



Draft Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standard Consultation

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The Australian Commission on Safety and Quality in Health Care
Email:
ccs@safetyandquality.gov.au

Lived Experience Australia Ltd
Contact: Sharon Lawn
Chair & Executive Director
slawn@livedexperienceaustralia.com.au
PO Box 12, Oaklands Park SA 5046
Phone 1300 620 042
ABN: 44 613 210 889

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Introduction

Lived Experience Australia Ltd (LEA) is a national representative organisation for Australian mental health consumers and carers, families and kin, formed in 2002 with a focus on the private sector. All members of our Board and staff have mental health lived experience as either a consumer, family carer or both.

Our core business is to advocate for systemic change to improve mental health care (including psychosocial disability) across the whole Australian health system, including within State and Territory jurisdictions. This includes advocating for empowerment of people with mental health lived experience (people with mental health conditions and their family, carers and kin) in the broad range of issues that impact their mental and physical health, and their lives more broadly. It includes empowering them in their own care and contact with health and social services, promoting their engagement and inclusion within system design, planning and evaluation and most importantly, advocating for systems promote choice, inclusion, justice and fairness, and address stigma, discrimination and prejudice.

Our current submission comes from the perspectives and experiences of families, carers and kin with lived experience of mental health challenges. We welcome the opportunity to provide our submission on the Draft Psychotropic Medicines in Cognitive Disability or Impairment Clinical Care Standards. Our comments relate to the following document:

1. Guide for consumers
2. Easy Read Fact Sheet

In summary....

Psychotropic Medicine in Cognitive Disability or Impairment Clinical Care Standard Quality statements

In the statements below, person means a person with cognitive disability or cognitive impairment.

1. Person- and family-centred care

A person receives healthcare that is driven by their individual preferences, needs and values, and upholds their personal dignity, and human and legal rights.

The person and their family are supported to be active participants and make informed choices about their care.

2. Informed consent for psychotropic medicines

If a psychotropic medicine is being considered, the person and their family are informed about the reason for prescribing, and its potential benefits and harms.

Where use of psychotropic medicine is agreed, informed consent is obtained and documented before use.

If the person's decision-making capacity is impaired, processes for supported decision making, proxy consent or exemptions under relevant legislation are followed as appropriate.

3. Assessing a person with behaviours of concern

A person who develops unexpected changes in behaviour is assessed for immediate risks to their safety and that of those around them.

When safe to do so, a systematic assessment is undertaken to identify factors that may be contributing to the behaviour, which takes into account any existing plans to support the person's care, and others who know the person.

4. Non-drug strategies

Non-drug strategies are used first-line when responding to behaviours of concern and as the mainstay of care to prevent recurrence, regardless of whether medicines are used.

The choice of strategies is individualised to the person's preferences, the situation, and underlying causes for the behaviour, and they are documented in a place that is accessible to all of those involved in their care.

5. Behaviour support plans

If a person has a behaviour support plan, it is used to guide their health care.

The person's response to the plan, including any use of psychotropic medicine, is continually monitored, documented, and communicated to inform regular updates to the plan.

6. Appropriate reasons for prescribing psychotropic medicine

Psychotropic medicine is considered in response to behaviours of concern only when there is a significant risk of harm to the person or others, or the person is in severe distress and non-drug strategies are not effective.

Psychotropic medicine is also appropriate for treating a diagnosed medical condition, or as a time-limited trial when a diagnosis cannot be made with certainty but is likely following a documented clinical assessment.

The reason for use is documented in the person's healthcare record at the time of prescribing.

7. Monitoring, review and deprescribing of psychotropic medicine

A person's response to psychotropic medicine is regularly monitored and reviewed to identify the benefits and harms of prescribing, and consideration of dose alteration or deprescribing.

The results are documented in the person's healthcare record, along with the timing of the next review.

8. Information sharing and communication at transfers of care

When the healthcare of a person is transferred, information about their ongoing needs is shared with the person, those who support them, and relevant healthcare and service providers who are responsible for continuing the person's care.

