St Vincent's Brisbane

# PALLIATIVE CARE SERVICES AND HOME AND COMMUNITY CARE SERVICES INQUIRY

## ST VINCENT'S HOSPITAL BRISBANE

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## AUGUST 2012

**ST VINCENT'S HOSPITAL BRISBANE**

St Vincent's Hospital Brisbane (SVHB) formally known as Mount Olivet Hospital is a 164 bed hospital that has been providing Palliative Care Services and Aged Care Services to the people of South East Queensland since its inception in 1958. The hospital which is owned by St Vincent's Health & Aged Care Australia recently completed a major redevelopment of the Kangaroo Point site. It provides a unique mix of specialty services focusing on chronic illness and disease as follows;

1. Palliative Care to both public & private patients
    a. Adult
    b. Adolescent (as of Sept' 2012)
    c. Day Palliative Program
    d. Community Specialist Palliative Care Services
    e. Out patients services

2. Rehabilitation Services to both public & private patients
    a. Adult
    b. Adolescent (as of Sept' 2012)

3. General Medicine
    a. Acute Geriatric Medicine
        i. Geriatric Evaluation & Management programs
        ii. Geriatric Rehabilitation
        iii. Geriatrician consultation to Nursing Homes
        iv. Interim Aged Care
    b. Neurosciences
        i. Adult
        ii. Adolescents (as of Sept' 2012)
        iii. Sleep Apnoea/EEG services

4. Pain Management
    a. Adult
    b. Adolescent
    c. Currently developing plans for a "Pain Management Centre" including an operating theatre required for some procedures that assist in the management of chronic/persistent pain. SVHB has seven Specialist Pain Physicians practising at the hospital, including one for adolescents.

This introduction highlights the hospital's interest in this enquiry, where the provision of services to the chronically ill, frail elderly and palliative care are the specialty groups to which it caters for. As such, the following comments and details are intended to assist the enquiry into these services with a **focus on the clinical service provision.**

## 2. DEFINITIONS

### 2.1 Palliative Care

Palliative care is the active holistic care of patients with advanced (the last year of life) progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is to achieve the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

Palliative care aims to:

- Affirm life and regard dying as a normal process
- Provide relief from pain and other distressing symptoms
- Integrate the psychological and spiritual aspects of patient care
- Offer a support system to help patients live as actively as possible until they die
- Offer a support system to help the family cope during the patient's illness and in their own bereavement

### 2.2 Palliative care providers

Palliative care is provided by two distinct categories of health and social care professionals:

- **Generalist Palliative Care** is the term used for health professionals and carers providing the day-to-day care to patients and carers in their homes and in hospitals (GP's Community Nurses, Non-Palliative Care Specialists). They provide care to patients with low to medium complexity of palliative care need.
- **Specialist Palliative Care Teams** are those who **specialise in palliative care** (Doctors, nurses and allied health professionals trained or experienced in palliative care). They provide specialist palliative care to patients with medium to high complexity of palliative care need.

Generalist Palliative Care providers (day-to-day care) should be able to:

- Assess the care needs of each patient and their families across the domains of physical, psychological, social spiritual and information needs
- Meet those needs within the limits of their knowledge, skills, competence in palliative care
- Know when to seek advice from or refer to specialist palliative care services

### 2.3 Specialist Palliative Care Services

These services are provided by specialist multidisciplinary palliative care teams and should include:

- Assessment, advice and care for patients and families in all care settings, including hospitals, the patients home and Residential Aged Care Facilities.
- Specialist in-patient facilities (in Specialist palliative Care Units or hospitals) for patients who need symptom control or end of life care
- Intensive co-ordinated home support for patients with complex needs who wish to stay at home. This includes medical, nursing and allied health support.
- Twenty-four hour access to specialist palliative care advice (telephone or visiting)
- Day facilities that offer a range of opportunities for assessment and review of patients' needs

and enable the provision of physical, psychological and social interventions within a context of social interaction, support and friendship.
- Specialist advice and support to personal and professional carers involved in a patient's care.
- Pre and post bereavement support services which provide support for the people involved in a patient's care following the patient's death.
- Education and training in palliative care.

