

Inquiry into the provision of primary, allied and private health care, aged care and NDIS care services and its impact on the Queensland public health system

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Submitter Comments:	

Committee Secretary
Health and Environment Committee
Parliament House
George Street
Brisbane QLD 4000

Dear Sir/Madam,

I wish to submit my personal view on the issues to be addressed by the Health and Environment Committee into:

1) *The provision of:*

- a. *Primary and Allied Health care;*
- b. *Aged and NDIS care;*
- c. *The private health care system;*

And any impacts the availability and accessibility of these services have on the Queensland public health system

2) *In conducting this inquiry, the Health and Environment Committee should consider:*

- a. *The current state of those services (outlined in 1) in Queensland;*
- b. *Bulkbilling policies, including the Commonwealth Government's Medicare rebate freeze;*
- c. *The Commonwealth Government's definition of the Commonwealth Distribution Priority Areas; and*
- d. *The availability of medical training places at Queensland universities, compared to other jurisdictions.*

I currently work for Queensland Health, in the Sunshine Coast, a region that covers Modified Monash Model MM1, 2, 3 and 5, spanning a metropolitan region (similar rating to a capital city) to small rural towns, with sparse service capacity. I have trained as a General Practitioner and have further specialised in Palliative Medicine. I have worked within the palliative care industry for nearly three decades, in three different states and territories, plus cared for remote Indigenous patients dying in their homelands.

My passion as a Palliative Medicine Specialist is providing quality end of life care, preferably in the place of choice, to terminally ill people. As a result of this professional experience, I have developed personal views regarding the impact of non-government and government service provision to this aim, particularly when caring for vulnerable people who do not confirm to expected social norms, that I wish to share with the Committee. In no way do these views represent the Sunshine Coast Hospital and Health Service (SCHHS) for whom I work.

I can make myself available to the Committee at any time, if any members would like to explore any aspects of my submission for further clarity.

1a. The provision and impact of primary and allied health care

In order to provide care for dying patients in an area encompassing the Gympie, Noosa and Sunshine Coast local government areas, inclusive of the Cooloola Coast, Sunshine Coast hinterland, Glass House Mountains and Caloundra region, I rely heavily on the support of community based primary and allied health care providers and services. This includes local General Practitioners, Community Nursing Services and Allied Health Providers. Developing relationships with and providing both in-working and after-hours support to this group improves the capacity for patients to stay out of the hospital system (referred place of care for many is within their own home), whilst still accessing high quality medical/nursing care and maintaining the personal independence of the person being attended to.

The quality of this care depends on the experience of the clinicians, the capacity and size of the engaged service and complexity of care needs.

On the Sunshine Coast, many GPs provide care for their terminally patients but cannot deliver after-hour support or home visits (please also see Medicare impacts at 2c). When care cannot be delivered, the responsibility then falls on to the service I work with, stretching our clinician capacity to cover the geographical expanse of the SCHHS. The Sunshine Coast Specialist Palliative Care Service has only two dedicated community-based palliative care medical practitioners and two nurse practitioners, to service a community population of over 430,000 people (with 21% over the age of 65 years).

Fortunately, the SCHHS has two specialised non-government home based palliative care nursing services that bookend the Coast, with a third service now becoming available to service part of the region. The two established services offer 24-hour contact support and can facilitate home visits anytime, if required, to support dying patients in the community. Cittamani Hospice Service covers the area from Caloundra to Landsborough in the south, Blackall Range (Montville to Flaxton) in the west and Peregrine to Yandina to the north. This is a small service that provides consultative care for terminally ill patients in the community. Referral criteria is strict due to limited staff capacity. Little Haven Palliative Care Service covers the Gympie Region, with a greater capacity and less strict referral criteria due to a larger workforce availability. Both services also provide allied health support and equipment to enable ongoing independence within the home environment.

I believe that both Little Haven and Cittamani services would increase service provision and geographical extent if increased state funding was available to support this. Silver Chain Nursing Service is increasing its service capacity within the SCHHS region and will soon be available to assist in caring for terminally ill patients in their homes, as they do in other states.

