



## Submission to the Mental Health Royal Commission: Neuropsychiatry Unit, Royal Melbourne Hospital

27<sup>th</sup> June 2019

### Neuropsychiatry Unit Overview

The Neuropsychiatry Unit (NPU) based at the Royal Melbourne Hospital (RMH) is a statewide service funded by DHS Mental Health Branch. NPU provides diagnostic and assessment services to people with complex co-morbid mental health, neurological and medical conditions. The NPU was first established in 1972 as the Neuropsychiatric Centre at Mont Park Hospital. It moved to the RMH in 1992 and has continued to provide a clinical neuropsychiatry service locally and nationally. The NPU is nationally and internationally unique in its ability to provide people with access to broad medical and allied health expertise. The NPU attracts interest from psychiatry and neurology trainees who have visited from every continent of the world to spend time observing our model of care and commenting on the need for such services in their own mental health system. The NPU looks after approximately 100 inpatients per year, and offers approximately 750 outpatient appointments per year, for those with young-onset dementia and other neurocognitive disorders, complex psychiatric disorders, organic psychiatric conditions, and runs a deep brain stimulation program for OCD (the first of its kind in Australia).

Inner West Area  
Mental Health Service –  
The Royal Melbourne  
Hospital

Neuropsychiatry Service  
Level 2  
John Cade Building  
The Royal Melbourne Hospital  
Grattan Street  
Parkville Vic 3052  
Tel 61 3 9342 8750  
Fax 61 3 9342 8483



Inner West Area Mental Health Service  
is a provider of services to  
The Royal Melbourne Hospital

[www.mh.org.au](http://www.mh.org.au)  
ABN 73 802 706 972

### What the NPU Does for Mental Health Patients in Victoria

The NPU sees **people (and families) who often fall through the service gaps**. This includes people with younger onset dementia, people with established mental health issues and neurological / medical comorbidity and people with neurological disorders who cannot access mental health services.

The majority of the people referred to NPU (70%) are in the care of mental health services or private psychiatrists and are referred due to the unique availability and access to expertise across clinical domains (neuropsychiatry, neurology, neurogenetics, neuropsychology, occupational therapy, social work, nursing and speech therapy) and investigational domains (MRI, PET, SPECT, lumbar puncture, prolonged video EEG, neurogenetics, metabolic testing).

For a large proportion of patients with mental health issues the logistics of accessing such services are prohibitive. The phenomenon of **diagnostic overshadowing** (attributing physical symptoms to mental illness), the stigma of mental illness and the fragmented nature of the medical health system means that people may not receive the care available to the rest of the population. The Neuropsychiatry Unit's ability to provide a 'one stop service' through inpatient admission and/or outpatient multidisciplinary assessment allows access to services that this vulnerable population would not otherwise receive.



## Y O U N G O N S E T D E M E N T I A



Effects approximately 6000-8000 Victorian's, with only a fraction of these receiving specialised care.

*"It was hard to convince the doctors that anything was wrong...due to their age"*



**5**



The average number of specialists seen preceding referral to the Neuropsychiatry Unit

These patients wait on average 3 years to receive a diagnosis

**3**



*"The journey is very long and traumatic"*

with mental illness and any co-morbid neurological (including intellectual disability, epilepsy, head injury) are outside their clinical expertise.

There are a number of disorders which are uncommon and difficult to diagnose and manage, that typically fall through service gaps, for which the NPU has specific expertise. One such condition is Young Onset Dementia (YOD), which is dementia with onset prior to the age of 65 years. This is a devastating illness, affecting predominantly people in middle age (though can be those in their 20s and 30s), resulting in wide ranging issues with financial stability, genetic burden and caring for young children, and a range of issues related to grief and loss. These patients under go diagnostic delays of up to 4-5 years (evidence consistent worldwide). When the average life expectancy in these conditions is between 6-8 years, patients have often lost employment, relationships as well as the opportunity to plan the last years of their life, before they may have even received a diagnosis.