The specialist teams should include palliative medicine specialists and palliative care nurses together with a range of expertise provided by physiotherapists, occupational therapists, dieticians, pharmacists, social workers and those able to give spiritual and psychological support.

## 3. PALLIATIVE CARE IN QUEENSLAND

Palliative care services in Queensland are delivered by both government and nongovernment agencies and are funded either by the Queensland Government, the Federal Government via the National Palliative Care Program (PCP) and Private Health Insurance Providers. Palliative care is also provided using funding from the Home and Community Care (HACC) program, aged care packages, Department of Veteran's Affairs (DVA).

Research indicates that the majority of people would prefer to die at home, yet the data shows that 50-60% of Queenslanders die in hospital usually in an acute medical ward without access to specialist palliative care services. This can cause distress to patients, families and staff working within these units where they have insufficient knowledge and the specialized skills to effectively manage the patients and their families in an effective manner. This is due to:

- Lack of referral to specialist palliative care services
- Too few Community Specialist Palliative Care Services
- Inadequate or lack of referral back to General Practitioners
- Inadequate numbers of community services available to care for the dying at home
- Inadequate or lack of access to certain types of equipment (SIP Ventilators as one example, needed to enable muscular dystrophy patients in their homes)
- Inability of Residential Aged Care Facilities to manage palliative care patients
- Lack of understanding of Palliative Care within both the medical community and the community at large.

After attending accident and emergency departments or continuing to see other Medical Specialists for palliative interventions such as palliative chemotherapy (not the same as palliative care) in the last twelve months of life, many terminally ill Queenslanders become disconnected from their General Practitioner. This leads to a continued association with the acute hospital rather than a return to community care. Patients should be encouraged to see their GP as the first port of call rather than the hospital.

Ideally, if generalist doctors received additional training in end of life care and if they had access to a specialist palliative care service for advice when they required it, fewer patients would need to be admitted to acute hospital wards.

A small percentage of patients and their families will have such complex needs that all of their care will have to be provided by a specialist palliative care team. Much of this care and support could be provided at home or in residential aged care facilities if there was sufficient resourcing available.

**There is no overarching state-wide palliative care service delivery plan or strategy for Queensland, and as such there is no formal link to the National Palliative Care Strategy. Palliative care service delivery in Queensland is inequitable and very fragmented as a result.**

## 4. CRITICAL ISSUES WITH PALLIATIVE CARE IN QUEENSLAND

### 4.1 The generalist resources required to keep patients at home are not available

Patients that are most likely to be admitted for non acute reasons are those living alone or with an elderly carer. In order to keep these patients at home packages of care need to be available and tailored to each individual situation. While some care packages can be accessed there are too few available and many still provide insufficient support to prevent carer fatigue which results in hospital admission. An acute hospital admission is an expensive alternative and not the appropriate place of care for many patients.

Many patients do not qualify for care packages as their prognosis is uncertain. This particularly applies to patients with non-malignant diagnoses. In addition funding for palliative care at home is limited to the last 3 months of life (which is not easy to predict) and as a result some patients may receive funding too late and others may run out of funding and require admission to hospital.

Patients need support in a number of ways if they are to remain at home. They require social care for the activities of daily living, assessment by allied health professionals as well as medical and nursing support as required, by generalists. The crucial support required is out of hours but many community nursing services and most GP's (particularly Metropolitan) do not provide cover out of hours. A considerable number of GP's do not even provide home visits during the day. A review of remuneration for this work could provide an incentive to services to provide out of hours services.

### 4.2 Specialist Palliative Care support may not be available

Patients with low to moderate need can be kept at home with their carers but where the patient and family needs are more complex the generalists will need the support of specialist services. This support may be in the form of telephone advice or face to face consultations. Patients can be assessed or followed up in a number of Specialist Palliative Care settings such as Medical out-patients, day assessment programs or in their own home depending on how ambulant they are. However, specialist palliative care may not be available for a number of reasons:

- In rural and remote locations it may not be viable to have specialist staff and even where funding is available the shortage of appropriately trained or experienced staff makes recruitment difficult.
- Inadequate numbers of qualified Specialist Palliative Care Physicians available to meet the needs of the community.

