



Chronic Conditions Network

SUBMISSION

ACT Government: **ACT Budget 2026-27**

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Health Care Consumers' Association

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About HCCA and the Chronic Conditions Network

The **Health Care Consumers' Association (HCCA)** is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. For the past two years HCCA has funded and facilitated the **Chronic Conditions Network (CCN)**.

The CCN offers community-based health and advocacy organisations a place to come together and collaborate on issues of importance to them. HCCA facilitates in-person networking events as well as online key focus topics available to all CCN members. We provide support, connection and opportunities for member organisations to amplify their voices and have their vast experience supporting people in the community who live with chronic health conditions recognised.

This budget submission highlights that strategic investment in ACT's network of community-based organisations in the 2026-2027 budget will create future health savings, and better support people to manage their health conditions in their homes, reducing their reliance on the health care system.

Executive Summary

The Chronic Conditions Network, facilitated by HCCA, provides community-based health and advocacy organisations a place to work together, share resources, ideas, and collaborate with each other on issues of importance that affect Canberrans. Although the CCN organisations are diverse, there are many shared goals among them including:

- To support people living with chronic conditions, as well as their families and carers, to manage their health and live well at home and where possible reduce acute care presentations. This may include case management, home visits and support to access health and community services.
- To provide support for people living with health conditions through education programs and resources.
- Advocating for their members and communities. This may include individual advocacy, systemic advocacy, peer support programs, peer navigation services, or working with HCCA on broader health advocacy.

The overall focus of the CCN organisations is to reduce the need for acute health care services, by supporting people to manage their own health and utilise support and health care in a community setting. Investment in these organisations, and their on-the-ground community-based supports, leads to long-term health savings, and is aligned with one of HCCA's key priorities for the 2026-2027 Budget – to **support consumers to actively manage our own health**.

HCCA wants to see the 2026-27 ACT Budget address this priority by investing in the **community sector** to meet demand through community-based services. We want to facilitate the integration of the disparate elements of health care in the ACT, including public, private, and community-based services to enable people with chronic conditions to better manage their health outside the hospital system.

To improve the experience and outcomes of health care **for people living with chronic health conditions**, the Chronic Conditions Network seeks a response from the ACT Government to the following priorities:

1. *Support individual advocacy by funding a project to scope, pilot and evaluate a broad-eligibility consumer health advocacy service for the ACT to meet significant unmet community need. (Organisations Across the CCN)*
2. *Funding community-based Parkinson's specialist nurses that offer supports and services to the community for people living with Parkinson's Disease. Following on from an election promise from Minister Stephen-Smith. (The Hospital Research Foundation Group – Parkinson's ACT)*

3. *Invest in bi-lingual educators, community-based education campaigns and improved health system navigation to help reduce and potentially eliminate chronic conditions disproportionately affecting the multicultural community in Canberra. (Hepatitis ACT)*
4. *Funding CCN organisations to develop and/or expand their peer support and community education services to help consumers manage their/others health conditions well at home (Epilepsy ACT, Carers ACT, ATODA, Hepatitis ACT).*
5. *Provide better connectivity between ACT health services and community-based health services. (Organisations Across the CCN)*

Please do not hesitate to contact HCCA if you wish to discuss any of the issues or proposals raised in our submission further.

Introduction

HCCA supports the delivery of a health system that is accessible, accountable and sustainable. We believe that long term sustainability in the health care system is vested in connecting and integrating health care services with the many community-based supports offered in the ACT and surrounding regions by the organisations in our Chronic Conditions Network (CCN).

The CCN, facilitated by HCCA since May 2023, provides community-based health and advocacy organisations a place to work together, share resources, ideas, and collaborate with each other on issues of importance. Although the CCN organisations are diverse, there are many shared goals among them including:

- To support people living with chronic conditions, as well as their families and carers, to manage their health and live well at home. This includes case management, home visits and support to access health and community services.
- To provide support for people living with health conditions through education programs and resources.
- Advocating for their members and communities. This may include individual advocacy, systemic advocacy, peer support programs, peer navigation services, or working with HCCA on broader health advocacy.

The overall focus of the CCN organisations is to support people to manage their health better and more comfortably in the community setting. Investment in these organisations, and their on-the-ground community-based supports, leads to long-term health savings.