Apart from these dedicated palliative care nursing services, general nursing support for areas outside the above boundaries is supplied by non-government home based services, such as Anglicare South Queensland or Blue Care. The skill set of the nurses depends on their experience in palliative care and what level of training in this expertise is available within the organisation. Fortunately, several new non-government nursing services have been approved through the SCHHS tendering process (example is Silver Chain Nursing Service) to support community-based care in the region, which will help to ease some of the impact that shortages in the outlined services have on Queensland Health.

However, despite having community services available, during the last 24 months I have noticed increasing shortages in capacity to deliver the level of care required (if any at all). Reasons noted include:

- COVID-related impacts, such as better working conditions and pay rates for nurses working in COVID specific clinics (attracting nursing staff to leave current positions or not apply for vacancies within community nursing services), inability to work due to vaccination status, fear of contraction of infection and possible rapid spread within small services, leading to restrictions in acceptance of referrals for patient for home-care;
- cyber network attacks rendering services unable to take new referrals (e.g. Blue Care/Wesley Hospital);
- size constraints of service, with no capacity to employ increased staffing despite interest, due to limited funding opportunities/income sources;
- restrictions by select services to only support care provision within the home environment for patients with full time carers (carer cannot continue to work outside the home, even if patient is deemed fit to leave for extended periods of time unsupervised).

Ongoing care within the home environment, up to and including time of death, is not just dependent on the capacity of the primary care medical and nursing services. Provision of equipment, plus social/psychological support and dietary advice is fundamental to help families provide the care they want for their loved ones within the home environment. Each family that can care for their dying loved one at home saves the government significant amounts of money, freeing up bed capacity within the hospital (or dedicated palliative care units) for patients with needs too complex to support effectively within the community.

Issues faced in the community to deliver allied health support include access to the clinicians to provide a home-based assessment and support (such as Occupational Therapists and Physiotherapists to help patients maintain physical independence at home), speed at which equipment can be sourced to enable appropriately timed discharge from hospitals and the changing physical needs within the home due to progressive illness. Due to limited access to clinicians through GP management Plans and Team Care Arrangements (proscriptive number of reviews available per year), this compounds the access issues as patients' condition and needs change.

Extension of the Medical Aids Subsidy Scheme Palliative Care Equipment Program (MASS PCEP) has enabled timely provision of daily living and mobility aids, plus oxygen concentrators and incontinence aids, for patients in the last six months of life. However, access to this scheme within the community can be delayed due to paucity of non-government community based or government employed Occupational Therapists (OTs). This can either delay patient discharge from the hospital/palliative care ward setting or creates demand for admission, to enable support due to high dependency needs unable to be serviced without home delivered equipment, for an interim period. To avoid either of these options, I am aware that our palliative care service, on several occasions, has decided to temporary financially support the equipment shortfall (money meant to enable increase community nursing support in last three months of life), whilst awaiting MASS PCEP assessment eligibility and approval to facilitate care within the home environment.

Lack of funding for dedicated OTs when this scheme was rolled out, to provide the necessary MASS PCEP assessment within the patient's home, has meant that government-based community OTs have had significant increases in work demands, leading to competition with other service obligations that assist in hospital discharge or avoidance. I

have personally participated in meetings with OTs, within the SCHHS, to develop other mechanisms to decrease the impact on their current workload. A further gap in funding for staff (in dedicated government and non-government palliative care services) to cover the time taken to approve these funding applications (especially from other specialty areas caring for patients with a life limiting illness) and complete administrative aspects of equipment delivery, has led to increase work pressure within palliative care services.

Geographic determinants also play into the lack of access to OTs in the community for patients located in the regional areas of SCHHS. Even if an OT was placed within our dedicated palliative care service, travel times limits the number of patients that can be seen within a day. The service I work for would need a couple of part-time OTs that could be spread apart to cover each end of the district, to enable efficient use of funds and time to achieve timely access to MASS PCEP.