- Lack of referral from other Medical Specialists which often leads to patients dying in environments without appropriate palliative care. Examples of this occurring on a regular basis in Queensland include those in RACFs, Dementia Units and in most acute medical surgical hospitals where referrals to Palliative care for non-malignant and incurable malignant diseases are often not sourced leading to patients dying in medical wards without the best possible care.
- Many RACF's do not have staff that are appropriately trained or qualified to care for the terminally ill. As a result, a number of elderly patients are transferred to an acute hospital when it would be in the patient's interest to be cared for in their place of home.

**4.3 Lack of Funding**

Palliative care services are poorly funded compared to other sub acute services.

Whilst the Government endeavors to provide appropriate services, the cost associated with home or hospital care for palliative care patients or the frail elderly often deters agencies from specializing in this area of medicine. Many private health insurance companies financially penalize hospitals with respect of length of stay and lack of funding to provide care for patients in their homes.

Specialist Palliative Care services need to include a 24 hour service to provide advice and support for health professionals, patients and families in the community, yet very few are funded.

Where psychosocial symptoms predominate patients can be kept in the community by providing counseling and social work input. Palliative Care is delivered by a multidisciplinary team because of the need to address not only the physical but also the psychological, social and spiritual needs of both the patient and family.

**4.4 A lack of knowledge and education/research in palliative care and the palliative approach**

Many health professionals caring for patients in the palliative part of their illness have had little or no training in this area. This includes General Practitioners, nurses (RN, EEN and AIN) and other hospital specialists, many of whom have difficulty managing patients with complex symptoms.

There is an urgent need for programs to "up skill" the existing workforce. In addition, palliative care education needs to be built into the undergraduate curriculum for medicine and other healthcare disciplines. Part of the role of the specialist palliative care workforce is to provide education to non-specialists however this is difficult given the demand on current specialists and their lack of time or funding to provide this service. Good clinical practice is underpinned by an evidence base but there is a dearth of funding for research in Queensland

**4.5 Poor coordination of services**

Quality care for patients requires recognition that the patient pathway is paramount. However, services tend to be defined according to service needs and budgets rather than patient needs. In an effort to reduce duplication of services, collaboration between both the public and private sectors needs to occur to maximize the capability of the service provision and the available funds.

Poor in-hospital discharge planning contributes enormously to the excessive length of stay in hospital for many patients. Discharge planning teams with the skills to access care from a number of sources in the community have been shown to reduce the length of hospital stay. However, community resources need to be available to support this. There needs to be a culture of discharge planning beginning at admission to enable patients to return to home where ever possible, as soon as possible with the right support when they get home.

In the community, planning across the various services is mandatory for the effectiveness of care for the patient. It is important that the nursing team & the GPs work closely to ensure that the patients and their family's needs are met and where other services are sourced in a timely manner. In addition, it is important for those in the community to have access to a Specialist Palliative Care service for advice, consultation or admission as required.

### 4.6 Lack of Research in Palliative Care For Queensland

Good Clinical Practice is underpinned by evidenced based research, which is lacking in Queensland. Further research is essential in this state to ensure that people receive good quality care in a timely and effective manner. SVHB is actively engaged with research with the University of Queensland and PaCCSC & is keen to participate in projects that will enhance the knowledge for palliative care in the future.

### 4.7 Lack of Paediatric Palliative Care Services across Queensland

Please refer to submission by Queensland Kids/Hummingbird House with respect of this issue which is a significant deficiency in the Healthcare landscape in Queensland. It is shameful that there is no service to support children or their families with a service that caters for their various and complex needs.

For this reason, St Vincent's Hospital Brisbane will be commencing a Palliative Care service to children/adolescents from 14 years - 18 years as of September 1, 2012 although this service will initially be only available for those with private health insurance.

St Vincent's Brisbane has also had discussions with Queensland Kids/Hummingbird House about the potential to develop a Paediatric service based at the Kangaroo Point Site. This discussion is recent, however further discussion relative to this need is anticipated in the near future.