Details on CCN Priorities for ACT Government Spending

1. Organisations Across the CCN

Support individual advocacy by funding a project to scope, pilot and evaluate a broad-eligibility consumer health advocacy service for the ACT to meet significant unmet community need.

HCCA continues to call on the ACT Government to address the significant unmet community need for individual health advocacy by funding a project to scope, pilot and evaluate a broad-eligibility consumer health advocacy service for the ACT.

An individual health advocacy service would support consumers to stay safe in the health system, access the services that will address need, and fully participate in decisions about our own care and have our decisions and concerns acted on appropriately. This is a focus of the Australian Commission on Safety and Quality in Health Care's National Quality and Safety Health Service Standards¹ and other health care standards including the Royal Australian College of General Practice's Standards for General Practice.² Organisations and professionals that engage positively with an advocacy services of the kind proposed in this submission will be well-placed to demonstrate their achievements against accreditation and professional standards.³

From across the CCN we hear of services that offer individual advocacy and case management being inundated with consumer requests for help. Our partner organisations in the disability space report being in *“crisis from sustained pressure in our individual and systemic advocacy work”*⁴.

Community based health organisations are experiencing similar burn-out. An advocacy service with a broad eligibility could help consumers navigate access to the right care at the right time across the system. We see it providing invaluable support for parents of neurodiverse children navigating assessments, diagnosis and appropriate therapies. This sort of support will be essential in the transition to Thriving Kids as more families seek and access supports through the ACT health system.

¹ Australian Commission on Safety and Quality in Health Care, 2017, *National Quality and Safety Health Service Standards*, viewed 25 February 2022, <https://www.safetyandquality.gov.au/sites/default/files/migrated/National-Safety-and-Quality-Health-Service-Standards-second-edition.pdf>

² Royal Australian College of General Practitioners, *Standards for General Practice 5th edition*, viewed <https://www.racgp.org.au/running-a-practice/practice-standards/standards-5th-edition/standards-for-general-practices-5th-ed>

³ Australian Commission on Safety and Quality in Health Care, 2017, *National Quality and Safety Health Service Standards*, viewed 25 February 2022, <https://www.safetyandquality.gov.au/sites/default/files/migrated/National-Safety-and-Quality-Health-Service-Standards-second-edition.pdf>

⁴ Advocacy for Inclusion *et al*, 2025, 'Joint Submission - Shared investment priorities for the ACT Government Budget 2025-26'.

Timely, knowledgeable advocacy has the potential to improve health outcomes for someone who is encountering complex issues with their care and who does not have the advocacy skills and systemic knowledge needed to resolve those issues.

2. The Hospital Research Foundation Group – Parkinson's ACT

Funding community-based Parkinson's specialist nurses that offer supports and services to the community for people living with Parkinson's Disease. Following on from an election promise from Minister Stephen-Smith.

Data extrapolated from the 2019 Monash University study reveals approximately 3675 people live with Parkinson's disease in the ACT⁵. Parkinson's disease is more than just a movement disorder, it is a neurodegenerative condition with symptoms such as stiffness, tremor, pain, memory challenges, depression, sleep problems and social isolation. This disease impacts all aspects of people's lives, and to live well at home with Parkinson's disease requires specialised support.

The need for specialised support for people living with Parkinson's disease in the ACT was recognised in correspondence from Health Minister Rachel Stephen-Smith in October 2024:

"I am pleased to let you know that we are committing to the delivery of expanded movement disorder services including establishing a community-based Parkinson's Disease service for patients in the ACT through the Brindabella Day Service. A re-elected Labor Government will support an additional Advanced Practice Nurse position to facilitate integrated care for people living with Parkinson's".⁶

HCCA want to see through-to-completion extant commitments. Provision of this community-based specialist Parkinson's nurse will bring the ACT on par with the gold standard of community care offered in South Australia where four state government funded community specialist Parkinson's nurses operate in the community for a population of approximately 15,000 people with Parkinson's disease⁷.

