

## Death Literacy Index: MySay report

### Introduction

The Death Literacy Index (DLI), developed in Australia, measures community understanding of death, dying, and end-of-life care. It assesses individuals' knowledge, skills, and confidence in navigating end-of-life issues. Western Sydney University defines death literacy as the knowledge and skills that enable people to understand and act on end-of-life and death-care options. *Source: [Developing death literacy - Western Sydney University](#)*

The DLI-9 is a validated nine-item self-report measure that captures four dimensions of death literacy: Practical Knowledge, Experiential Knowledge, Factual Knowledge, and Community Knowledge. Higher levels of death literacy are associated with greater awareness of services, policies, medical procedures, and planning processes, often supported by strong caring networks. *Source: [Death Literacy Institute](#)*

The original 29-item DLI was designed to foster meaningful community engagement in conversations, program development, and planning. The shorter DLI-9 was subsequently developed in response to community requests for a more accessible assessment tool. <https://journals.sagepub.com/doi/10.1177/26323524241274806>

Both the DLI and DLI-9 produce scaled scores that enable measurement of death literacy across communities or respondent groups. In Australia, national mean scaled scores serve as benchmarks, providing researchers, community organisations, and project teams with a consistent reference point for interpreting results. These benchmarks support evidence-based project planning, progress monitoring, and impact evaluation.

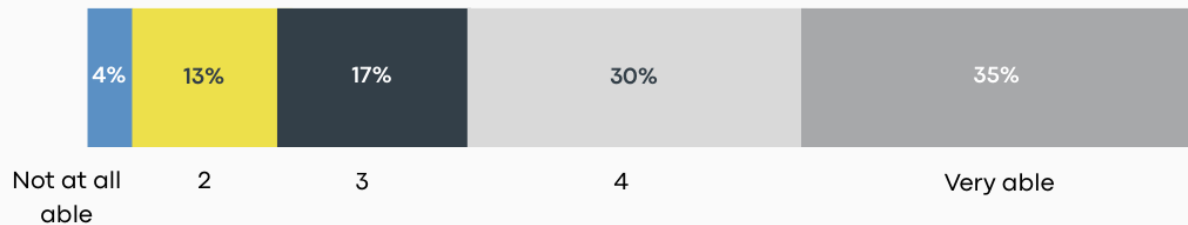
In October 2025, Capital Health Network (CHN) used MySay, CHN's community engagement tool, to invite ACT stakeholders to complete the DLI-9. Forty-six participants responded, offering insight into community awareness, confidence and social capability regarding end-of-life matters. These findings will inform CHN's planning, future initiatives and targeted interventions.

### Results

#### Practical Knowledge

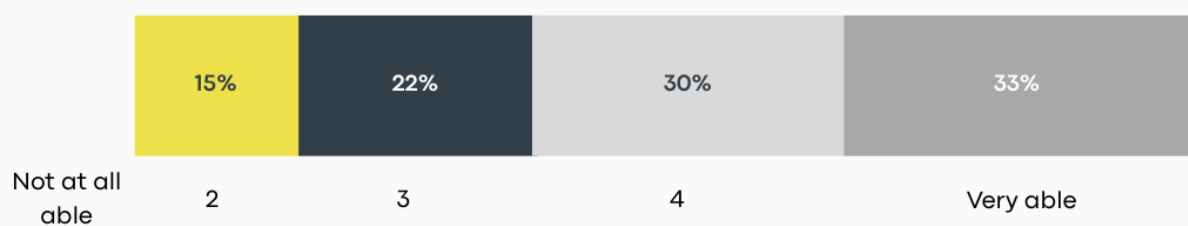
Question one assesses the respondents' ability to provide hands-on care for individual in end-of-life (EOL) situations. Ratings were moderate indicating being comfortable with feeding assistance.

Please rate your level of ability with the following:  
How able are you to feed or help a person to eat?



Question 2 measures respondents' confidence and ability to talk about death, dying and grief with different individuals. Ratings indicate the most people feel comfortable discussing death with individuals.