This includes information about their medicines, and any plans to support their behaviour.

Where psychotropic medicine is prescribed, the reason for use, the intended duration, timing of last administration and plans for review are documented and communicated.

Response to Questions about each Quality Statement and Indicators (1-8)

1. Does the quality statement adequately describe the quality of care that should be provided?

a. How could the quality statement be improved?

- The prioritisation of person and family centred care (Quality Statement 1) could be improved by ensuring that the definitions and processes that lead to this practice are used consistently and accurately across the different context of the healthcare system and therefore, integrated in all aspects of system design, delivery, education and evaluation.
Mention is made of 'any wishes or goals for care that you have expressed' – Would it be useful to mention 'Mental Health Advance Directives. We know from a recent survey LEA undertook for Mental Health Australia and the Australian Digital Health Agency on My Health Record and Advance

Directives that many people and the family and carers do not trust that these Advance Directives will be accessed, respected and followed by mental health service providers, even when they are made. This survey's results also found that many people wanted to know more about how to make an Advance Directive and needed support to develop them.

- In relation to the informed consent for psychotropic medicine (Quality Statement 2), the person and family members should be encouraged to ask questions and clarify all the relevant details about possible harms and benefits. As noted on p.3 the person is assured that they can withdraw their consent or seek more information if they wish to, even after they given it. This is clearly important because, in our experience, it is a common experience to be asked initially or be given very brief information upon which to base the decision at a time when the person may not be in a position to fully grasp the information. Also, providing consent for something when one doesn't even know what the actual impacts might be is somewhat a nonsense and arguably unfair. No one would sign up to something before they had tried it without having the option of then being able to change their mind. Too often, however, people are threatened with coercive treatment if they do change their mind, what medication changed, or want to discuss their concerns about medications with health professionals.

One friend of LEA told us, 'I am worrying about depot injections, often given under compulsion, increasing dementia risk in those with antipsychotic medication. The risks in older folk of giving antipsychotic medication are well known. I am thinking of the younger cohort too. I think they are starting to give antipsychotic medications to even children.'

- While we acknowledge that non-drug strategies (Quality Standard 4) can't be determined immediately and could be a mix of many types of intervention, we believe it is important to mention some of these methods in the document such as behavioural interventions and cognitive interventions, environmental modifications, music, and pet therapy. In some cases, an educational session about non-drug strategies for the person or their family is important to communicate the benefits as not all individuals or groups are aware of the benefits of non-drug strategies.
- Healthcare providers and professionals should consider deprescribing the medication when it is no longer needed or necessary. As one consumer told us, "I still recall my session with my doctor when I decided that I wanted to continue my life without medication. It was a decision that was understood, respected and supported. I was able to gain my life back because of this".
- With regard to behaviour support plans (Quality Standard 5), the statement 'Your plan should also change over time as your needs and preference change' should also include wording that reflects the person's agency and development of self-care knowledge over time. For example, they and their family and health professionals are all learning over time and gaining more understanding about what works and doesn't work, when and under what circumstances. It's core to recovery for the person to gain their own sense of agency, control and lived experience knowledge to apply to new situations and their lives over time. (There is also a small typo on p.6 'who works with to understand').
- For the standard on appropriate reasons for prescribing (Quality Standard 6), there is wording here about these medications making people calmer, sleepy, etc that would have been useful to include in the definition on p.1. Again, the issue of dose may be useful to mention too. We note that the easy read guide for this standard mentions it. Also, we strongly encourage the revision of the words 'your healthcare provider will assess you thoroughly' which we consider is stigmatising language;

assessing your needs and preferences or some other terms that don't objectify the person would be preferred.