A recent independent evaluation of this program in South Australia, undertaken by the University of South Australia, showed that for every \$1.00 invested in this program, the social returns were \$1.86. This means the program was paying for itself through an overall cost reduction from fewer hospital admissions for people with Parkinson's disease, and shorter lengths of stay in hospital due to better home supports. The program achieved other social and wellbeing benefits resulting from more effective and safer care for people at home.⁸

⁵ Ayton D, Ayton S, Barker AL, Bush AI, Warren N. Parkinson's disease prevalence and the association with rurality and agricultural determinants. *Parkinsonism and Related Disorders*, 2019 Apr;61:198-202.

⁶ Stephen-Smith, 2024, Personal Communication to The Hospital Research Foundation Group President.

⁷ Ayton D, Ayton S, Barker AL, Bush AI, Warren N. Parkinson's disease prevalence and the association with rurality and agricultural determinants. *Parkinsonism and Related Disorders*, 2019 Apr;61:198-202.

⁸ Jarvis, A, Mezzini, A, Forsythe, D, Eckert, M, Sharrad, S, Banerjee, R, Kumar, S & Sharplin, G 2025, Evaluation of the Parkinson's Nurse Specialists Service, Rosemary Bryant AO Research Centre, University of South Australia, Australia

The funding of this position aligns with both the ACT Government's Wellbeing Framework and the Canberra Health Services Exceptional Care Framework which aspire for Canberrans to “*access the services they need to lead healthier lives and manage illness*”, and that health services will “*make sure our consumers receive care when and where they need it, and by the right team members*”.^{9 10} We look forward to seeing this position in operation in the ACT to meet this important community need.

3. Hepatitis ACT

Invest in bi-lingual educators, community-based education campaigns and improved health system navigation to help reduce and potentially eliminate chronic conditions disproportionately affecting the multicultural community in Canberra.

Rates of chronic health conditions like Hepatitis B, type 2 diabetes, dementia, mental health conditions and asthma can be disproportionately higher in some multicultural communities in Canberra¹¹. The funding of culturally responsive care, bi-lingual or translated education facilitated and run by trusted community organisations in the community, would significantly reduce the prevalence and impact of some chronic health conditions in multicultural populations. If this was coupled with specific multicultural navigation services, also run through trusted community health organisations, multicultural communities that are vulnerable to specific chronic conditions would be better able to understand and access ACT health services. This would increase the uptake of earlier intervention and preventative care, improving health outcomes and reducing demand for expensive, acute healthcare.

HCCA support Hepatitis ACT in their bid to see more community education delivered in targeted languages to help the multicultural community access testing, vaccination, specialist referrals and treatment for Hepatitis, to avoid late-stage diagnosis and preventable mortality.

Bi-lingual education and information sessions done in the community, linked into a culturally responsive navigation system for multicultural community members to help them access screening, testing, treatments and support for living with chronic health conditions is the gold standard model. This type of integrated support service could have far reaching, positive implications for hepatitis and many other preventable chronic health conditions.

⁹ Australian Capital Territory, Chief Minister, Treasury and Economic Development Directorate 2020, *ACT wellbeing framework*, ACT Government, Canberra.

¹⁰ Canberra Health Services, 2024, *Exceptional Care Framework 2024–2029*, ACT Government, Canberra.

¹¹ Capital Health Network. (2024). Multicultural health needs assessment 2024. Capital Health Network. <https://www.chnact.org.au/wp-content/uploads/2025/02/FINAL-V2-2024-Multicultural-health-needs-assessment.pdf>

4. Epilepsy ACT, Carers ACT, Hepatitis ACT and ATODA

Funding CCN organisations to develop and/or expand their peer support and community education services to help consumers manage their/others health conditions well at home (Epilepsy ACT, Carers ACT, ATODA, Hepatitis ACT).

3.1 Epilepsy ACT

Epilepsy is one of the most common neurological conditions, and many individuals with epilepsy and their families and carers experience social isolation, stigma, mental health impacts, and difficulty navigating fragmented service systems.

Epilepsy affects approximately 1 in 25 Australians at some point in their lifetime. Community-based organisations report increasing demand for peer support and education services, particularly following diagnosis and during key transition points (school entry, adolescence, employment). In fact Schools and workplaces continue to seek epilepsy education and seizure first aid training to improve safety and inclusion. They need appropriate guidance from the health system.

Newly diagnosed people and their families/carers frequently report feeling isolated and unsure where to turn following diagnosis. There is currently no formalised or consistent referral pathway ensuring that individuals diagnosed in hospital or specialist settings are connected with community-based supports (more on this in Section 4).