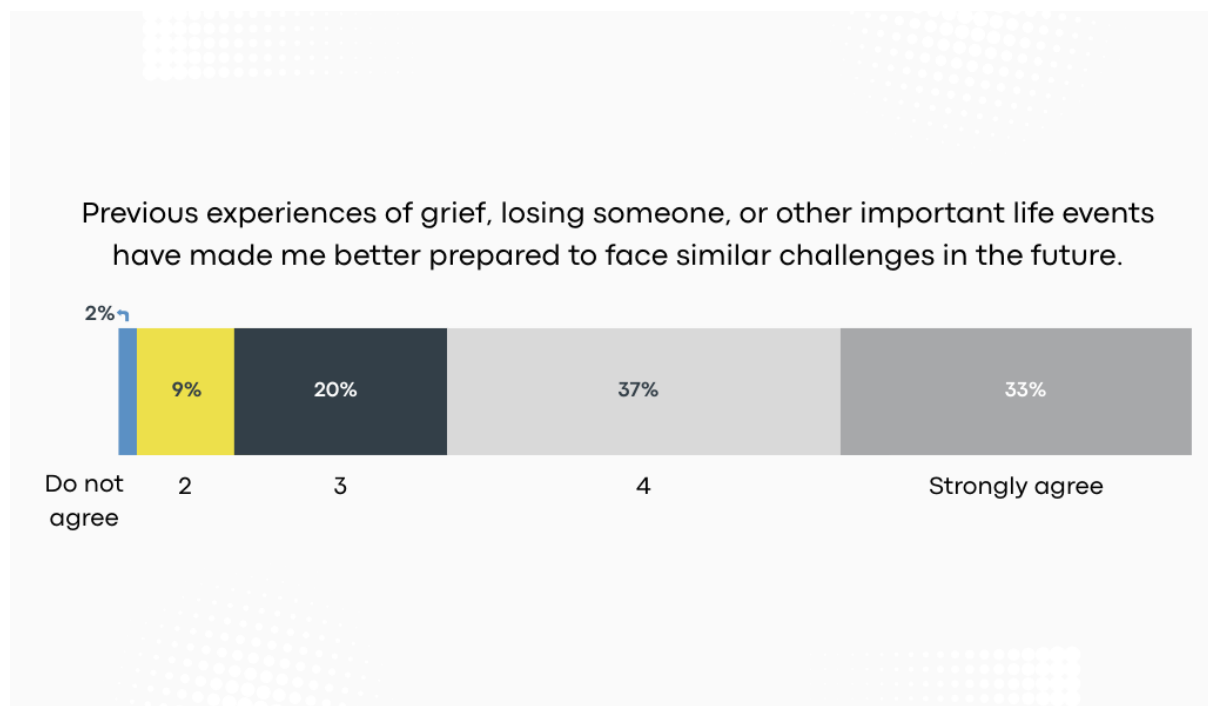
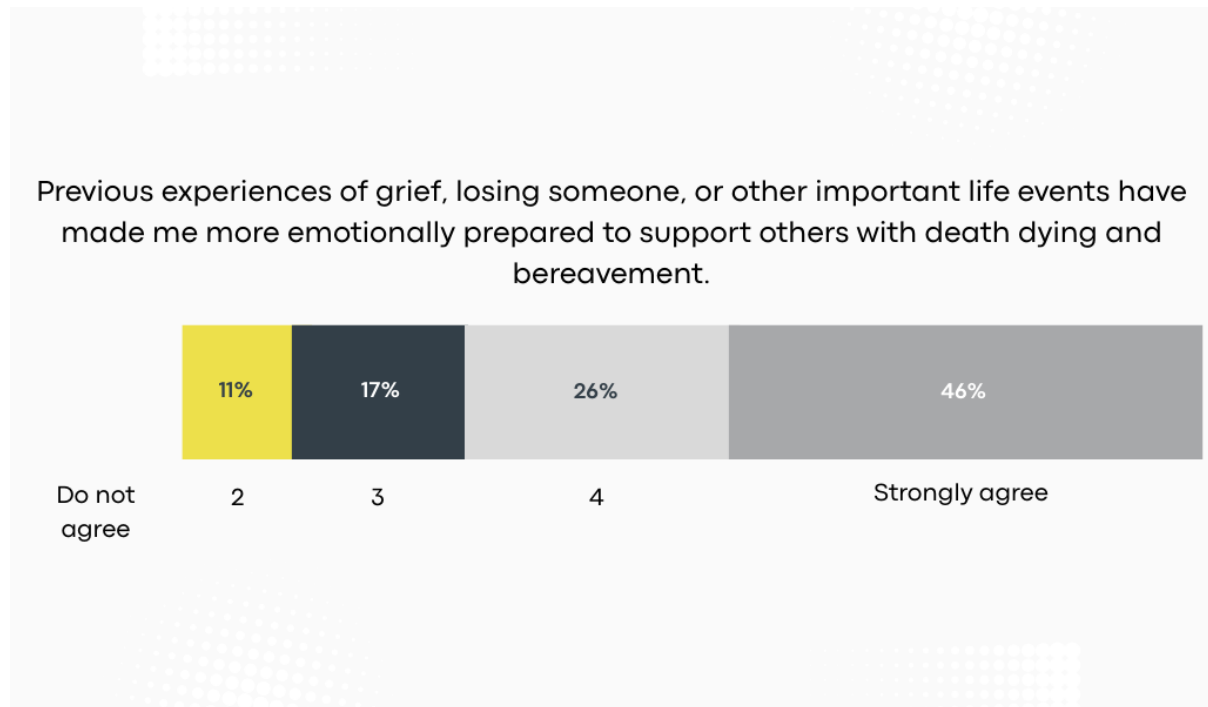
Please rate your level of ability with the following:  
How able are you to talk to a grieving person about their loss?