## 5. CARE OF THE ELDERLY

As noted in the opening text, SVHB provides acute geriatric medical services, including geriatric evaluation, neurosciences and interim care. Caritas Care (Aged care Group owned and operated by St Vincent's Health & Aged Care) has seven Residential Aged Care facilities operating in Queensland. In addition, Caritas Care have a Community Team where they co-ordinate care within the community for the elderly living in their homes.

Over the last 12 months, SVHB & Caritas Care has worked closely to maximize the benefits of the links between the Aged Care Facilities and the hospital. One initiative that has been very successful has been the introduction of a Specialist Geriatrician visiting each of the sites to consult with patients, as well as providing advice, support & education to the visiting GPs and staff. The purpose of this initiative was to;

- Enable the frail elderly to remain in their place of residence yet be able to receive specialist medical attention without the need to travel.
- To enable all residents to have access to specialist care as deemed appropriate by the visiting GPs without the need for travel and to enable effective management of the individual healthcare needs to prevent any need for unnecessary hospital admission or crisis management.
- To provide both GPs and Staff with education and guidance with respect of those under their direct care.
- To refer to other specialist medical services as deemed appropriate.

This service has been welcomed by the Residents as well as the staff & GPs. Over time, as we continue to evaluate the effectiveness of the service, it is anticipated that the need to transfer residents to emergency departments will have reduced.

Further to this service, the hospital is now planning to introduce a "hospital in the nursing home" model of care beginning with the Caritas Care Facilities. In time, it is also anticipated that this service will be extended to "Common Ground" which is a recently opened facility in South Brisbane for the homeless. In this situation, SVHB will enable residents to access the Medical specialists on consultation either at "Common Ground" or at SVHB or through telemedicine.

In addition, it is anticipated that with one of the QLD Universities, a multidisciplinary teaching school will be established with a focus on the care of the aged utilizing the RACFs and SVHB as their base.

## 6. CRITICAL ISSUES RELATIVE TO THE FRAIL ELDERLY

**6.1** Staffing numbers and mix are insufficient to meet the needs of;

- **a.** Recognition of the deteriorating resident resulting in crisis management & admission to an acute care setting.
- **b.** Palliative care patients receiving poor pain management & clinical care in their last few days of life.
- **c.** Ill residents who should be able to stay in their residence are often transferred due to lack of knowledge and or skills to cope with a sick patient whose wishes & directives are to not be actively resuscitated. This is not enabling residents to have their choice recognized or considered.

**6.2** Lack of access to resources and linkages that are needed for patients living in RACFs.
**6.3** Too few Doctors to care for the elderly
**6.4** Lack of General Practitioners who are willing to provide 24 hour on-call services to RACFs
**6.5** The need for Medical Specialists to visit RACFs for consultation to enable the frail elderly to remain in their place of residence. For example, General Physicians, Geriatricians, Psych Geriatricians, Neurologists.
**6.6** Lack of appropriate linkage with the Acute Care facilities for advice & support.
**6.7** The need to "up skill" the current GP workforce in psycho-social aspects of aged care.
**6.8** Lack of palliative care services for the residents
**6.9** Lack of palliative care services for those residents suffering from dementia.

## 7. ST VINCENT'S HOSPITAL BRISBANE – PALLIATIVE CARE SERVICES

St Vincent's Hospital Brisbane has been providing high quality Palliative Care Services for people living with an advanced progressive illness for many years. Our Palliative Care Services include a 30 bed in-patient unit, Community Specialist Palliative Care Services, a Patient & Family Support Unit including Bereavement services as well as Out-Patient Services.

The hospital has recently expanded its services following the redevelopment of the hospital, and is planning further expansion in the next 12 months. As noted earlier, the hospital provides palliative care services for both public & private patients in a "state of art & purpose built facility overlooking the Brisbane River.

The Community Specialist Palliative Service provides multidisciplinary palliative care for patients, in a setting appropriate to their needs. Additionally, the Community Palliative Service provides a 24 hour phone service and when required a 24 hour in-home consultative service. The aim of this service is to provide;

- Care that enables each patient to live at home as actively as possible, with good symptom control
- Support to families during the patients illness and in their bereavement
- Support to other Health Care professionals in caring for their patients

The service assesses and treats patients with life limiting illness (malignant or non-malignant) with physical, psychological, social or spiritual problems. This includes patients who may still be undergoing treatment from their primary treating specialist or GP and with whom the hospital's team works co-operatively in the patient's best interest.