Prognosticating is becoming increasingly difficult, especially for patients undergoing novel therapeutic options (last ditch treatment efforts) for those with a terminal illness. The longer patients live with life limiting illnesses, the frailer they become, with increasing inability in maintain their independence due to disease progression, or treatment complications. Restrictions in availability to access MASS PCEP support only in the last 6 months, especially whilst still under the care of a specialised palliative care service due to complex symptoms or psycho-social determinants of health (that provide for patients in their last 12 months of life), has led to increased difficulties for families trying to provide care to an increasingly frail and dependent loved ones. Trying to either extend the MASS PCEP support or finding other means of supporting the cost of equipment increases unnecessarily the stress placed on family and service providers alike. MASS PCEP should be available for patients at least during the last 12 months of life. In my experience, the risk of abuse of this service is minimal and would provide comfort of security for patients and families alike, struggling to come to terms with the finality of a life limiting illness.

1b. The provision and impact of aged and NDIS care

Access to services and support under the NDIS has been a boon for a select group of patients with a life limiting illness. It has enabled patients with a life limiting neurodegenerative illness, such as Motor Neurone Disease, to live with enhanced dignity and independence, allowing them to live a fuller life than previously possible under earlier funding models. I applaud the steps governments (both state and federal) have made in this area of need.

However, as a Palliative Medicine Specialist, I find it increasingly frustrating that arbitrary decisions are made about who can claim significant disability and access support under NDIS, particularly for cancer diagnoses. I have supported the applications for several of my younger terminally ill patients (under 65 years), who have a prognosis of six months or more, with a close future of significant disability. I am aware of a couple rejected outright or had further onerous submission requirements placed on them, detailing every possible infirmity that could befall the patient in the very near future. The level of detail required to complete the application for a terminally ill patient is both time consuming and not in proportion to length of time the support will be required to maintain the individual in the community (less than twelve months). Finding funding for under 65-year-olds, at end of life, to support them in the home whilst they die, is problematic and limited. Easier access to NDIS would go a significant way in minimising hospitalisations of this age group to provide for ongoing care, especially for young families and isolated individuals with few familial or social supports.

Another frustration with NDIS is the age eligibility criteria. I can have two patients with the same cancer/neurodegenerative illness, similar disabilities and lack of social and independent financial support, but on either side of the age cut off. The under 65-year-old can apply for NDIS support (and may well be successful) whilst the over 65-year-old must apply and wait for an aged care package to become available. Disability should be based on dependency or infirmity, not on age of the client. NDIS should be available to **all** severely disabled Australians, irrespective of age and diagnosis. It should also not be based on prognosis, unless measured in weeks, when another funding source should be developed to support families and communities to support their loved ones at home, with options such as overnight carers (to address carer fatigue) and increased specialist nursing services to enable all individuals the possibility of dying in their preferred place of death, home.

I have noted that the quality of the NDIS packages is dependent on the provider accessed. As this funding opportunity is provided by "for profit services", significant administration costs (according to information provided by Social Workers involved in accessing care) are incurred by patients and their families, leading to less overall financial support to pay for services delivery. High administrative fees need to be monitored by government organisations that are responsible for the delivery of this scheme.

In terms of aged care, waiting for Level Four packages to become available in the community is very problematic. I have had many experiences where patients have died during the waiting period, even when highlighted by the Aged Care Assessment Team (ACAT) as needing urgent support. If a patient is dying, packages are needed immediately facilitate support in the home, not some months away (when a package becomes available due to the death of a stranger).

I have held patients within our dedicated palliative care ward for several days (though medically fit for discharge) whilst awaiting either for an ACAT assessment or for home service funding (usually at a lower support level than needed by the patient) to become available. This is an unnecessary expense for Queensland Health. Providing ongoing inpatient care due to inability to discharge home, as a result of no immediate community support packages, can prevent medically unstable patients from being transferred from other hospitals (ie Sunshine Coast University Hospital) to our dedicated unit for care, potentially adding to the bed blockage pressures that have been experienced on a regular basis in our health sector. The funding value of that extra hospital bed day could have been better utilised (and probably at a lesser cost) enabling the patient to return home with temporary service provision, whilst awaiting a funding package. The cost to state government of having a patient medically fit for discharge sitting in a hospital bed, due to shortage of federal community funding options, needs to be urgently addressed, so appropriately ill patients occupy hospital beds, not those awaiting ACAT funding to prevent failed discharge (and unnecessary readmission) due to lack of community support at home.

