

Submission 1b

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SERVICES COMMITTEE


Parliamentary Committee Inquiry into Palliative Care
Services and Home and Community Care Services in
Queensland.

Health and Community Services Committee
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Mater Health Services
Submission to the Inquiry
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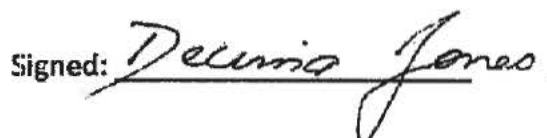
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We would like to forward our submission for consideration to the Health and Community Services Committee, as part of the inquiry into palliative care services and home and community care services in QLD.

The perspective from which we are submitting is based on our experience of providing a hospital based Specialist Palliative Care Service at Mater Health Services. We will provide an overview of our service to give an understanding of the service we are providing to patients, families, colleagues and community service providers.

We are members of the Palliative Care Clinical Sub-Network Group. They have submitted a thorough and comprehensive submission to your committee to which we have contributed and endorsed. We have not included in our submission, many of the points already covered in this group's submission, instead we have focused on our experiences working in an acute hospital environment and the challenges and barriers around admissions, discharge planning and collaborating with community services to provide continuity of care for our palliative care patients. We have included some innovative as well as some established ways of facilitating these processes that provides benefits for the patient and their family, and for the organisation.

Service Overview

- The Mater Palliative and Supportive Care Service is integrated into the Cancer Services Division of Mater Adult Hospital.
- It is staffed by 1.2 FTE Palliative Care Physicians, and 1 FTE Clinical Nurse Consultant. We share some additional nursing hours following the introduction of a Supportive Care nurse.
- We share junior medical staff with oncology for inpatients, along with a full complement of Allied Health Professionals, including Pastoral Care.
- We have significant Palliative Care Research interests

Inpatient Service

- Palliative Care patients are integrated into a 22 bed ward with Medical Oncology, Haematology and Radiation Oncology patients. There are no dedicated palliative care beds. Patients are admitted under the Palliative Care Consultant, though many are also cared for in a shared care model with Oncology teams.
- The Palliative care team consults on other patients under the medical, surgical teams, and gynae-oncology teams within the Adult and Mothers Hospital and Mater Private Hospital. We review patients in the Emergency Department, assisting with symptom management, family distress, end of life care and discharge planning for their palliative patients.
- In the previous 12 months, we have seen 300 new inpatients through these referral processes. We average 8 inpatients under our direct care.

- Patients are admitted for acute care symptom management, if they require hospice care, we refer them to St Vincent's Hospital at Kangaroo Point or to a local palliative care service. Many patients will deteriorate and die during their admission on our ward.

Outpatient Support Service

- Our service has 4 palliative care outpatient clinics each week. We are referred 150 new patients through the clinics, and saw 650 patients through these clinics in the last 12 months.
- The outpatients under our Palliative care service are supported with follow up phone calls for ongoing symptom management, emotional support for patients and carers, education around pain and symptom management, referrals to community service providers, facilitating admission if needed.
- Patients continue to attend clinic appointments while they remain ambulatory. When it becomes difficult to attend the clinic we refer them to a local palliative care service to provide home care support. This arrangement helps to relieve some pressure on local home care services, as we are referring the patients most in need of home visits.
- At any one time we are supporting 50-60 outpatients through clinics and phone call follow up.

Research Department

- We run an active research program with up to 12 clinical trials running at any one time
- The trials are funded through competitive grants, pharmaceutical companies and charitable donations
- We are the largest recruiter to palliative care trials in Australia
- We play a key role in both local (Centre for Palliative Care Research and Education) and national (Palliative Care Clinical Studies Collaborative, PaCCSC) research networks
- We have a number of local, national and international research collaborations
- It is supported by a research co-ordinator (1.0FTE), part-time research officers (1.0FTE) and data manager (0.1FTE)

Palliative Care Service to the Mater Private Hospital – Consultancy Approach

- We provide a consultancy service within the Mater Private Hospital and see an average of 4-6 patients there each day
- Palliative care patients with private cover are occasionally admitted to the MPH under the primary care of the palliative care consultants
- We have developed a multidisciplinary care structure for palliative care patients despite the fact that few of these services are paid for by private health funds
- There is dedicated palliative care nursing support (1.0FTE) for office hours only