**Day Palliative Care Program** where the patient attends the hospital and their needs are assessed and managed by the most appropriate multidisciplinary team members. Patients are then either discharged from the program knowing that they can come back to the hospital at any time or join the Home Care program, or they are transferred to the home care service or other suitable community support programs.

**Outpatient clinics** at SVHB are provided by the Specialist Palliative Care Physicians who assess & monitor each patient individually in an effort to enable the patient to remain at home for as long as they wish. Patients can be referred, discharged and re-referred as their condition requires.

**Community Specialist Palliative Care Team Home Visits** are provided for patients who are no longer able to travel to appointments and who are in the later stages of their illness. These patients are visited by the multidisciplinary team in their home, where after the initial assessment a treatment plan is devised in consultation with the patient and their family or carer. The patient is then reviewed on a regular basis by the team until they are stable. Once stable, they are reviewed as required and reassessed as their disease progresses or a problem arises. During the financial year, 2011 – 2012 this service provided 16,468 occasions of service to patients admitted into care in this program. Between 50-70% of patients admitted into this program are now dying peacefully in their home which is much higher than the Victorian state average of 25%. On an average, there are 130-150 patients under SVHB Community Palliative Home Care Services.

**Inpatient Specialist Palliative Care Unit** comprises a 30 bed unit where patients are admitted when their symptoms are difficult to control. It is our aim to maximize the patients' potential by treating reversible conditions and where possible return the patient to their home. For the financial year 2011-2012, the hospital provided for 700 episodes of care for in patient palliative care.

It is the hospitals goal to implement **Telehealth & Telemedicine** services in the next 12 months to provide consultative palliative care services to patients who are unable to visit the specialist at the hospital.

## CONCLUSION

As noted in the text of this document, the intent of this submission was to provide information relative to the enquiry for Palliative Care & Home & Community Services in Queensland. Whilst SVHB provides a comprehensive range of palliative care services, the ability to expand at present is dependent on the private sector, yet it is apparent that there is still a great need within the community for more palliative care services.

Services at this hospital are all supported through the synergies gained from the specialty profile of the hospital each of which complement each other in so many ways. The Medical Specialists work with the hospital executive to enhance our capabilities and commitment to excellence as do each of the staff. Their input into this submission has been valued and in summary, the following key points highlight areas that are perceived to be deficient in the care of palliative patients, including the frail aged in Queensland.

1. Increased numbers of General Practitioners who are willing, educated & skilled in the care of palliative care patients in the community.
2. Improved palliative care support for those choosing to stay at home through their palliative journey, with capability of accessing services and or advice 24 hours per day.
3. Increased numbers of Palliative Care Specialists who are willing to work in rural & regional QLD, or prepared to work in telemedicine in conjunction with GPs in these areas.
4. Increased and ongoing education of General Practitioners in the community in the care of the Aged & Palliative Care patients.
5. Attraction & retention of good staff to work in both palliative care & aged care
6. Consideration be given to the funding of more:
    a. Palliative Care Services in the home & RACFs
    b. Specialist Services consulting in RACFs
    c. Increased education for Nurses working in RACFs to enable appropriate assessment and appropriate management of residents when they are unwell or dying.
    d. Improved discharge planning for all hospital admissions with appropriate referral to available community services.
7. Improved care of palliative care for dementia patients. This can be managed through consultation with specialist palliative care teams.
8. Improve access for telehealth & telemedicine for both palliative care & aged care services.
9. Develop Specialist Paediatric Palliative Care Services across QLD, including the ability to provide in home care for both patients and their families.

Finally, could consideration be given to the "breaking down" of the silo mentality between departments or organizations' where the patients' best interests are not necessarily at the forefront of decisions? With respect of public & private hospitals or aged care facilities, the emphasis should be on the provision of care and not who provides the care. Funding considerations should focus on the needs of the communities and the ability of organizations to fulfill the needs and where providers work together in achieving optimal patient outcomes.

Cheryle A Royle
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