Another aspect of impact of aged care packages on QH services is that, previously, funding could be accrued whilst patients were in hospital and not using community services, allowing increased care access when needed on discharge. I believe that this may no longer be an option due to changes to ACAT arrangements. If true, this will have a significant impact on the paucity of funding available to keep terminally ill dependent people home, out of state-owned facilities or private residential options. If this is the case, urgent action needs to occur to address this previous option of accruing funds (be it only for short periods whilst temporarily not accessing home based services) to enhance capacity to stay within own residence for as long as possible.

1c. The provision and impact of the private health care system

Access to the private health system within the SCHHS for end of life is limited due to:

- a dearth of private doctors willing to provide the high-level care within the private hospitals needed to address complex symptom management (only two such specialists on the Sunshine Coast);
- several health funds do not cover end of life care, despite supporting palliative intent treatment by Medical Oncologists, etc ;
- the need for a holistic team approach to support a terminally ill patient and their loved ones, which may not be available within the private hospital facility (e.g., having availability to Social Workers to gain access to My Aged Care, Centrelink support etc);
- inflexibility in visiting hours and access (especially during COVID restrictions);
- poor monetary return for bulkbilling of services (to minimise financial cost to distress family members, especially if palliative care is not funded by private health care fund).

Katie Rose Cottage Hospice, (KRC) is a private three bed renovated house in Doonan, that provides end of life care to residents in the region. This unit is supported by private General Practitioners, who care for local terminally ill patients. The SCHHS provides support for this unit, through weekly multidisciplinary meetings discussing complex patient care and direct funding of nursing care and the cost of disposables for patients referred by the dedicated palliative care service within the health sector. Transfer from the SCHHS dedicated unit at Caloundra (Dove Unit), or other hospitals in the sector, directly to Katie Rose Cottage Hospice is actively encouraged where appropriate, to facilitate care closer to home for Noosa region residents. I believe that KRC is interested in providing a community home based service in the future that could improve the end-of-life care delivered in this region, if funding was available from the state government to help support this.

In terms of private specialist engagement, I personally work well with a General Physician that practices at Selangor Hospital (Nambour), who has specialised in palliative care, to enable access to private care for patients with appropriate cover. One of my SCHHS colleagues provides some out of hours support to the Sunshine Coast University Private Hospital but this is limited due to time constraints and commitment to servicing SCHHS patients primarily.

Apart from these two individuals, there are currently no other dedicated physicians primarily providing end of life care on the Coast. Other specialists, such as Medical Oncologists, do provide end of life care to their private patients, but will commonly refer to the government service, that I work for, to enable ongoing care in the community and access to specialist services (such as bereavement services).

I am aware that the provision of end-of-life care, during periods of heightened COVID restrictions, placed significant stressors on some of the private hospitals, with tight constraints on visitor access and length of time able to spend with dying loved one, impacting on care received by private patients.

The dedicated palliative care unit within the SCHHS fortunately has set up access to a vacant room at the end of the ward, with separate supervised outside access, that facilitated families (under COVID quarantine restrictions) to visit dying loved ones (whilst wearing full

Personal Equipment Protection). This is a luxury not available easily within the private health system.

2b. Consideration of bulkbilling, including the Commonwealth Governments Medicare rebate freeze.

The Medicare rebate freeze and the level of reimbursement for services provided to terminally ill patients has a significant impact on provision of end of life care, both within the community and in the private health system. GP remuneration for home visits does not cover the cost of service provision, nor the travel time taken to reach our more isolated patients on the Coast. This is similar for Specialists wishing to charge only the Medicare rebate to minimise the financial strain on patients and their families during the final phase of illness.

