



## Chronic Conditions Network

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### SUBMISSION

# ACT Government: ACT Budget 2025-26

February 2025

#### 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.

To this end, we have put together the below budget submission to show HCCA's support for the CCN members and highlight that strategic investment in this network of community-based organisations in the 2025-2026 budget will create future preventative 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. 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 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 2025-2026 Budget – to **support consumers to actively manage our own health**.

HCCA wants to see the 2025-26 ACT Budget address this priority by investing in the **community sector** to meet demand for community-based services. This includes connecting the disparate elements of health care in the ACT, i.e. public, private, and community-based services, so there is more integration, and people with chronic conditions can be better supported 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. Funding of community-based specialist Parkinson's nurses for people living with Parkinson's Disease. Following on from an election promise from Minister Stephen-Smith. (*The Hospital Research Foundation - Parkinson's ACT*).
2. Funding for Motor Neurone Disease NSW (MNDNSW) who currently support members across a very broad geographical range that includes the ACT as part of Southern NSW. Given that many people with MND use ACT health care services from this region, the availability of support and case management from MNDNSW needs to be bolstered. (*Motor Neurone Disease NSW*).

3. Better and more equitable access to Hepatitis B treatment through S100 prescribers. There are no bulk billing options available for this treatment in the ACT, and three of the five GPs who prescribe Hepatitis B treatment have their books closed to new patients (**Hepatitis ACT**).
4. Better and more equitable access to ADHD treatment through primary health S8 prescribers. This includes upskilling and authority for GPs to diagnose, manage and prescribe medication for ADHD. (**ADDACT**)
5. Better and more equitable access to the Pulmonary Rehabilitation Program run through CHS, for people living with lung disease. Currently the waitlist is 12months+ to access this program, yet it is lifechanging for people with lung disease and breathlessness. (**Canberra Lung Life Support Group**).
6. Support for more hydrotherapy services. Currently only 1 in 3 people can be offered hydrotherapy through Arthritis ACT and their waitlist is long. (**Arthritis ACT**).
7. Support for Allied Health services in the home for people who do not meet the NDIS diagnostic criteria yet have significantly reduced functional capacity due to chronic health conditions. There are no Allied Health services offered on an ongoing basis through CHS (**Arthritis ACT, ADDACT, MNDNSW and others**).
8. Funding CCN organisations to develop and/or expand their peer support and peer navigation services to help consumers manage their health conditions well at home (**QENDO, ADDACT, and others**).
9. Funding CCN organisations to develop and/or expand their community education and support programs to give consumers access to quality health information in a local community context (**QENDO, Hepatitis ACT, and others**).
10. Provide better connectivity between ACT health services and community-based health services so consumers on outpatient waitlists or discharging from hospital have health condition management options to pursue in the community, making them less likely to need increased/further acute care. (**Organisations Across the CCN**).
11. 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**).

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 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 reduce the need for acute health care services by supporting people to manage their health better and more comfortably in the community. 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 2025-2026 Budget – to **support consumers to actively manage our own health**.

HCCA and our CCN partners seek the delivery of a 2025-2026 ACT budget that meets significant and increasing demand for many health, hospital, and community services.

We know that there is significant pressure on our public health services. We consider that appropriate and strategic investment in the community sector can improve the efficiency of the ACT health system, provide a person-centred connected care pathway for people living with chronic conditions, and deliver long term savings. We are committed to exploring innovative ways to deliver care that meet consumers' needs and optimises resource use across our health system.

## Details on CCN Priorities for ACT Government Spending

### 1. *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 ACT<sup>1</sup>. 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 who said:

*"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".<sup>2</sup>*

HCCA believe it is important 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 disease<sup>3</sup>.

We look forward to seeing this position in operation in the ACT to meet this important community need.

### 2. *Motor Neurone Disease NSW (MNDNSW)*

***Funding for Motor Neurone Disease NSW (MNDNSW) who currently support members across a very broad geographical range that includes the ACT as part of Southern NSW. Given that many people with MND use ACT health***

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<sup>1</sup> 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.

<sup>2</sup> Stephen-Smith, 2024, Personal Communication to The Hospital Research Foundation Group President.

<sup>3</sup> 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.

***care services from this region, the availability of support and case management from MNDNSW needs to be bolstered.***

MNDNSW currently provides support for people diagnosed and living with MND in the ACT. This includes advocacy support, case management, home/hospital visits with patients and family members, transition support between home and health care settings, education for health practitioners, and running monthly support groups with community education focus topics. The geographical area covered by the MNDNSW community adviser ranges from the Southern Tablelands, down to Bega, up the South Coast and the ACT. Across this broad area, one MNDNSW advisor covers up to 50 members living with MND, and most people diagnosed with MND in this area will use health care services in the ACT (particularly neurology and rehabilitation services) at one time or another.

