

# Barriers and Facilitators to Remaining in the Community for Younger People with Life-Limiting Conditions: Research Findings



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**Background:** Younger people (under 65yrs) with life-limiting conditions often prefer to stay in their homes and communities rather than moving into residential aged care. However, many frequently encounter barriers such as insufficient funding, limited access to services, and inadequate support from informal (unpaid) and formal (paid) carers. A study investigated the barriers and facilitators to remaining in the community.

**The Process:** A multi-phase mixed-methods study collaboration between Ability First Australia (AFA) and La Trobe University was conducted during 2022 and 2023. Case notes from 48 clients with life-limiting conditions, along with interviews with 15 clients and/or their informal carers, were analysed. Survey data from 57 healthcare providers and in-depth interviews with 19 of these providers were also analysed.

[For context, the data on next page, provides a snapshot description of the entire cohort of younger people with life limiting conditions supported by AFA during the research study period].

## What barriers do younger people and their informal carers experience?

### Care from Family and Friends

*"I was there every day and some nights I stayed, or I was there 10-11 hours a day to make sure my brother's needs were met.....I gave up my career. I gave up my job. Everything. I gave up everything to take care of my brother and I'm glad about that but that experience that I had at – I'll never get over it.* (Informal Carer ID01)

*"If you haven't got family, you need at least a good social support of some description. You need to be able to go out for lunch or something with friends. If you don't do that, you're just going to sit here and wallow."* (Client ID05)

### Paid In-Home Support

*"There is nothing available on weekends. It's nine to five, Monday to Friday."* (Informal Carer ID10)

*"In remote areas, there's just no way to get some of the services out there, and even if we do, it's infrequent and unreliable."* (Health Professional ID17)

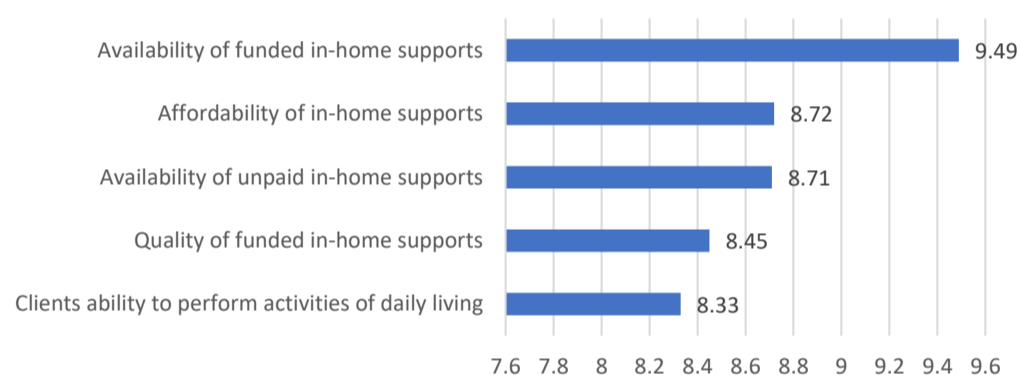
### System and Processes

*"...it was like I had to fight for everything that we got at the time. It was difficult because I didn't know the system very well."* (Informal Carer ID11)

*"...they have quite strict criteria on times, for really just end of life palliation and for people who have high medical needs; so they have difficult symptoms to manage. So that's the criteria for New South Wales Health to accept people into a palliative care unit..."* (Health Professional ID13)