I believe that if Medicare rebates reflected the real cost of providing care, especially the time taken to have extensive family discussions (can take over one hour depending on the size and complex relationship dynamics of the family itself), then more clinicians would be able to have in-depth discussions that may lead to less presentations to hospital and more realistic expectations of what treatment should be pursued (depending on the disease presentation). Family meetings require discussion about the history of the illness (as many family members have not experienced the patient journey with their loved one), what symptoms and signs to expect, the level of care needed to be provided with supports available and how to prepare for the inevitable terminal event. Involved clinicians also need to provide emotional support during these meetings, which also takes time. Currently, Medicare Rebates do not recognise what it takes to have detailed end of life discussions. I believe that as a result, the conversations that lead to better treatment decisions regarding aggressive interventions at end of life, etc., do not happen, resulting in patients opting in inappropriate medical management of presenting symptoms and disease progress. Conversations regarding "not for resuscitation" and advanced care planning take time and clear explanations, not reimbursed properly under the current rebate model.

Medicare rebate levels can be vastly different (based on type of medical specialist delivering the service) for the exact same activity. Within the Palliative Medicine specialty, Medicare item numbers are different dependent on what nominals you have attained from the Royal Australian College of Physicians (FRACP versus FACHPM). For Palliative Medicine Specialists who have sat their "Part One Physician Exams" (FRACP) and completed the Palliative Medicine Specialty Training Program, the rebate for patient consults is different from a Palliative Medicine Specialist (FACHPM) who has completed the same training program, but joined through association with a different specialist college (eg Royal Australian College of General Practitioners). Both have undergone the exact same Palliative Care Training Program and provide the exact same care during the patient consult but get different Medicare Rebates depending on their previous training. This prohibits many Palliative Medicine Specialists (FACHPM) from offering private services to patients as a result of inequitable remuneration, thereby adding to the dearth of care available to patients with private medical cover. This non-sensical distinction within the Medicare Benefits Schedule needs to be addressed to allow increased private activity by Palliative Medicine Specialists, thereby taking some of the load of the public system.

Summary

I thank the Committee for holding an inquiry into the provision of primary, allied and private health care, aged care and NDIS care services and its impact on the Queensland public health system. I am grateful to the Committee for accepting my submission and considering the issues I have highlighted above, which I believe impact greatly on the capacity of QLD Health to provide for quality end of life care in a patient's preferred place of death, usually within the home environment.

If the Committee would like to explore any of my above concerns, I am very willing to make myself available to discuss further.

Yours sincerely,

M. Mitchell

Dr Maureen Mitchell

Palliative Medicine Specialist

BSc. MBBS. GCHPE, MPH, FRACGP, FACHPM

December 15, 2021

Contact Details

[Redacted contact details]

From: [REDACTED]
To: [Health and Environment Committee](#)
Subject: Inquiry into the Provision of Primary, Allied and Private Health Care, Aged Care and NDIs Care Services and Impact on the Queensland Public Health System
Date: Friday, 17 December 2021 1:02:09 PM

Dear Committee Secretary,

I submitted a submission to this Inquiry as a private individual who works within Queensland Health as a Palliative Care Specialist.

I would like to provide further information that highlights the issue of lack of capacity within the primary health care sector and its impact on patient care.

Today (17/12/21) the service in which I work has 739 active clients.

We have 5 terminally ill patients requiring urgent community based palliative care nursing services, for which we cannot access care to ensure their ongoing comfort and support outside of the hospital system. One of these is currently admitted to the Sunshine Coast University Hospital and cannot be discharged, due to no support available in community.

Currently, all private community nursing services on the Sunshine Coast have closed their books to new clients and will review their workloads again next week, to determine if they can take on new clients over the Christmas/New Year period.

The only private hospice on the Coast (Katie Rose Cottage) has closed for the festive season.

The Sunshine Coast Specialist Palliative Care Service is now developing contingency plans to use Qld Health staff to cover the shortfall, especially if the community nursing services book remain closed next week.

The urgency of enabling patients to remain at home to die is further impacted by COVID restrictions regarding unvaccinated visitors to Qld Health facilities as of this week.

Thank you for your indulgence in considering this email. The situation is becoming dire for the care of terminally ill Queenslanders and providing the right care in the right place at the right time.

Your sincerely,
Dr Maureen Mitchell
Palliative Medicine Specialist
[REDACTED]
[REDACTED]