Strengthening community supports reduces crisis presentations, improves self-management, and supports better long-term health and psychosocial outcomes.

HCCA supports Epilepsy ACT in seeking funding to strengthen and expand community-based epilepsy support across the ACT through three interconnected initiatives:

1. Expansion of Peer Support Programs

Increase access to facilitated peer support groups (in-person and online) for people living with epilepsy and their families and carers. Peer support for people living with epilepsy has shown to have emotional and instrumental benefits such as increased confidence, improved self-management and access to better information through shared experience.¹²

2. Expansion of Community Education and Training Programs:

Deliver increased epilepsy education in schools, workplaces and community

¹² Evett, D., Hutchinson, K., Bierbaum, M., Perikic, N., Proctor, C., Rapport, F., & Shih, P. (2021). Peer support and social network groups among people living with epilepsy: A scoping review. *Epilepsy & Behavior*, 124, 108381. <https://doi.org/10.1016/j.yebeh.2021.108381>

settings to improve seizure first aid knowledge, reduce stigma, and support inclusion.

3. Improved Connectivity Between ACT Health and Community-Based Services:

Develop structured referral pathways and collaborative models between Neurologists, Paediatricians, GPs and Epilepsy ACT to ensure people diagnosed with epilepsy are connected early to community-based support and self-management education. (More on this in Section 4).

These initiatives align with Epilepsy ACT's strategic objective to enhance person-centred, accessible, community-based supports for people living with epilepsy.

3.2 CCN Peer Support Initiatives

Carers' ACT also want to see investment in peer support to enable a sustainable Carer Peer workforce across the public health system to embed lived experience expertise and provide practical support to carers with navigation, discharge planning, education, risk identification, wellbeing, and recovery. Having a carer peer worker alongside unpaid caregivers can help support this often-overlooked group who provide foundational support for people living with chronic conditions. Caring for the carer provides emotional support, shared knowledge and experience, increased resilience and coping and therefore overall, a more stable support base to care for someone at home or in the community.^{13,14}

Carers' ACT want to see these roles supported by appropriate leadership, supervision, governance, and organisational structures in line with national lived experience workforce guidelines. HCCA support their request, as established evidence shows that peer support improves quality of life and empowers individuals, and their carers, to be active in managing chronic conditions^{15 16}.

ATODA also encourage the ACT Government to continue funding to support the ACT AOD peer workforce. This was a commitment made in the ACT Drug Strategy Action Plan 2022-26 and HCCA want to see fulfilment of extant commitments.

3.3 CCN Community Education Initiatives

Hepatitis ACT are seeking support to deliver education on Metabolic Dysfunction-Associated Steatotic Liver Disease (MDAST) – the 'silent epidemic' rising in the

¹³ Cui, S., Crowe-Cumella, H., Fortuna, K.L. & Jain, F.A., 2025. *A state-of-the-art narrative review of peer support for family caregivers of people with dementia: from in-person to digital delivery*. *mHealth*, 11, p.9.

¹⁴ Farhall, J., Cugnetto, M.L., Mathews, S., Ratcliff, K., Farnan, S., Higgins, K. & Constantine, E., 2020. *Outcomes and change processes of an established family education program for carers of adults diagnosed with a serious mental health condition*. *Psychological Medicine*, 50(7), pp.1099–1109

¹⁵ Evans, C., Daaleman, T., & Fisher, E. B. (2021). Peer support for chronic medical conditions. In L. S. Rotenstein & J. T. Hawkins (Eds.), *Peer Support in Medicine: A Quick Guide* (pp. 49–69). Springer.

https://doi.org/10.1007/978-3-030-58660-7_3

¹⁶ Harris and Chislett, 2018, 'How support groups can boost your health and make chronic conditions easier to live with', *The Conversation*, Victoria University ([How support groups can boost your health and make chronic conditions easier to live with](#)).

ACT. Steatotic liver disease is associated with obesity, diabetes and metabolic syndrome, and can be effectively managed if caught in the early ‘prevention window’. This disease currently affects one in three Australians¹⁷, and it is projected to be the leading cause of liver transplants in the next 20 years¹⁸. HCCA support Hepatitis ACT’s aims to raise awareness, encourage early detection and provide resources for better management of MSASL to reduce the burden on the healthcare system.