Like the community need identified by THRG – Parkinson’s ACT, this type of degenerative motor disease requires specialised support to live well at home, which often includes integration between hospital care, allied health supports, nursing and assistive technology across a number of funding platforms.

HCCA would like to see support from the ACT Government provided to MNDNSW to bolster their services in this region given that the majority of MND patients across southern NSW will use ACT Health services for acute, sub-acute and rehabilitation needs.

### **3. Hepatitis ACT**

***Better and more equitable access to Hepatitis B treatment through S100 prescribers. There are no bulk-billing options available for getting this treatment prescribed in the ACT, and three of the five accredited GPs who prescribe Hepatitis B treatment have their books closed to new patients.***

Currently in the ACT, there are only five medical practitioners who are accredited S100 prescribers for hepatitis B treatment. Barriers for GPs to become an S100 prescriber including finding the time required to complete the accreditation course and relevant continuing education, and clinical experience and knowledge in best practice management of Hepatitis B<sup>4</sup>. With GP shortages in Canberra there are many competing priorities for GPs, and the time and motivation to become an S100 prescriber needs further consideration.

Of the five S100 prescribers in Canberra, three have closed their books to new clients, while the other two do not provide bulk-billing services, creating financial barriers to access. This bottleneck significantly impacts equitable access to hepatitis

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<sup>4</sup> Xiao, Y., van Gemert, C., Howell, J. *et al.* A survey of knowledge, attitudes, barriers and support needs in providing hepatitis B care among GPs practising in Australia. *BMC Prim. Care* **23**, 137 (2022). <https://doi.org/10.1186/s12875-022-01754-3>

B treatment, particularly for low-income or vulnerable individuals. Hepatitis ACT is requesting funding to incentivise GPs to become S100 prescribers, which would alleviate unnecessary strain on the health care system, and improve access to care for patients with hepatitis B.

#### **4. ADDACT**

##### ***Better and more equitable access to Attention Deficit Hyperactivity Disorder (ADHD) treatment through primary health S8 prescribers.***

Currently in the ACT only paediatricians, psychiatrists and neurologists can prescribe schedule 8 medications for consumers with ADHD. There are long waitlists to see these specialists (both public and private) and the private fees can range from \$350-\$800 per session with limited rebates. This is after paying \$1500-\$4000 privately for a diagnosis or waiting 12months plus for Child Development Services through CHS.

ADDACT want to see additional incentives and training for GPs to become schedule 8 prescribers with more authorities in the management of ADHD. A significant body of work needs to be done to look at the role of GPs and primary health professionals in ADHD management, both pharmacologically and in terms of allied health supports (as will be described in item 7). The current model is not only financially prohibitive for consumers but also leaves people waiting for treatment while their symptoms are unmanaged, leading to increased physical health and mental health challenges.

The Royal Australian College of General Practitioners have welcomed the proposal of a model where GPs can diagnose, manage and prescribe medications in Western Australia, stating the move is a *'breakthrough for patients'*, with Vice President and WA Chair Dr Ramya Raman saying it is *'a welcome step forward'*<sup>5</sup>.

Although ADDACT acknowledges there is some provision for GPs to manage ADHD prescriptions when the treating psychiatrist or neurologist authorises this 'supervised care', GPs have no authority to make tweaks or changes to the treatment when circumstances change, and they also cannot substitute medications in cases where there are global shortages. For example, there is a current Extended-Release Methylphenidate medication called Teva/Concerta which is out of stock across Australia with the TGA reporting restocking may not occur until December 2025<sup>6</sup>. People with ADHD in the ACT who rely on Teva/Concerta are having to revisit their specialists (at a high cost) to switch medications to other long-acting substitutes and will have to do the same when stock becomes available again.

There are other significant problems with the treatment of ADHD in the ACT including when a child reaches the age of 16, they are no longer seen by a

<sup>5</sup> Burge, 2025, 'GPs to diagnose and prescribe for ADHD under a 'breakthrough' plan, *NewsGP*, (<https://www1.racgp.org.au/newsgp/clinical/gps-to-diagnose-and-prescribe-for-adhd-under-break>)

<sup>6</sup> Therapeutic Goods Administration, 2025 ([About the shortage of methylphenidate hydrochloride modified-release tablets | Therapeutic Goods Administration \(TGA\)](#))

paediatrician, yet psychiatrists and neurologists do not usually accept patients until they are 18 years old. There is a two-year service gap for young adults with ADHD during a significant life transition stage when many are completing year 11 and 12 education.