## What were the most challenging barriers identified by health and social care survey participants?

Top 5 Barriers Identified by Care Providers



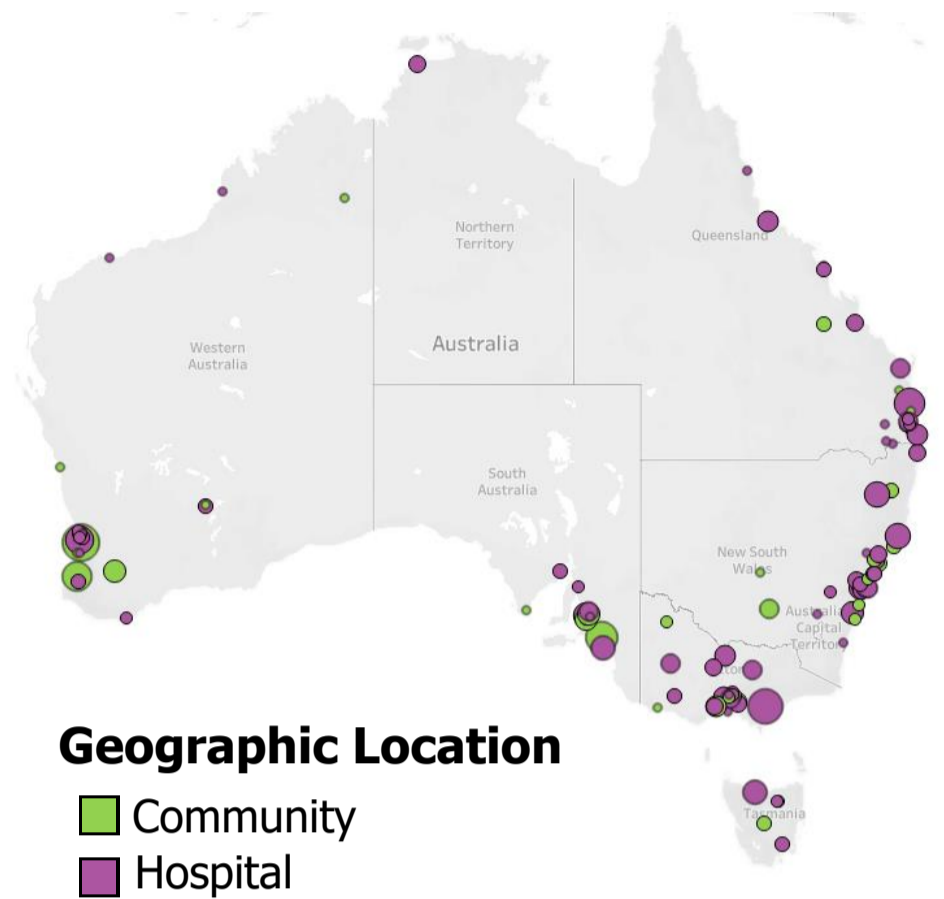
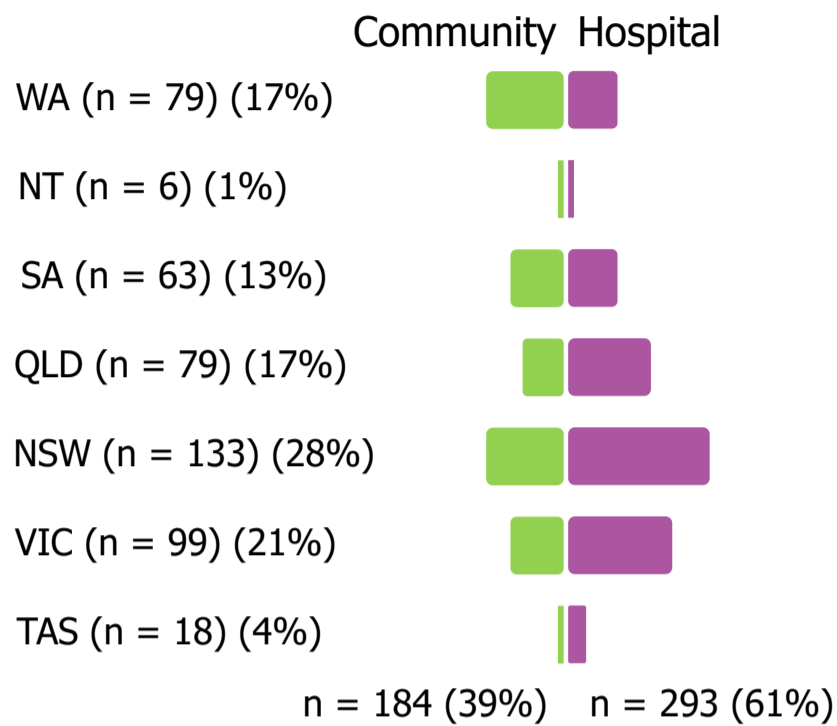
## What could help younger people with life-limiting conditions remain in the community?

**Funding and Support Programs and Reform:** The need for more robust funding mechanisms, consistent across States and Territories, to support younger people who fall outside the eligibility criteria for existing programs. This funding for non-clinical supports should be integrated into the broader health sector program.