There are also significant costs associated for patients and carers in accessing specialist services. Evidence from the literature suggests that for these less common neuropsychiatric disorders (YOD, Huntington's disease), that flexible, centralised specialist services are the gold standard care. The quality of life for these patients is significantly reduced. If a 5 year survival is presumed, the Quality Adjusted Life Years (QALYs, where 1 QALY is 1 year with perfect health and wellbeing) is

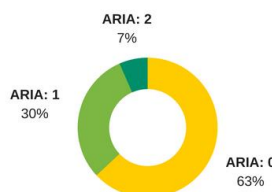


**751**

Outpatient appointments were offered to 350 unique patients in 2017-2018

Only 25 appointments were conducted via telehealth

**3%**



130 patients were from inner and outer regional areas, making up 276 outpatient appointments.

The average one way distance for these patients

**150-180km**

*"Young onset dementia is one of the cruelist things I have ever experienced, for the patient and their family members."*



only 2 years and 1 month (or QALY of 0.423 compared with 1).

Actuarial modelling conducted at the NPU suggests that that average cost for rural patients living more than 100km from our unit, when travel, accommodation and other productivity costs are considered, is \$633 per appointment. This doesn't take into account the costs of running the specialist service and considering the size of Victoria compared with other states, it is easy to imagine how much more problematic this may be in other parts of Australia. Given this, the NPU has developed a telehealth service to try and address this area of need. A 12-month project to undertake this has recently been funded by Better Care Victoria, but more needs to be done to ensure sustainability and provision of service. (Project plan attached as appendix for further information).

Other specific psychiatric disorders where patients fall through the cracks are functional neurological disorders (also known as conversion disorders) are those disorders which lead to neurological symptoms (blindness, weakness, sensory changes, walking disturbance, movement disorders, seizures) without associated neurological lesions. Patients with FND are now better managed within the neurological rehabilitation model but a small proportion continue to require specialist input from neuropsychiatric services. There is currently only [REDACTED] (at the [REDACTED]) with a [REDACTED]. There is a need to resource services for this patient group who have high levels of psychiatric, functional and psychosocial disability.

## The Lived Experience for People with YOD and their families.

The lived experience for people with Young Onset Dementia is often one of social isolation, grief, loss and disempowerment. [REDACTED], [REDACTED] is married to [REDACTED], who has Young Onset Alzheimer's disease. They live in a rural area [REDACTED] hour's drive from Melbourne. [REDACTED] was a highly respected school principal until his diagnosis and then was unable to work, due to cognitive and sensory changes. His wife [REDACTED] works full-time to support the family, as [REDACTED] is no longer able to contribute to the family income. They have supportive children, who have been affected by their Dad's diagnosis in different ways. [REDACTED] had difficulties obtaining an accurate diagnosis in a rural setting. Once he was eventually diagnosed with Alzheimer's disease, he was told 'there was nothing more that could be done, sort out your affairs and tick off your bucket list'. [REDACTED] and [REDACTED] walked into the appointment as a wife and husband, and left with labels of 'patient' and 'carer'. This negative diagnostic experience still stays with them to this day. [REDACTED] and [REDACTED] found out about the Neuropsychiatry Unit through informal networks and have been supported by Neuropsychiatry Unit since this time.

[REDACTED] continues to fall between service gaps, as he is too young for aged care services and unsuitable for mental health or disability services. Their family experience, along with numerous others has been that there is no clear pathway to access specialist services or care for people with Young Onset Dementia. There is a lack of appropriate services and those that exist are poorly funded and understaffed. Families often have to rely on the lived experience of others to navigate 'My Aged Care' and the National Disability Insurance Scheme system, at a time when their partner/family member has been diagnosed with a terminal illness and they are at their most vulnerable.



█████ has a National Disability Insurance Scheme package, which the government want to reduce, just as his care needs continue to increase. █████ is only able to work due to the support of National Disability Insurance Scheme funding. Due to the nature of his illness, █████ will continue to decline and he will require flexible care delivery over his lifespan (approximately 8-10 years). There are no support groups for people with Young Onset Dementia in his rural area or nearest regional centre (1.5 hours away). As he has a 'hidden' disability due to cognitive, psychological and behavioural changes (rather than a physical disability), support organisations, including the National Disability Insurance Scheme cannot understand or meet his various needs.

