

Submission: Senate Inquiry into Epilepsy in Australia

1. Overview

COTA Tasmania welcomes the Senate Inquiry into Epilepsy in Australia and supports its focus on diagnosis, treatment access, drug-resistant epilepsy, psychosocial and economic impacts, community awareness, support after diagnosis, the NDIS, research funding, and related matters.

The Inquiry's Terms of Reference include barriers to diagnosis and treatment, drug-resistant epilepsy and its psychosocial and economic impacts, community awareness, post-diagnosis support including the NDIS, Commonwealth research funding, and other related matters.

COTA Tasmania's submission focuses on older people. This includes:

- older people newly diagnosed with epilepsy;
- older people who have lived with epilepsy for many years;
- people whose epilepsy co-exists with other chronic conditions, cognitive impairment, disability, or frailty;
- older carers and family members;
- people living in residential aged care; and
- older people living in regional, rural, and isolated communities.

Epilepsy in later life can have significant consequences for independence, confidence, mobility, social connection, driving, employment, housing, caring relationships, and access to services. These impacts are particularly important in Tasmania because of the State's older age profile and regional distribution.

COTA Tasmania submits that epilepsy in older people should be recognised as a public health, aged-care, disability, primary care, workforce, transport, and community participation issue - not only as a specialist neurological condition.

2. Why this matters in Tasmania

Tasmania's demographic profile makes this Inquiry particularly relevant.

In the 2021 Census, Tasmania had a median age of 42 years, compared with the Australian median age of 38 years. Almost two-thirds of Tasmania's population lived outside Greater Hobart, meaning many people face additional barriers to specialist services, transport, and coordinated care.

The Tasmanian Government has recognised that Tasmania is ageing both structurally and numerically. Around 21 per cent of Tasmania's population was aged 65 years and over in 2023, and Tasmania continues to have the oldest population in the country.

This ageing profile matters because epilepsy is more common in older age than many people realise.

The Australian Institute of Health and Welfare (AIHW), the Australian Government's national agency for health and welfare data and reporting, shows that self-reported epilepsy was most prevalent in the 65+ age group, at 0.9 per cent, and notes that self-reported data may underestimate true prevalence.

AIHW data also indicates that around 70 per cent of people living with epilepsy can become seizure-free with anti-seizure medications, leaving around 30 per cent with drug-resistant epilepsy who may require other treatment and support options.

Hospital data also highlights the relevance of older age. AIHW reported that hospitalisations where epilepsy was recorded as either a principal or additional diagnosis were highest among people aged 85 and over.

For Tasmania, these facts point to a clear conclusion: any national response to epilepsy must include the needs of older people, and must be designed for jurisdictions with older, regional, and service-thin populations.

For older people, delayed diagnosis or poorly coordinated support can quickly affect independence, confidence, mobility, social connection and the ability to remain safely at home.

3. About COTA Tasmania

COTA Tasmania (Council on the Ageing Tasmania) is Tasmania's peak body representing older Tasmanians.

For more than 60 years, we have been a trusted voice for older people, promoting positive attitudes to ageing, advancing social inclusion, and championing the rights, interests, and value of people as they age.

Our vision is for a Tasmania where people are valued, respected, and supported to age well. Our mission is to improve outcomes for older Tasmanians through independent, evidence-based policy and advocacy, informed by the lived experience of older people and engagement with stakeholders across government, community services, industry, and the broader community.

Our values underpin everything we do.

- Older people first - we listen to older Tasmanians and place their voices, lived experience and priorities at the centre of our work.
- Respect and inclusion - we value diversity, challenge ageism, and support the right of all people to age with dignity, independence, and connection.
- Integrity and independence - we are trusted, accountable and evidence-based in our advocacy, partnerships, and public contribution.
- Collaboration and influence - we work constructively with governments, services, communities, and partner organisations to achieve practical and lasting change.
- Purposeful action - we focus on reforms that make a real difference in the everyday lives of older Tasmanians.

These values shape how we engage with older people, how we work with others, and how we contribute to policy, public debate, and community life.

We recognise that older Tasmanians are diverse in identity, background, health, culture, geography, life experience, and circumstance.

We are committed to ensuring that all older people are respected, included, and able to live with dignity, security, and opportunity in the communities they choose.

COTA Tasmania works across a wide range of issues affecting older people, including health and wellbeing, housing, transport, digital inclusion, ageism, elder abuse prevention, social connection, and the design of systems and services that support people to age well.