Hepatitis ACT seek to expand their self-paced digital education for detainees at the Andrew Machonachie Centre because correctional populations have disproportionately high hepatitis prevalence (8% for hepatitis C vs. <0.28% general population)¹⁹. Similarly, ATODA want to see increased availability of specialist AOD education programs in AMC to help improve the health and wellbeing of people in contact with the custodial system. HCCA support these proposals to reduce the documented gap in accessing healthcare for people in, and exiting prison, who are at risk of poor health outcomes²⁰.

This is aligned with the education and life-long learning domain listed in the ACT Government Wellbeing Framework which states *“Canberrans have equitable access to education and learning opportunities, through all ages and stages of life, to development gain the skills needed to live life well”*.²¹

Suggested funding for peer support and community education aligns with ACT Government priorities in the ACT Health Services Plan 2022–2030 relating to:

- Chronic disease prevention and management,
- Integrated, person-centred care,
- Strengthening community-based education and services,
- Reducing avoidable hospital presentations,
- Improving health equity and inclusion, and
- Supporting mental health and wellbeing for both consumers and carers.

Improving community education and peer support contributes to early intervention, health literacy, and safer, more inclusive environments across the ACT.

5. Organisations Across the CCN

Provide better connectivity between ACT health services and community-based health services.

¹⁷ Liver Foundation, 2025, *Fatty liver disease*, <https://liver.org.au/your-liver/liver-diseases/fatty-liver-disease/>

¹⁸ Adams, LA., Roberts, SK., Strasser, SI., Mahady, SE., Powell, E., Estes, C., Razavi, H. and George, J. 2020, ‘Nonalcoholic fatty liver disease burden: Australia, 2019–2030’, *Journal of Gastroenterology and Hepatology*, vol. 35, no. 9, pp. 1628–1635

¹⁹ National Prisons Hepatitis Network, 2025, ‘NPHN Surveillance Dashboard’, [NPHN Surveillance Dashboard | National Prisons Hepatitis Network](#)

²⁰ Capital Health Network 2022, *Capital Health Network (ACT PHN) 2021–2024 needs assessment*, Capital Health Network, Canberra.

²¹ Australian Capital Territory, Chief Minister, Treasury and Economic Development Directorate 2020, *ACT wellbeing framework*, ACT Government, Canberra.

There is currently no effective system for linking people on waiting lists or people discharging from hospital/outpatient clinics to community-based support organisations for their conditions.

This is a missed opportunity to:

- a) keep people better supported while they wait for health care services, potentially preventing acute deterioration and hospitalisation, and
- b) support people to manage their conditions at home, so there is less likelihood of them returning to the health care system.

Preventable hospitalisations cost the Australian Government \$7.7 billion dollars in 2023-24 and nearly half of preventable admissions were the result of chronic conditions.²² Linking people to community health supports and integrating care to prevent or lessen hospitalisations is an obvious choice to improve on health spending.

HCCA wants to see integration between the systems to better support Canberrans waiting for, or discharging from, our public health system. This could be achieved through:

- The creation of data sharing agreements between ACT Health and Community Services Directorate, Canberra Health Services and relevant Chronic Conditions Network Organisations. These agreements could optimise referral of consumers to relevant chronic condition organisations and community care services through DHR.
- Linking information on services and supports through chronic conditions organisations (i.e. peer support, community groups, health condition education, allied health supports and social groups) to after visit summaries and health documents available through MyDHR.

Effective access and linking of services across the health and community sectors is aligned with the ACT Government's Wellbeing Framework which seeks to improve access to health services, which states *“having access to health services where and when people need them has an important bearing on their sense of wellbeing”*. HCCA contend that better connectivity and referral pathways between public health and community health services will improve wellbeing, enable people to manage their health better at home and reduce emergency department presentations.

²² Australian Institute of Health and Welfare (AIHW) 2025, *Cost of potentially preventable hospitalisations in Australia, 2014–15 to 2023–24*, AIHW, Australian Government, viewed 27 February 2026, <https://www.aihw.gov.au/reports/health-welfare-expenditure/cost-pph-in-australia-2014-15-to-2023-24/contents/total-pph-spending>