Capacity and Future Needs

The Palliative and Supportive Care Service has continued to have a steady growth rate each year. In the previous 12 months, our outpatient workload has increased by 20% as compared to the previous 12 months and our new patient referrals have increased by a similar percentage. Despite the growing demands on our service, we have had minimal increase in funding for staff since 2004. Referrals to the oncology services are increasing annually and are likely to continue to increase as the population ages. As 90% of our service referrals are for patients with advanced cancer, we will continue to have increased demands on the need for Palliative care support. Over the past 8 years, we needed to find ways to continually meet the demands on our service, while maintaining the level of care and support that our patients require. During this time we had to discontinue home visits and instead make regular contact and follow up of patients by phone. We rely heavily on patients and families to contact us if symptoms are difficult to manage. We have ceased our palliative care on-call telephone support for after-hours advice-calls are now taken by ward nurses. This has led to an increase in admissions, especially after hours and at weekends. This demand can be reflected in admissions and length of stays, as complex discharge planning needs of inpatients, competes with the needs of the outpatients who are under our care. Increased nursing hours, would address both of these barriers. Despite our limited resources, we have continued to strive towards and reach the National benchmarks for Palliative Care, as evidenced by PCOC data collection (Palliative Care Outcomes Collaborative, a National quality program that measures activity across most Palliative Care services). These benchmarks are met in both our inpatient and outpatient settings.

Capacity and future needs for palliative care must take into account the increased complexity of patients that are being seen by Specialist Palliative Care Services. With the increase in treatment options available, especially for cancer patients, we are seeing a population of patients with chronic symptoms such as difficult pain, constipation, nausea, dyspnoea, fatigue, and lymphoedema, these symptoms require ongoing palliative care review in conjunction with their oncological treatments. We see patients who are living longer, with an increase in severity and complexity of symptoms that can be difficult to manage in an acute phase, outside of the hospital environment, e.g. recurring bowel obstructions, delirium, respiratory distress, pleural effusions and complex pain management.

There has also been a change in the availability of carers over the last decade. It is more difficult for full time carers in the home to support patients at the end of their life, impacting on the ability for patients to die at home. Many family members are in full time employment and the financial constraints around taking unpaid leave, can leave families with little options to care for loved ones at home. This can be especially true for patients with young children, with a partner needing to work to provide for the family. For the elderly patient, whose partner and/or carer is elderly too, a greater physical strain is often seen as the patient requires more complex care for daily living.

Research has shown that most people when asked where they would choose to die, chose home; but often the realities, around the complexity of their care and symptom control, and their need for carer support, make this a more difficult situation than they anticipate. Many patients are admitted to hospital, in the last days/weeks of life because it has become too difficult for families to manage their care at home. For patients with complex needs to be able to remain at home, they usually require a daily nursing visit, support from the GP, after hours support from a palliative care service,

and more than one family member in the caring role. The availability of respite care, especially overnight, has been identified as a key element to supporting patients to die at home. (1)

Collaboration between services is essential to providing continuity of care between hospital and home environments. This has proven difficult as there can be a disparity of definitions as to what a palliative care patient is, e.g. some services will not accept patients who are continuing on with palliative chemotherapy treatments. There are differences in what some districts will fund, with palliative care scripting money. (2) This can cause difficulties for patients who cross over several districts. Many services are not resourced to respond to a crisis or to the rapidly changing needs of patients. For palliative care patients, it is not infrequent for their condition to deteriorate rapidly. Without the ability to have a health assessment at home, carers feel like they have no choice but to call an ambulance and have their loved one admitted to hospital. These admissions are more frequently after hours and at weekends. Many palliative care admissions to the Emergency Department could have been avoided if excellent end of life services were available to the patient at home. Similarly, this could be said for many patients admitted from aged care facilities. (3, 4)

With regular follow up in clinics and by phone contact, as a team we are able to support and educate patients and carers, through a difficult problem or symptom, without the need for admission to hospital. At other times, when admission is unavoidable, we are often able to facilitate a direct admission to the ward, thus alleviating the need to present to the Emergency Department. This can be facilitated on weekdays through office hours. The nurses on our ward will take after hours calls from patients/ carers, and give advice, but generally direct patients to present to the Emergency Department. In these situations, the nurse will alert the Emergency Department that the patient will be presenting and give a handover of their condition and symptoms, to help ensure the patient's flow through the department is smooth.

With fewer GP's doing home visits, it can be difficult for patients who are bedbound at home to be reviewed. These patients' conditions change rapidly, and they often require changes to their medications. There is some reluctance for some GP's to provide scripts for patients without reviewing them, so it can mean that patients run out of medications and their symptoms become unable to be managed and they represent to hospital.