### Experiential Knowledge

Question 3 and 4 measure how experience with death and dying influence personal growth, understanding, and resilience. A significant proportion of respondents rated

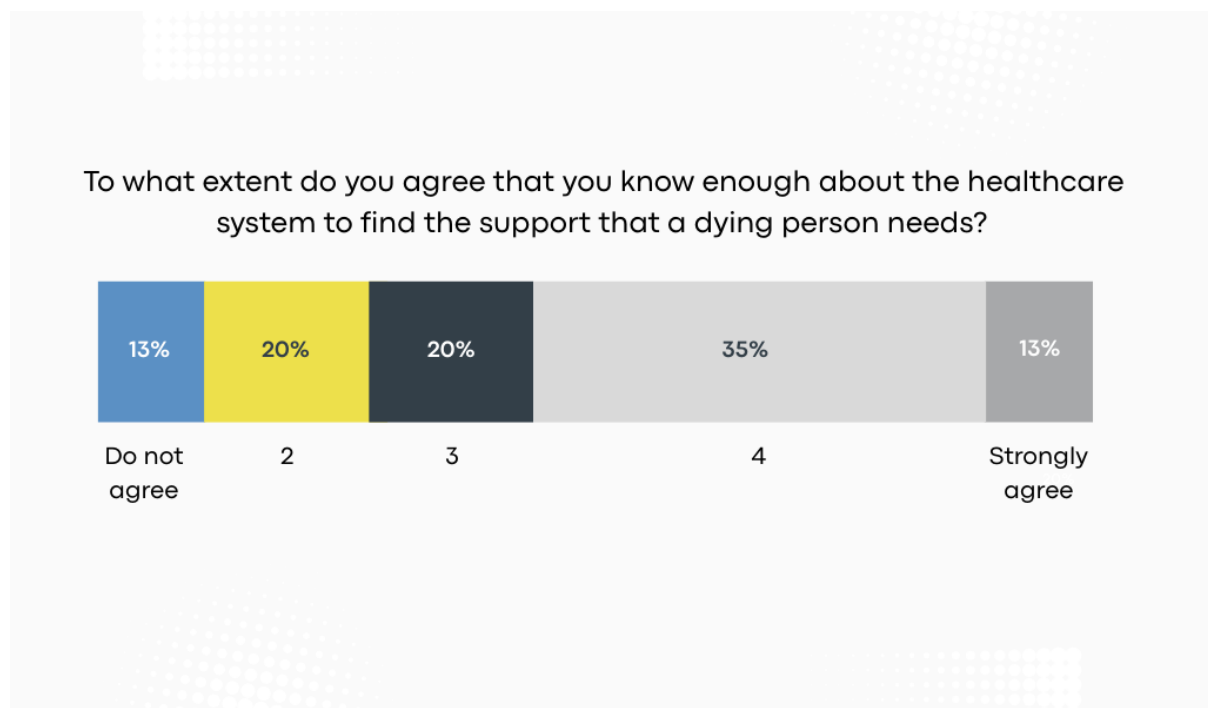
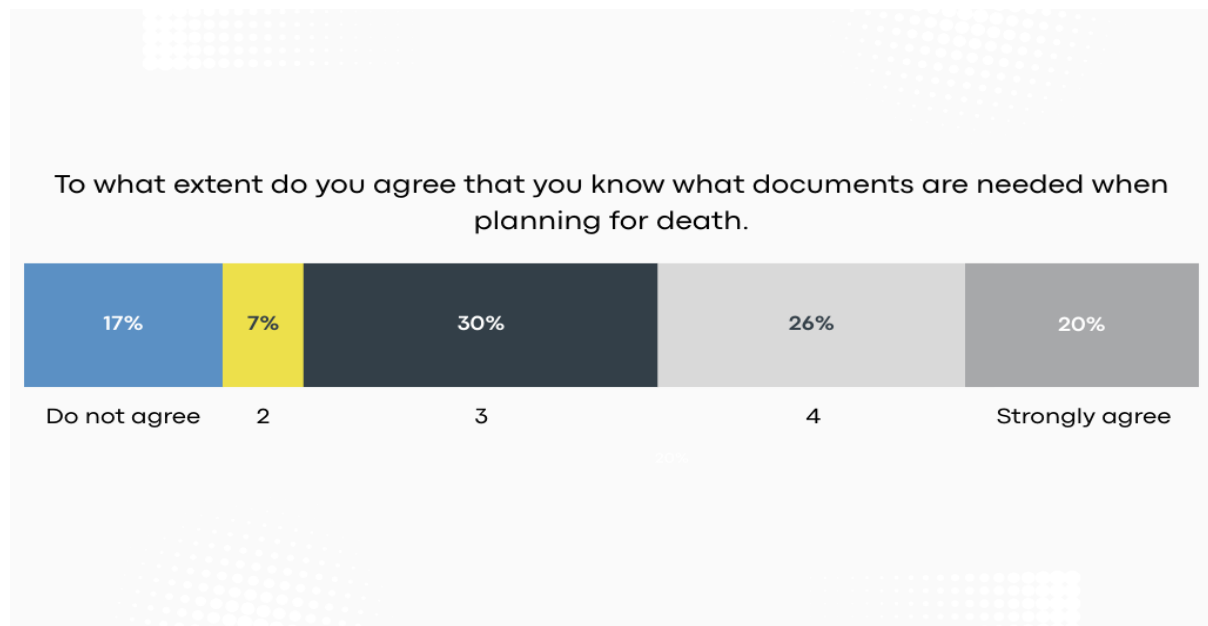
themselves strongly agreeing that they are better able to support others due to their own experiences with death. Fewer respondents indicated they have gained emotional resilience from their experiences.