- The information about information sharing and communication at transfer of care (Quality Standard 8) is crucial, given that errors can be made, the person's version can be overlooked or dismissed, family carers often have to fill in the blanks in the core information because of failures in communication between healthcare providers, and there may have been little or insufficient time spent with the person or their family to provide information and education about the medication, what side effects to be alert to, or other basic important information. The 4 dot points about why the medication was prescribed, when it was last given, how long it should be taken for, and when to check to review how well it is working is a good starting list of transfer information. We believe that this could be expanded to also include the need for information about common side effect to look out for and also the potential for interactions with other medications that the person may be taking for any physical health conditions, interactions with stimulants (legal and illegal drugs), etc.
- Integration: it is critical to ensure a shared understanding about these statements that relies on the integrated nature of each one of them. For example, all statements should be implemented with a person centered care, the quality of the treatment plans and strategies relies heavily on conducting a comprehensive, systematic and standardised assessment, the review and monitoring process is a critical part and opportunity for the patients and their families to make future decisions.

2. Do the proposed indicator(s) capture information that can be used to support local clinical quality improvement activities?

a. How could the indicator(s) be improved?

We believe that the range of indicators provides useful information across the broad range of issues and concerns that need to be considered to support clinical quality improvement activities. We note, however, that statements about what should occur are not always enacted in practice. Pressures on time, individually held stigmatising attitudes, and the culture of services also contribute to whether quality care is provided or not, among many other circumstances and factors.

3. The quality statements focus on areas identified by the Commission as being a priority for quality improvement. Are there additional areas or aspects of care that should be included?

a. If so, please provide further detail.

As stated above.

4. Are you aware of any current or planned initiatives that could support implementation of this clinical care standard?

a. If so, please provide further detail.

Although the role of peer workers is necessarily non-clinical, there are many assumed values and attitudes underpinning statements within these standards for which the presence of a peer worker would help to create a more positive respectful culture in which service is delivered, including how the person and their human rights are respected and included in decisions about use of psychotropic medications.

5. Do you agree with the suggestions relating to cultural safety and equity?

a. If not, how could this be improved?

We believe cultural safety and equity considerations are important in any current or planned initiatives, so that diverse cultural views and perspectives on health, illness, wellness, help-seeking, authority figures, past trauma experiences, health and language literacy, and so forth are fully considered and respected.

6. Is the Consumer Guide useful?

a. If not, how could this resource be improved?

The definition of 'What are psychotropic medicines?' on p.1 states 'using medicine for the least amount of time that you need'. However, we believe that it should also state something about the minimum dose needed too. Far too often, people are overmedicated with doses that are clearly higher than the person needs at the time. This can be because it is convenient to the service provider, the system of care, the setting, the service culture, and the workforce supply at the time to have the person 'over-sedated', passive and cooperative. We worry that over-use of medication (a dose issue) is a default option for better clinical skills development and delivery. The iatrogenic consequences for consumers of long-term use of psychotropic medicines on their physical health are significant and contribute to them dying or developing chronic health conditions much earlier than they should. The evidence for the harms of over-use and long-term use of these medicines is well established, despite their potential benefits to supporting the person with their mental health.

7. Is the Easy Read Consumer Guide resource useful?

a. If not, how could this resource be improved?

There are several sections and statements in the easy ready guide that capture the core of the issues and the relevant standard very well and much more clearly than the consumer guide does.

p.7 of the easy read guide states 'some medications might make a person feel too tired to show they are not happy'. We wonder if this might be hard to understand. Should it be 'too tired to let others know they are sad or angry' or something like this? We are guided by easy read experts here.

Contact

We thank the ACSQHC for the work it is doing on this important national and community issue. We wish you every success with the next steps and would be keen to be involved in any future discussions about this important topic.

Your sincerely

Sharon Lawn

Professor Sharon Lawn
Lived Experience Australia Ltd
Board Chair and Executive Director
Email: slawn@livedexperienceaustralia.com.au
Mobile: 0459 098 772

John Khateeb

Mr John Khateeb
Lived Experience Australia Ltd
Board Director
Email: jkhateeb@livedexperienceaustralia.com.au