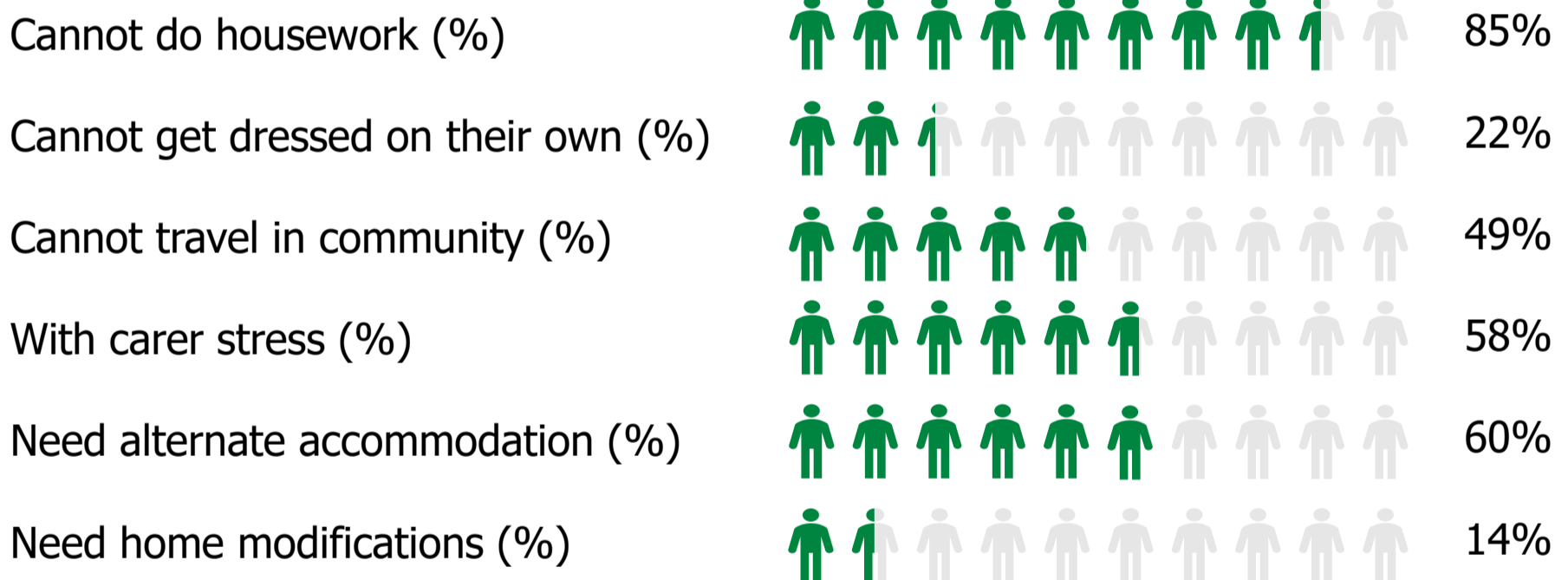
**Respite and Informal Carer Support:** Support systems for informal carers should address both practical needs and the psychological impact of caregiving, offering resources such as timely and flexible respite options and access to mental health services.

**Service Navigation Support:** A centralised and comprehensive database of services would benefit healthcare providers and community organisations, facilitating coordinated care and informed decision-making for clients and their carers. Consistent case management could streamline access to essential services, advocating for clients in navigating complex health care and support systems.

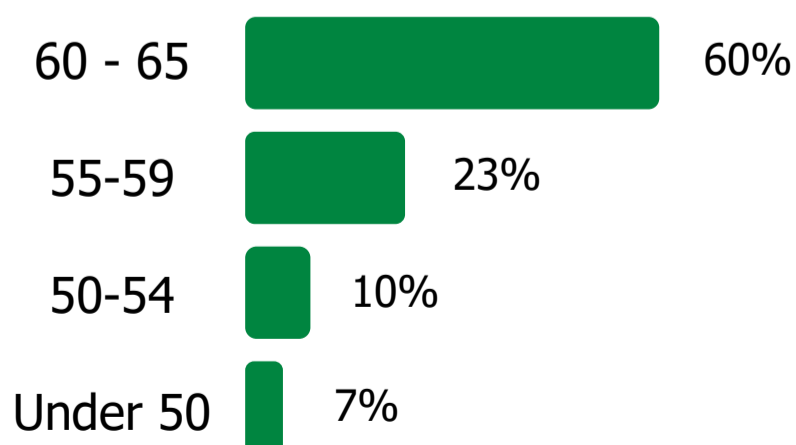
## Younger People At Risk of Accessing Aged Care Services (January 2022 - August 2023)



## Service Needs



## Age Distribution



## Australia-modified Karnofsky Performance Status