ADDACT and HCCA believe there needs to be an investigation undertaken in the ACT into the barriers and challenges to treating ADHD across specialists, primary health and allied health, in order to better understand and advocate for change in this model of care.

## **5. Canberra Lung Life Support Group**

### **Better and more equitable access to the Pulmonary Rehabilitation program run through CHS for people living with lung disease.**

A key issue for Canberra Lung Life Support Group members is access to the Pulmonary Rehabilitation exercise and education program for people with lung disease, run by the Canberra Health Service. For those who have had a chance to take part in the program it has been life changing. The pulmonary rehabilitation program has helped set attendees on the right path for life, by building an understanding of their condition, helping them to confront their fears, and building self-management skills to help people cope with breathlessness. A Canberra Lung Life Support Group representative says:

*“It's a real life-changer but access is incredibly limited. The program can only occur be accessed with referral from a specialist, and waiting lists are over a year”.*

HCCA and Canberra Lung Life Support Group would like to see increased availability of this program, and easier access given through referral from GP's. This program promotes self-management of this chronic conditions and equips people with the skills and education they need to limit their visits to acute care.

## **6. Arthritis ACT**

### **Support for more hydrotherapy services. Currently only 1 in 3 people can be offered hydrotherapy through Arthritis ACT and the waitlist is long.**

In Australia in 2022–23 the third highest category of health system spending by disease group was for musculoskeletal disorders, costing the Australian health system \$15.9 billion dollars<sup>7</sup>. The conditions within this disease group with the highest spending in 2022–23 were injuries from falls (\$5.1 billion), osteoarthritis (\$4.9 billion) and back pain and problems (\$3.9 billion)<sup>8</sup>. It is clear from these figures that arthritis and musculoskeletal conditions account for a significant portion of health

<sup>7</sup> Australian Institute of Health and Welfare (AIHW), 2024, [Health system spending on disease and injury in Australia 2022–23, Summary - Australian Institute of Health and Welfare](#)

<sup>8</sup> Australian Institute of Health and Welfare (AIHW), 2024, [Health system spending on disease and injury in Australia 2022–23, Summary - Australian Institute of Health and Welfare](#)

expenditure, and funding for preventative measures could provide significant savings long term.

Joint movement and exercise programs are comparatively low-cost, they are evidence-based and have proven to be one of the most effective management strategies for arthritis, which can delay or avoid expensive joint replacement surgery<sup>9</sup>. With Canberra's aging population, the demand for water-based exercise for arthritis and pain is increasing, however the availability of hydrotherapy has gone down.

While the building of a new hydrotherapy facility in Tuggeranong is welcome, it is not clear that this will address fully the level of need in the ACT. The appropriate spread of hydrotherapy facilities needs to look at other resources to determine if these can also be utilised to provide such services across all of Canberra.

Only 1 in 3 people who need hydrotherapy can be offered a place in the current program model run by Arthritis ACT. Therefore, we support Arthritis ACT in seeking funding to expand the hydrotherapy services offered. This is an important preventative health activity that improves the quality of life of people living with arthritis and pain.

#### **7. Arthritis ACT, MNDNSW, ADDACT, Canberra Lung Life Support Group and others**

***Support for accessible Allied Health services for people who do not meet the NDIS diagnostic criteria yet have significantly reduced functional capacity due to chronic health conditions. There are no Allied Health services offered on an ongoing basis through CHS.***

A significant issue created by the arrival of the NDIS was to open up a divide between people who have functional capacity challenges and need significant support as a result of chronic health conditions, and those who have similar challenges and support requirements but for a diagnosed disability. There is a large disparity in the affordability and availability of allied health services dependent on whether a person qualifies as an NDIS participant or not.

The average cost of private allied health appointments for people in Canberra can range from \$120-\$200/hour across the specialities, however many providers are influenced by the published NDIS rates (which are currently \$193.99 per hour for most allied health professions including physiotherapy, occupational therapy, speech therapy, podiatry, nutritionist and \$222.99 for psychology).

Private allied health sessions for people who do not qualify for NDIS can attract a Medicare rebate under a chronic disease management plan (CDMP) to make them more affordable. A rebate of \$60-\$80 is offered per session, however, to receive these rebates, a GP needs to create the CDMP plan (often at the cost of a double

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<sup>9</sup> Arthritis Australia, 2024 ([Microsoft Word - 20231218 2024 Arthritis Australia Pre-budget submission1](#))

GP appointment) and then the rebated sessions are capped at five per calendar year. The person is still required to pay the gap fee between the provider rate and the Medicare rebate. One allied health session per two-and-a-half months (on average), that may still cost the consumer up to \$100, is often too infrequent and too expensive in the context of managing chronic health conditions.