█████ and █████ have to justify █████'s request for services via a disability lense, which focuses on what he can no longer do, rather than his retained skills. Diagnostic and support services approach service provision through a disability and deficit model, rather than focusing on retained skills and 'living well with dementia'. This deficit model is demoralising for people living with dementia and has affected █████'s dignity and sense of self. It has also affected the way his family and friends view him, leading to greater isolation, loneliness and stigma and a reduction in his quality of life. █████ wants to be supported to live a productive and meaningful life, despite his terminal dementia diagnosis.

As dementia affects the entire family system, █████ and █████ expressed a need for counselling and support, inclusive of children, family and friends. As █████'s disease progresses, they face the challenge of finding appropriate residential care. Currently there are very few facilities that are suitable for younger people with dementia or other neurodegenerative conditions, with many having to be placed in nursing homes with limited ability to participate in appropriate recreational activities or be around people of their own age.

█████ and █████ expressed the need for greater community awareness and government support for those living with Young Onset Dementia, particularly in rural areas. Rural families are often unable to access centralised hospital services, due to distance, lost opportunity costs and how unsuitable hospital based care is for people with dementia that have cognitive, behavioural and sensory changes. People with dementia often find coming to hospital a frightening experience and become disorientated, agitated and confused. █████ and █████ endorsed the need for flexible and innovative service delivery, including telehealth assessment, follow-up and support services.

(The above information was obtained with consent from both █████ and █████).

## Why Specialist Neuropsychiatry Services Are Essential

Unfortunately, people have mental health, neurological and medical conditions simultaneously. They should not be denied mental health (or medical) services; our service system prefers to 'pigeon hole' people according to their diagnosis, and often determines that 'someone else can look after them". The NPU, through decades of input to the Victorian health system, has an established and renowned reputation not only within psychiatry but also within neurology and other medical specialities. The ability to span



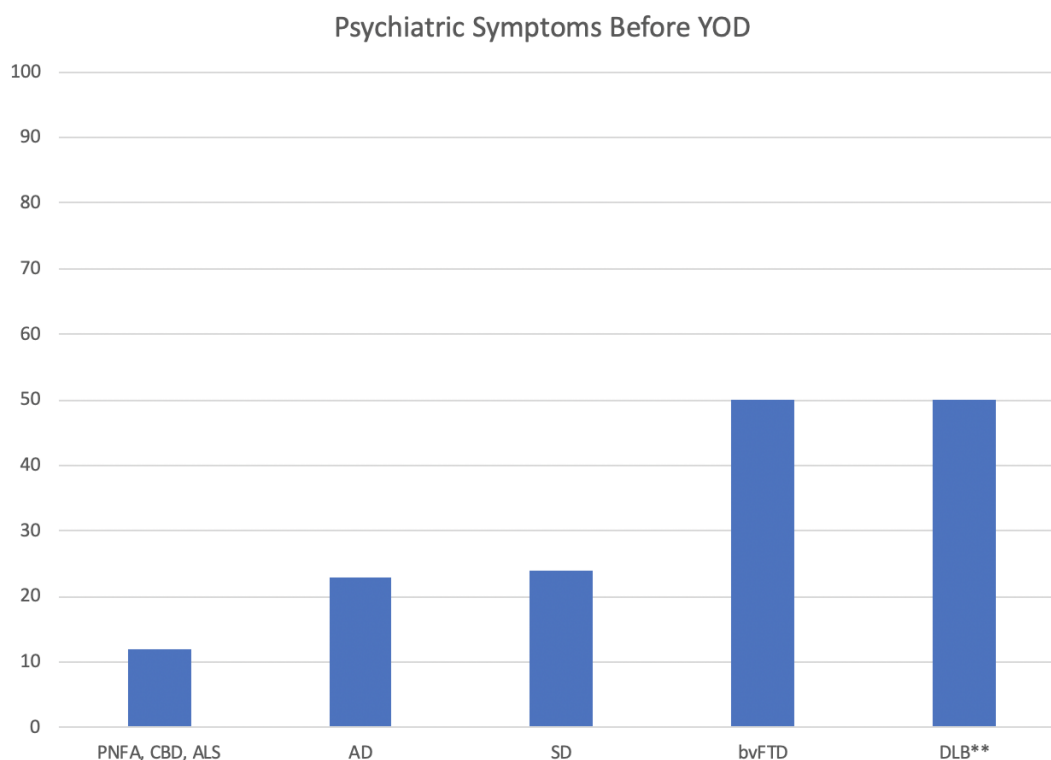
multiple medical specialities and to be acknowledged by other medical specialities reflects the holistic and multi- disciplinary model of care that the NPU has developed.