4. Summary of recommendations

COTA Tasmania recommends that the Committee:

- Explicitly recognise older people as a priority group in national epilepsy policy, including people newly diagnosed in later life and people ageing with longstanding epilepsy.
- Recommend improved awareness of epilepsy in later life among GPs, aged-care workers, home care providers, hospital staff, pharmacists, families, carers, and older people themselves.
- Recommend better diagnostic pathways for older people, recognising that seizures may be mistaken for falls, fainting, stroke, confusion, dementia symptoms, medication effects, or general frailty.
- Recommend improved access to neurologists and specialist epilepsy advice for older people in regional and rural Tasmania, including through supported telehealth and shared-care models.
- Recommend that epilepsy care for older people include medication review, falls prevention, driving and transport advice, social participation, carer support, mental health support, and practical safety planning.
- Recommend that aged-care services, including residential aged care and home care, be required and supported to develop epilepsy-aware care planning, seizure response protocols, and workforce training.
- Recommend that post-diagnosis supports be accessible to older people regardless of whether they are in the health, aged-care, or disability system.
- Recommend improved support for older carers and family members supporting someone with epilepsy.
- Recommend increased Commonwealth investment in research into epilepsy in later life, including diagnosis, treatment, polypharmacy, aged-care settings, psychosocial impacts, hospitalisation, carer impacts, and rural access.
- Recommend that community education campaigns challenge ageist assumptions and improve public understanding that epilepsy can emerge or continue in later life.

5. Response to the Terms of Reference

5.1 Barriers to diagnosis and access to appropriate treatment options

Older people can face particular barriers to diagnosis.

Epilepsy in later life may be under-recognised or misattributed to other causes.

Seizures may be mistaken for falls, fainting, transient confusion, medication side effects, stroke, dementia symptoms, cardiac events, or general frailty. This can delay diagnosis and appropriate treatment.

For older Tasmanians, barriers may be compounded by:

- regional and rural location;
- limited access to neurologists;
- transport barriers;
- cost of appointments and travel;
- digital barriers affecting telehealth access;
- reliance on carers or family members for appointments;
- co-existing conditions and polypharmacy; and
- fragmented communication between primary care, hospital care, aged care, and community services.

Tasmania's regional distribution makes this especially important.

Almost two-thirds of Tasmania's population lived outside Greater Hobart at the 2021 Census. Older people outside major centres may face longer travel times, fewer specialist options, higher costs, and greater difficulty coordinating care.

COTA Tasmania recommends that the Committee support models of care that improve timely diagnosis and treatment for older people, including:

- GP education on epilepsy in later life;
- better access to neurologist advice;
- supported telehealth, not telehealth-only models;
- shared care between specialists, GPs, pharmacists, aged-care providers, and community services;
- clearer referral pathways following suspected seizures, unexplained falls, or episodes of confusion; and
- accessible information for older people and carers.

Telehealth can improve access, but it must not be assumed to solve all access problems. Some older people need support to use digital systems, and many still require face-to-face care, assistance with transport, or help from a carer or support person.

5.2 Drug-resistant epilepsy and psychosocial and economic impacts

Drug-resistant epilepsy can have profound impacts for older people.

For older people, ongoing seizures can affect:

- safety at home;
- confidence to leave the house;
- driving and transport;
- ability to work or volunteer;
- social participation;
- mental health;
- housing decisions;

- relationships and family roles;
- need for formal or informal care; and
- entry into residential aged care.

The psychosocial consequences can be significant. Fear of seizures, fear of falling, embarrassment, stigma, and loss of confidence may reduce a person’s willingness to go out, participate in activities, use public transport, travel, volunteer or remain engaged in community life.

For some older people, epilepsy may interact with other conditions such as cognitive impairment, dementia, stroke, acquired brain injury, cardiovascular disease, frailty, depression, anxiety, or disability. This makes care more complex and increases the need for coordinated support.

COTA Tasmania emphasises that the impact of epilepsy should not be measured only by seizure frequency. For older people, the functional and psychosocial impacts may be just as important. A person may need help with safety planning, medication management, falls prevention, transport alternatives, home modifications, social connection, care coordination, or support for carers.

Economic impacts should also be understood broadly. Older people may leave work earlier than planned, reduce hours, stop volunteering, require more support from family, pay for transport, need home modifications, or enter aged care earlier than necessary. Families and carers may also experience lost income, increased stress, and reduced participation.

5.3 Community awareness and understanding of epilepsy and treatment options

Community awareness of epilepsy in later life is limited.

Many people associate epilepsy with childhood or young adulthood. There is less public understanding that epilepsy can begin in older age, or that older people may experience seizures in ways that are not always immediately recognised.

The Epilepsy Tasmania research document *Epilepsy: A Focus on Tasmania* noted that people can be diagnosed with epilepsy at any age and that one of the largest groups affected is people aged 65 years and older. It also highlighted the need for sufficient support for older people living at home or in residential care, and for better understanding among older people, families, carers, and aged-care staff.

COTA Tasmania recommends community education that:

- explains that epilepsy can occur or continue in later life;
- helps older people and families recognise possible seizure symptoms;
- addresses stigma and embarrassment;
- explains when to seek medical advice;
- supports carers and families to understand seizure management;
- improves understanding among aged-care and home care workers; and
- provides accessible information in plain English and appropriate formats.

Awareness campaigns should include older people and should avoid reinforcing stereotypes that confusion, falls or changes in behaviour are simply “normal ageing.”

5.4 Barriers to access support services after diagnosis, including the NDIS

Older people may face complex and confusing service pathways after diagnosis.