We see that the role of palliative care is to capture more patients during hospitalisation, prevent crises and rehospitalisation for manageable problems and to improve quality of life. Many patients with advance disease are readmitted frequently in an ever increasing tempo until a final terminal admission. If patient and carers are educated to manage symptoms, advised what to do and who to call if the patient was to deteriorate and given back up support, the fear and anxiety around a crisis time can be decreased. Preparing carers and families who are taking a patient home for end of life care is critical. Advising them on what to expect, how to administer medications, and how to care for the patient before and after death are important educational points that take time to talk through. For most of our palliative care patients, we arrange family meetings to discuss future care plans, prognosis, and the management of symptoms, advance planning, and availability of services as part of our discharge planning. Family meeting are attended by the family, and the multidisciplinary team, consisting of medical, nursing, social work, physio, OT, and other key personnel involved in the patients care during their admission. The feedback from these meeting is very positive, and keeps the focus on the patient and carer. We provide written information to

families outlining the care needs, and how to support them after discharge, with contact numbers where they can access help through their community service providers. Referrals to the community are completed prior to the discharge of the patient, and where the patient is being discharged home to die, a phone call is made to the patient's GP advising him/her of the patient's poor condition, and need for follow up medical support. (5, 6)

Carer Perspective

Some of the concerns of carers, who are providing physical, emotional and social support of their loved one are:

Financial strain on household budgets as the main carer often needs to work and care for the patient at the same time and find they aren't able to do both effectively. With a longer disease trajectory, the cost of equipment hire, medical supplies, extra washing, parking and transport to appointments, cost of medications, and the contribution to domiciliary nursing services all contribute to the financial strain on the family's ability to care for patients at home.(7, 8)

The emotional strain on the main carer and extended family is often built up over an extended period of time, with anticipatory grieving, and physical exhaustion contributing to the strain. Add to this, they often have to learn new skills regarding care provision e.g. administering medications, injections, changing stoma and catheter bags, turning, transferring and lifting patients, mouth and pressure area care, oxygen administration, and sometimes dressing changes. This can be overwhelming to carers and families under stress. If there is only one carer skilled to manage this care, it places the carer under pressure to never leave the patient.

Competing responsibilities and roles also have an impact, especially if they also need to care for young children in the setting of a partner who is dying. Other relationships within the family can be strained and commitments to other activities can be neglected, as the focus of care is commitment to the patient who is dying. Carers report a loss of self- identity during this time of caring for a loved one. (9) This can lead to social isolation, that can be attributed to society's decreasing social engagements in community, with less neighbourhood supports, family members scattered geographically, smaller families, and family and friends needing to work.

Respite services have limited flexibility to help carers maintain their social engagements that may be important to carers and provide emotional support. With no regular overnight respite available, the strain on carers to be on 24 hour call to attend to the caring needs of their loved one is almost impossible to maintain over any length of time. Though crisis respite is available through Commonwealth funding, this will not prevent carer strain.

Carers are under enormous pressure emotionally and physically, and often have their own health concerns. For some elderly carers providing physical care can be challenging and take its toll over time. Many put off their own health maintenance while in this caring role. (10)

Carers report that GP support can be difficult to access, especially for home visits, and after hours GP's are reluctant to intervene or order changes in treatment, and more likely to recommend hospitalisation. Palliative care services are rarely able to visit after hours or in a crisis, but the needs can and do change quickly.

Carers report that having a contact person for advice, support and education provides invaluable support. Carers find it difficult when they have to repeat a patient's story and problem to different people all the time. They are relieved when they call and speak to someone who knows the patient and his condition, providing reassurance and decreasing stress. (11)

Hospital Perspective

Difficulties around discharge planning for Palliative Care Patients

- Hospitals are reliant on prompt access to community services to see patients within a day or two of discharge home (especially for those patients going home to die).
- Difficulty with prognosticating life expectancy for access to palliative care and funding in the community.
- Inequities in what each district will fund for palliative care patients at home.
- District referral restrictions around palliative care - some services will not accept patients onto their program while they are still having treatments such as chemotherapy.
- There are few Hospices and they can be far from home. Some palliative care units have time restrictions around life expectancy and accepting transfers, due to the pressure on their beds. The other alternative is the ACAT process for residential care, but patients often deteriorate during this time and either not live long enough to be admitted to a facility, or die within a few weeks of getting to one.
- Maintaining a large Outpatient population (generally those who are still ambulatory) to minimise strain on community services.