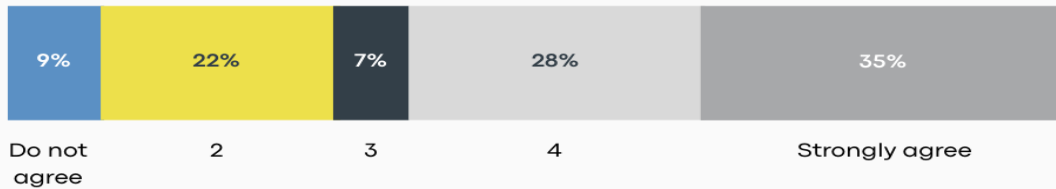
### Factual Knowledge

Question 5 to 7 assess respondents' awareness of legal, medical, and procedural aspects of EOL planning. Procedural awareness – Lowest awareness is seen in knowledge of necessary documents for death planning. Palliative care services – Moderate to highest awareness is seen in knowledge of how to access palliative care.

Moderate awareness was reported of the healthcare system to access support for a dying person.



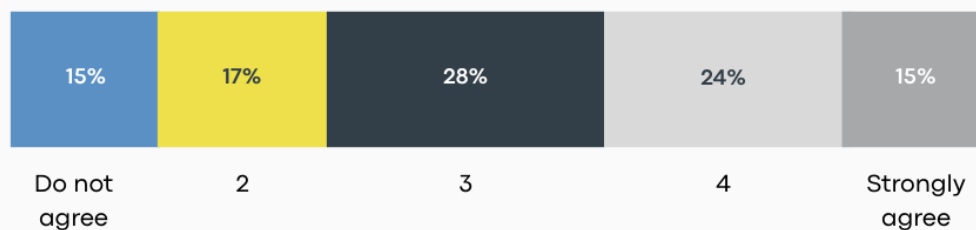
To what extent do you agree that you know how to access palliative care?



### Community Knowledge

Question 8 and 9 measure respondents' awareness and ability to access community-based support and resources related to EOL care. Awareness of EOL culturally specific resources was evenly spread across the respondents however their respective ability to access community-based resources when caring for a dying person varied.

If I were to provide end of life care for someone, I know people who could help me to get support that is culturally appropriate for a person.



There is support in my community for people who are caring for a dying person.



## Discussion

The overall DLI Score from the CHN MySay respondent group is 6.46 indicating a moderate to moderately high level of death literacy within the respondent group compared with the Australian national DLI benchmark of 4.83.

The CHN MySay - Practical and Experiential Knowledge of DLI Score is 7.12 and is the highest-scoring category, indicating that personal experiences with death contribute emotional growth and understanding. As well as the respondents being comfortable providing hands-on care and discussing death.

The CHN MySay- Factual and Community Knowledge DLI Score is 5.20 is the lowest scoring indicating potential knowledge gaps accessing or navigating the health system, support, resources and community support systems.

## Conclusion

The DLI-9 findings indicate that the CHN MySay respondent group demonstrates a moderate to moderately high level of death literacy, with an overall mean score of 6.46 which is substantially higher than the Australian national benchmark of 4.83. The highest-scoring domain, Practical and Experiential Knowledge (7.12), suggests that respondents feel relatively confident providing hands-on care, discussing death, and drawing on personal experiences to navigate end-of-life situations. In contrast, the lowest-scoring domain, Factual and Community Knowledge (5.20), points to potential gaps in understanding how to access or navigate health services, resources, and community support systems available in the ACT.

Together, these results provide a picture of strengths and areas for development within the ACT community. The insights gained will support CHN in shaping targeted initiatives, strengthening community capability, and guiding future planning to enhance death literacy across the region.