Arthritis Australia notes that “consumers face high out of pocket costs from the accumulated costs of care including general practice, specialist and allied health appointments, diagnostics and medicines”.<sup>10</sup>

Managing chronic health conditions well at home requires affordable and accessible allied health support and it is often financially prohibitive in the ACT for many people living with chronic conditions without any funded assistance, or a more comprehensive and appropriate rebate scheme.

This issue has been echoed across the CCN, with some specific examples listed below.

- Arthritis ACT is experiencing a significant demand for affordable allied health support services and programs for people who have chronic pain and/or decreased functional capacity in their daily lives due to arthritis but cannot access or afford private allied health programs, and do not qualify for NDIS.
- ADDACT, the Canberra and Queanbeyan ADHD Support Group experiences significant demand for advocacy and support around where to find appropriate and affordable diagnostic and allied health services for their members with ADHD. People with ADHD can experience significant emotional dysregulation and functional capacity loss in their daily lives, particularly in workplaces and school environments, which requires regular and accessible allied health support. However, as ADHD is classified as a health condition, rather than a disability, there is no eligibility under NDIS and most treatment options need to be fully funded privately, or face long wait times to access public health services.
- Canberra Lung Life Support Group report that the maintenance programme called ‘Lungs in Action’ recommended by the Lung Foundation for anyone who has completed the Pulmonary Rehabilitation Programme, is a great benefit for their members as a means of maintaining the physical benefits of their rehabilitation over the longer term. Currently there are only two providers listed in Canberra, and both are private physiotherapy companies that charge fees that are a financial barrier to members. In addition, there are only two classes offered in Canberra per week making this valuable program inaccessible.

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<sup>10</sup> Arthritis Australia, 2022 (<https://arthritisaustralia.com.au/wordpress/wp-content/uploads/2022/02/Arthritis-Australia-pre-budget-submission-2022.pdf>)

- Motor Neurone Disease when diagnosed under the age of 65 attracts NDIS support, however given this disease is diagnosed by elimination, and often takes years to receive the final diagnosis, the majority of people get diagnosed when they are over 65 years of age, which means their support requirements falls under the remit of aged care funding packages which are neither timely or resourced for people with significant disability owing to degenerative neurological and motor disease.

MND Australia notes:

*“Currently the maximum funding available through a Home Care Level 4 Package is \$53,268 per annum. In contrast, a report published by the NDIS, Participants with a neuro-degenerative condition in the NDIS (31 March 2021) reported the average annualised committed supports for the 2020-2021 financial year was \$242,000 for participants with MND.”<sup>11</sup>*

This highlights the disparity between NDIS versus other funded systems that support people with chronic conditions and shows that a vast chasm exists in accessibility and affordability of supports available for comparable levels of functional capacity loss under private health, Medicare and aged care systems.

HCCA and our CCN partners want to see investment in the CHS community care program to be provisioned appropriately to provide more allied health support in the community at low/no cost.

#### **8. QENDO, ADDACT, and others**

##### ***Funding CCN organisations to develop and/or expand their peer support and peer navigation services.***

Many of the CCN organisations offer peer support and peer navigation services to their members. Peer support is an evidence-based proven system which helps reduce social isolation, improves coping and self-management skills and ultimately leads to better and cheaper disease management for people with chronic conditions.

<sup>12</sup>.

CCN members seeking support to expand their peer support and peer navigation are described below.

- **QENDO** is a national charity that has been supporting people with endometriosis, adenomyosis, PCOS, and chronic pelvic pain since 1988. We

<sup>11</sup> MND Australia, 2023, ‘2023-24 Pre-Budget Submission ([https://www.mndaustralia.org.au/getattachment/1c1f8462-65ba-4fda-a128-ca61b0bb9a96/2023-24-Pre-Budget-Submission\\_MND-Australia.pdf?lang=en-AU](https://www.mndaustralia.org.au/getattachment/1c1f8462-65ba-4fda-a128-ca61b0bb9a96/2023-24-Pre-Budget-Submission_MND-Australia.pdf?lang=en-AU))

<sup>12</sup> 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](#)).

are the national free services and programs provider across every state and territory, fostering local communities to reduce isolation, improve health literacy, and advocate for better healthcare outcomes. Our ACT group has been active for several years and continues to be a key voice in local advocacy and support. QENDO is looking to expand the ACT-based “Peer Support and Advocacy Network”. They require additional funding to grow our peer-led groups, which will allow more frequent sessions to connect and support individuals, and their families, living with these chronic conditions. In addition, QENDO also want to expand their ‘Healthcare System Navigation Services’ by expanding their ACT volunteers’ capacity to assist those struggling to navigate referrals, appointments, and multidisciplinary care.