Depending on age, eligibility, disability status and care needs, a person may be expected to navigate:

- Medicare and specialist care;
- state hospital systems;
- primary care;
- community health;
- pharmacy services;
- My Aged Care;
- home care;
- residential aged care;
- the NDIS;
- transport assistance;
- carer supports; and
- mental health services.

These systems do not always work well together. Older people and families may be left to coordinate care themselves, even when seizures affect safety, independence, and confidence.

The NDIS is particularly complex for older people. People who acquire a disability after age 65 are generally directed to aged-care systems rather than the NDIS. This can create inequity where an older person's epilepsy creates significant functional impacts but their support is treated primarily as an aged-care issue or health issue rather than a disability-related support need.

COTA Tasmania does not suggest that all older people with epilepsy should need to enter the NDIS. Rather, we submit that no older person should be left without appropriate support because epilepsy falls between health, aged care, and disability systems.

Post-diagnosis pathways should include:

- accessible information about epilepsy in later life;
- seizure management plans;
- medication review and pharmacy support;
- falls and injury prevention;
- home safety assessment;
- transport and driving advice;
- mental health and social connection support;
- carer education;
- referral to community and peer supports; and
- aged-care service planning where relevant.

Aged-care providers should be supported to respond appropriately to epilepsy. Residential aged care and home care workers need practical training, clear seizure response protocols and access to clinical advice when needed.

5.5 Adequacy of Commonwealth funding for research into epilepsy

COTA Tasmania supports increased Commonwealth funding for epilepsy research, including research focused on older people.

Research priorities should include:

- epilepsy diagnosis in later life;
- distinguishing seizures from falls, syncope, stroke, delirium, dementia symptoms, and medication effects;
- treatment safety and effectiveness in older people;
- drug-resistant epilepsy in later life;
- polypharmacy and medication interactions;
- epilepsy and dementia;
- epilepsy and stroke;
- epilepsy in residential aged care;
- epilepsy in home care settings;
- rural and regional access to diagnosis and specialist care;
- carer impacts;
- psychosocial impacts and social isolation;
- hospitalisation and emergency department use among older people;
- culturally safe care for older Aboriginal Tasmanians; and
- accessible education for aged-care and community care workers.

COTA Tasmania also recommends research into Tasmanian-specific service pathways and outcomes. Tasmania's older age profile, dispersed population, and health workforce constraints make it an important jurisdiction for understanding how epilepsy care works outside large metropolitan centres.

5.6 Other related matters

5.6.1 *Epilepsy and aged care*

Epilepsy should be better recognised in aged-care policy and practice.

Older people living with epilepsy may receive Commonwealth-funded aged care at home or in residential settings. Care workers may be present when seizures occur, may be involved in medication support, or may be responsible for implementing care plans. Yet epilepsy training is not always embedded in aged-care workforce development.

COTA Tasmania recommends that aged-care quality and workforce systems include epilepsy awareness, seizure response, medication support, and escalation pathways.

5.6.2 *Transport, driving, and independence*

Driving restrictions can have major impacts on older people with epilepsy, particularly in Tasmania's regional communities where public transport may be limited.

Loss of licence or driving confidence can affect access to medical appointments, shopping, social activities, volunteering, caring responsibilities, and community participation.

COTA Tasmania recommends that epilepsy care include practical transport advice and referral to local transport supports where driving is restricted.

5.6.3 Carers and family members

Older carers may support partners, adult children, siblings, or friends with epilepsy. They may need information, respite, emotional support, emergency planning and recognition of their own health and wellbeing.

Family members and carers should be included in education and care planning where the person with epilepsy consents.

5.6.4 Ageism and diagnostic overshadowing

COTA Tasmania is concerned that ageist assumptions can affect diagnosis and care. Symptoms may be dismissed as “just ageing,” “confusion,” “falls,” “frailty” or “dementia,” rather than properly investigated.

National epilepsy policy should explicitly challenge ageism and support older people’s right to timely diagnosis, treatment, rehabilitation, support, and participation.

6. Conclusion

Epilepsy is a whole-of-life condition. For older people, it may emerge for the first time in later life, continue across decades, or interact with other health, disability, cognitive and social needs.

In Tasmania, the issue is particularly important because the State has the oldest population in the country, a high proportion of people living outside the capital city area, and significant regional access challenges.

COTA Tasmania encourages the Committee to ensure that older people are visible in its findings and recommendations. This includes older people living independently, people receiving home care, people in residential aged care, older carers, people in regional and rural communities, and older people whose epilepsy intersects with disability, dementia, stroke, acquired brain injury or other chronic conditions.

A national response to epilepsy must include older people. It must improve diagnosis, specialist access, post-diagnosis support, aged-care awareness, community understanding, carer support, and research into epilepsy in later life.

COTA Tasmania would welcome the opportunity to contribute further to the Inquiry or to any subsequent consultation on epilepsy policy, aged-care practice, community education, or support pathways for older people.