt extremely worried by a member of staff who indicated that the continuation of a person's stay in a care home was contingent upon them taking a regular dose of an antipsychotic drug. They were told that the drug would calm their relative's disruptive behaviour and aggression towards other residents. Panel members were concerned that such use of medication could be for others' benefit but not for the person being given it. There was agreement amongst Panel members when one said, "*It seems medicines are used as the first port of call for treatment rather than staff looking at why people are acting the way they are*" (a medical model rather than a psycho-social model).
11. **'Rocking the boat:'** Many Panel members said they felt apprehensive initiating discussions about medication with staff or requesting a review of a person's medication for fear of possible reprisals for the patient/resident with many in agreement that 'not rocking the boat' was their necessary intention.
12. **Record keeping/drug charts:** All Panel members were content that appropriate records were being kept concerning the prescription and administration of medications by all health care professionals.

- 13. Options to opt-in or opt-out of involvement in discussions concerning a person's medication and other treatments:** Panel members were in total agreement that they (both people with dementia and carers as next of kin with consent, or Power of Attorney) should be involved in decisions about any change to a prescription or care plan. However, many said that changes had been made without their involvement.

Panel members' recommendations concerning medication

The following recommendations were made by the Panel.

- 1. Alerts regarding changes to the shape, colour, size and packaging of medications:** Although the Panel members were aware that there could be some problems implementing this recommendation, they were in agreement that warning notices should be added into medication packages to draw people's attention to any such changes.
- 2. Medication alert cards:** Panel members agreed that all prescribers should supply and promote the use of such cards and that the Green Cross alert system for people's homes should be reintroduced and promoted.
- 3. Discussion with relatives/Attorneys concerning medications:** While Panel members did not know how they could ensure such discussions would take place, they believed that they should be mandatory. Panel members said that if a person with dementia had previously appointed an Attorney, or given consent for medical details to be shared with another person, their rights to such representation or voice would be being denied if this does not happen.
- 4. Information about the use of antipsychotic medications:** The Panel recommended that statistics should be sourced and made available concerning the extent of the use of such medications in all care settings in Jersey. Further, the Panel recommends that if it appears that antipsychotic medications are being used more in Jersey than in the UK, an explanation is made available as to why this is so. They recommend further discussions about the prevalence of what appears to be a greater reliance upon a medical model of care rather than a psychosocial care model, particularly with the rolling out of the new Jersey Care Model.
- 5. Medication reviews:** The Panel recommends that all patients are routinely given a date for a review of all medications and details given of who will be doing this review (for example, a GP or hospital specialist).