Patients with complex disorders such as Young Onset Dementia's (YOD), have heterogeneous presentations, and frequently present with psychiatric symptoms (*see Figure 3 below*), and are commonly misdiagnosed with a mental illness, or end up in acute inpatient units. The greatest strength of the NPU is in helping the diagnostic process for these people who may not otherwise access such services.

In contrast, our greatest fear is that we make a non-mental health diagnosis and that the referring mental health service then 'discharges' the patient from care because they no longer have a mental health issue. This is particularly the case with patients who we diagnose with a Young Onset Dementia. Our diagnosis should lead to better access to care and services, yet ironically it can lead to the termination of mental health care.

Neuropsychiatry services are expensive to run. The diagnostic needs of people with neuropsychiatric issues require the input of 'expensive' medical staff (neuropsychiatrists and neurologists). The assessments may involve expensive imaging or blood tests and result in the diagnosis of rare disorders unheard of by most mental health clinicians.

**Figure 3.** Percentage of patients with YOD presenting with psychiatric symptoms before diagnosis. bvFTD: behavioural variant frontotemporal dementia, DLB: dementia with lewy bodies, SD: semantic dementia, AD: Alzheimer's dementia, PNFA: progressive non-fluent aphasia, CBD: corticobasal degeneration, ALS: Amyotrophic Lateral Sclerosis.



The nature of the work undertaken by NPU is not such that generic mental health clinicians or psychiatrists can be 'trained up'. It is only through training and working *within* NPU that psychiatrists can learn about imaging, genetics, metabolic medicine, epilepsy and rare



disorders. We have trained psychiatrists who have gone on to work in all parts of Australia and have used the skills learnt in NPU for the benefit of people that the NPU would otherwise not have seen. Unfortunately, as of 2020 funding for two of our psychiatry training positions (sourced through the Commonwealth STP program) has been frustratingly terminated on the grounds that our service is based in a major teaching hospital.

## Limitations to the Current Service Model

The Neuropsychiatry Unit's ability to provide services is limited in that we are hospital based and without an appropriately funded community arm. We have recently been successful in obtaining a 12-month Better Care Victoria grant to provide telehealth services to Victorians and their families/ carers with Young Onset Dementia. This program must be self-sustained after the 12 month grant ends and is only available to people / families with Young Onset Dementia. Already this program has had great benefits for individuals with Young Onset Dementia, as well as treatment of behavioural disturbance and mental illness, reviewing metropolitan patients in inpatient units or community mental health teams who cannot attend the outpatient clinic due to psychiatric symptoms, mobility, social isolation, or cognitive impairment.

## Better Meeting the Neuropsychiatric Needs of Victorians in the Future

In addition to our current hospital-based services Neuropsychiatry could better meet the needs of Victorians through:

- Appropriate funding of our community/outpatient Neuropsychiatry service to allow assessments outside the Royal Melbourne Hospital
- Funding to provide follow-up care for people living with dementia and their families post-diagnosis. Families repeatedly request the need for continuous care from diagnosis to death with the one service, rather than the current highly fragmented service model.
- Provision of a 'YOD nurse' to provide smoother transition from inpatient to outpatient care, as well as transition to nursing home care for patients.
- Ongoing funding of the neuropsychiatry telehealth service
- Re-establishment of funding for the two STP training positions which allowed trainees from Australia and New Zealand to gain experience in Neuropsychiatry
- Funding for a clinical service for patients with functional neurological disorders/ movement disorders
- Funding of multidisciplinary neurostimulation services for psychiatric patients (i.e. OCD, Depression, Eating disorders).

## Appendices





**2. Younger onset dementia (Better Care Victoria)**  
Submission to BCV for telehealth funding