Innovations and Processes in the Provision of Palliative Care Support in a Metropolitan Hospital.

The Mater has a strong Multidisciplinary team approach. This includes weekly case conferencing with Oncology and Haematology teams, a Multidisciplinary Action Group (MAG), Oncology Screening Tool and weekly meeting to link patients with the most appropriate resources. Patients with complex palliative care problems, difficult to manage symptoms, challenging care decisions, and family distress are identified and referred to our Specialist Palliative Care Service for ongoing management.

With a strong and dedicated Allied health team, there is the opportunity to facilitate a smooth discharge plan. This usually begins with assessments and is followed by a family meeting to discuss the patient's goals, condition and level of function and the amount of care the patient requires. The patient is central to this meeting, and is provided with the opportunity to openly discuss their concerns. Family members are encouraged to have their voice in the process. We are currently undertaking some research in the area of family meetings and carer support.

Mater Health Services centres its mission and values on providing holistic care to patients. In recognition of spiritual needs, pastoral care staff are employed to visit with patients. Importantly, spiritual care that is not based on religion, but on what gives meaning to a person's life. It can include some religious activities and engagement in rituals, if required, but the most significant benefit comes from having someone to listen to their life story, to visit and provide care and support that is removed from the medicalization of what is happening around them.

The Supportive Care nursing role was introduced 3 years ago, to fill an unmet need, and to bridge a gap, particularly where Oncology and Haematology patients need symptom management, home supports and facilitation of Palliative Care referrals. (12, 13) It is staffed by a full time Clinical Nurse with a strong Palliative Care background. This role has enhanced the quality of life of patients, the smooth transition to Palliative Care, and has heightened awareness of patient choices, particularly in Haematology. Those receiving active treatment can also enjoy the best supportive care, and are able to make choices about advanced care planning, and around treatment choices. (14)

The strength of our service is in the close integration with Oncology Services. A shared care model approach has ensured early referrals and provides patients and families with symptom management support, psychosocial support, and advanced care planning. This transitional care model benefits patients, as they don't feel abandoned by their Oncology team, when there are no more treatment options, as they have built up relationships with the Palliative Care team along their illness trajectory. Patients and families have had opportunities to discuss their future care and where they would like to be cared for, (home, hospice). Their carer has had time to be educated regarding the level of care needed at home. Patients are linked with community services, and have been given advice about EPOA, AHD, and the importance of wills. Patients can bring completion to things they may have put off, thinking they might have more time, or because they may not understand how unwell they may become quickly. With this advanced planning, avoiding the situation that sees patients admitted in a crisis, and told in the Emergency Department or soon after admission, that they are likely to die and no preparation has been done. Many times, this can be the referral situation that Palliative Care teams are asked to see. There is a great level of distress for the patient and their family, and they have little time to prepare. Many times, death is expected by the treating medical team, but this has not been properly communicated to the family, and so they see it as a shock. (15)

Having a network of strong community links to services is important as it enables us to provide continuity of care across from hospital to home or back to hospital or hospice if needed. The Palliative Care nursing role is paramount to this coordination. Communicating the patient's condition, their treatment, the urgency of a home visit, and the support the family needs are essential to the smooth transition of their care. Liaising with GP's, and informing them of changes in their patient's condition and medication, is an important role, especially as the patient deteriorates. The advantages of tele-health and funding for case conferencing would be both an educational tool and would provide support for many GP's who may not see many palliative care patients through their practice.

Palliative Care education and advice is needed in the hospital sector, and we participate in and deliver this education to generalist staff (medical, nursing, Allied health, students and Indigenous workers

- Within hospital environment
- Community service providers
- Through PEPA program

With an increase in funding we could provide a more systematic and regularly engage in the ongoing education of health workers. Education needs time and commitment, but most of our clinical time is absorbed in meeting the demand of responding to patient's needs. Little time is found to prepare and present educational talks to staff on a regular basis.

Finally, I believe our greatest resource comes from the dedication of our staff. The commitment to providing excellent palliative care to our patients and support to their families is what underpins the strength of our service. This, along with the depth and level of experience of the Palliative Care Clinicians and the network of support amongst the team, both within Cancer Services and within our colleagues in the broader community enhances our physical and emotional capacity to continue to meet the demands on our service and encourages us to move forward.

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