- **ADDACT** was previously funded for over 22 years in the ACT however this funding was discontinued when NDIS came in. There are no funded advocacy or peer support groups in the ACT for people with ADHD, and ADDACT relies on a small group of volunteers to provide these services on an ad-hoc/as need basis across the whole of the ACT. ADDACT currently supports 400+ members and is seeking funding to develop peer and advocacy services to fill this service gap and provide support for the growing needs of families and individuals with ADHD in our region.

#### 9. **QENDO, Hepatitis ACT, Haemochromatosis Australia and others**

##### ***Funding CCN organisations to develop and/or expand their community education and support programs.***

Many of the CCN organisations offer community education and information resources to their members aimed at prevention, improved health literacy and/or better management of their health conditions. This is aligned with the ACT Healthy Canberra Plan which sees “*empowering Canberrans with the knowledge, skills and attitudes to live well*” as a key aim, alongside “*prioritising early detection and intervention to reset pathways and minimise ongoing harm*” where health conditions have already started to occur<sup>13</sup>.

CCN members seeking support to expand their community education programs are described below.

- **QENDO** is seeking funding to deliver educational workshops aimed at improving health literacy, symptom management, and self-advocacy, especially for young people and newly diagnosed individuals in relation to endometriosis, adenomyosis, PCOS, and chronic pelvic pain.
- **Hepatitis ACT** is seeking support to deliver their ‘Liver Health Campaigns’. With liver diseases such as steatotic liver disease, liver cirrhosis and liver

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<sup>13</sup> ACT Health, 2020 ([Healthy-Canberra-ACT-Preventive-Health-Plan-2020-2025.pdf](#))

cancer on the rise, we are requesting funding for public awareness campaigns. Steatotic liver disease currently affects one in three Australians, and it is projected to be the leading cause of liver transplants in the next 20 years. We aim to raise awareness, encourage early detection and provide resources for better management of these diseases to reduce the burden on the healthcare system.

- **Haemochromatosis Australia** wants to see expanded knowledge and awareness that public hospitals around the country provide venesection services to those ineligible, or unable to access other services. ACT Health can assist by ensuring adequate resources at ACT public hospital hospitals to provide this crucial treatment. **HA**

HCCA actively promote timely and effective access to information and resources to strengthen health literacy for consumers in the ACT region and we support all opportunities granted to our CCN partners to do the same.

### **10. Organisations Across the CCN**

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

There is currently no good 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 and b) support people to manage their conditions at home so there is less likelihood of them returning to the health care system.

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

- Improving discharge planning by including referral information to CCN organisations and the community care services in discharge summaries (achieved through optimisation of DHR functionality), and
- Funded 'link workers' (similar to the NHS model in the UK) who link people on waitlists, and people discharging from the health services to community-based supports and services offered through CCN organisations.

### **11. 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 meet our needs, 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 Standards,<sup>14</sup> and other health care standards including the Royal Australian College of General Practice's Standards for General Practice.<sup>15</sup> Organisations and professionals that engage positively with an advocacy service of the kind proposed in this submission will be well-placed to demonstrate their achievements against accreditation and professional standards.<sup>16</sup>

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"*<sup>17</sup>.

Community based health organisations are experiencing similar burn-out and an advocacy support service like we are proposing with a broad eligibility could help parents of neurodiverse children navigate assessments, diagnosis and appropriate therapies or help someone with chronic pain to access allied health support in the community care program, whilst providing a warm-referral to the NDIS to understand what eligibility they may have for funding.

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.

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<sup>14</sup> 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>

<sup>15</sup> 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>

<sup>16</sup> 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>

<sup>17</sup> Advocacy for Inclusion *et al*, 2025, 'Joint Submission - Shared investment priorities for the ACT Government Budget 2025-26'.

## **Appendix A: What Our Partners in the Chronic Conditions Network Have to Say**

### **Haemochromatosis Australia (HA)**

HA is a small but mighty national organisation run by volunteers, with representation, support via Info Line and online information available across Australia. The Treasurer and an active consumer advocate are both members of the Chronic Conditions Network (CCN).

The CCN provides invaluable support to HA, providing local networking opportunities including with Capital PHN - keeping the Haemochromatosis HealthPathway up to date.

The Haemochromatosis Patient Registry is now open nationwide for people living with haemochromatosis to register with the Australian Haemochromatosis Registry

( <https://registry.haemochromatosis.org.au/i-have-haemochromatosis/> ).