

Supported decision making



Summary



Dementia is a progressive condition that causes a change in cognitive ability over time requiring a responsive approach to decision-making



For someone living with dementia, decision-making ability can be influenced by a variety of physical, psychological and environmental factors



Supported decision-making enables people with cognitive disabilities to make decisions about their health care with the appropriate assistance



The 'spectrum model' of supported decision-making recognises that people living with dementia will require different levels and types of support to maximise involvement in decision-making for as long as possible




Dementia Australia acknowledges that depending on the context, both supported and substitute decision-making approaches can offer appropriate assistance

Background

Decision-making capacity encompasses a person's ability to understand information that may be relevant to a decision, including the consequences, to retain this information for decision-making purposes (even if only briefly) and to communicate those decisions (in any form). Dementia is a progressive condition with associated physical and cognitive changes. These changes will vary for each individual and require a responsive approach to every aspect of dementia care and support, including involvement in decision-making.

Traditional decision-making processes for people living with a cognitive disability consisted of guardianship laws, which in their intent to 'protect' the person and their property, have been described as 'exceedingly paternalistic.' From the 1960s onwards, a more inclusive, substitute decision-making approach has gained increasing acceptance. Substitute decision-making involves a legally appointed person making decisions for the person with the disability when they are no longer able to do so. These decisions may be about financial, lifestyle or medical issues and are underpinned by the principle of acting in the individual's best interests.

The more recent model of supported decision-making represents a further and significant shift in recognising the importance of making decisions **with** rather than **for** the person. Supported decision-making enables people with cognitive disabilities to exercise their legal rights about decisions that affect their lives, including medical and financial matters, with support from a team of people they know and trust. It is an approach that acknowledges both the relational nature of decision-making (making decisions in genuine partnership), and that support must be tailored to meet the needs of the individual.



In implementing a supported decision-making process, psychosocial, clinical and other non-legal considerations are important. For someone with dementia, decision-making ability can be influenced by a variety of environmental and psychosocial factors. Studies emphasise the importance of ensuring conditions are conducive to supported decision-making so that the person with dementia is not discouraged from, or deprived of, the opportunity to express their preferences.ⁱⁱ Maximising comfort and familiarity, minimising noise and other sensory disruptions and choosing an appropriate time of day (fatigue can be a significant issue) are important considerations. Acknowledging differences in understanding and beliefs about dementia and decision-making in the ethnically, culturally and socially diverse communities that characterise contemporary Australia is critical. Presenting information in an appropriate language and accessible format will encourage engagement in the process.

Medication, clinical issues and psychological factors, including anxiety, can also have potential impacts on a person with dementia's decision-making ability. Other factors can also influence decision-making capacity. People living with dementia can experience neuropsychiatric symptoms or be socially positioned in a way that limits their opportunities for decision-making.ⁱⁱⁱ

Issue

The 2008 UN Convention on the Rights of Persons with Disabilities (UN-CRPD) acknowledged that people with disabilities, including those living with dementia, have legal capacity regardless of their impairments. The convention gave supported decision-making an important, formal legal dimension but there has been a subsequent debate about the approach, and significant challenges in the legal interpretation and implementation of the process. It has been argued that the context, scale and implications of the decisions requiring support will vary significantly, and that the supported decision-making process must take this into account accordingly.^{iv}

A range of supported decision-making models have been developed nationally and internationally over the last two decades. A recent Australian pilot project proposed the ‘spectrum model’ of supported decision-making, a model involving a ‘relational and interpersonal process’ that unfolds over time. The spectrum model recognises the kinds of complexities outlined above, and that different levels and types of decision-making support will be required at different stages of the dementia trajectory.^v

More than a decade on from the landmark 2008 UN-CRPD, the development and implementation of legal frameworks for supported decision-making represents a significant and ongoing challenge. Early adopter countries including Canada and Sweden have not produced convincing evidence for the legal efficacy of their respective supported decision-making schemes. In Australia, the development and implementation of legal frameworks for both substitute and supported decision-making vary across States and Territories, reflecting the complexities and challenges associated with these decision-making processes.^{vi}

Dementia Australia's position



Dementia Australia believes that the 2008 UN-CRPD represents an important recognition of the rights of people with a cognitive disability to make decisions about all aspects of their lives. Dementia Australia strongly supports the principles of supported decision-making for people living with dementia as this approach places the person with dementia at the centre of the decision-making process. Dementia Australia also recognises that dementia is a progressive condition, and there will be contexts in which substitute decision-making is an appropriate approach.



Acknowledging this complexity, Dementia Australia endorses the spectrum model of supported decision-making. The provision of different types of support at different stages of dementia, tailored specifically for each individual, offers an appropriate model to guide supported decision-making for people living with dementia in this country. Dementia Australia also believes that supported decision-making processes can play an influential role in educating the broader community about recognising and supporting the strengths and abilities of the person living with dementia, including their decision-making capacities.



Finally, Dementia Australia endorses further research into the implementation and effectiveness of supported decision-making models to ensure that this approach underpins the future delivery of high quality, person-centred dementia support and care.

ⁱAustralian Government, Australian Law Reform Commission, 'Supported and Substituted Decision-making,' <https://www.alrc.gov.au/publication/equality-capacity-and-disability-in-commonwealth-laws-dp-81/2-conceptual-landscape-the-context-for-reform/supported-and-substituted-decision-making/>

ⁱⁱJ.N.Viaña, F. McInerney & H. Brodaty (2020) Beyond Cognition: Psychological and Social Transformations in People Living with Dementia and Relevance for Decision-Making Capacity and Opportunity, *The American Journal of Bioethics*, 20:8, 101-104, DOI: 10.1080/15265161.2020.1781960

ⁱⁱⁱJ.N.Viaña, F. McInerney & H. Brodaty (2020) Beyond Cognition: Psychological and Social Transformations in People Living with Dementia and Relevance for Decision-Making Capacity and Opportunity, *The American Journal of Bioethics*, 20:8, 101-104, DOI: 10.1080/15265161.2020.1781960

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^vNational Health and Medical Research Centre, Cognitive Decline Partnership Centre (CDPC). (2019). Supported Decision-Making in Dementia Care: Final Project Report. Sydney: NHMRC Cognitive Decline Partnership Centre. <https://cdpc.sydney.edu.au>

^{vi}National Health and Medical Research Centre, Cognitive Decline Partnership Centre (CDPC). (2019). Supported Decision-Making in Dementia Care: Final Project Report. Sydney: NHMRC Cognitive Decline Partnership Centre. <https://cdpc.sydney.edu.au>, p18