

**PARLIAMENTARY COMMITTEE
HEALTH AND SERVICES COMMITTEE**

**Inquiry into palliative care services and home and
community care services in Queensland**

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Submitted by



37 Chermside Road

Eastern Heights Qld 4305

Phone: 3812 0063 Fax: 3812 0232

Contact: Ms Ros Holloway, Director Hospice Services

Executive Summary

Ipswich Hospice Care offers 24 hour a day, in-patient palliative care and bereavement support in a seven bed home-like facility for the Ipswich and the surrounding communities. We have been operating our service for over 18 years, and we believe the key to our high quality care is a strong working relationship with the local Ipswich Public Hospital, and being located within one kilometre from the two largest Hospitals in the area.

In this submission, we have discussed our two future areas of need, being concern for increasing labour costs in the palliative care area and providing services for complex admissions.

We discuss a number of innovative ways we believe the industry could consider to meet future and current needs in the Ipswich Health District. These are improvements in the communication of need for services throughout the District between the various providers and the suggestion of a review of the rationalization of resources and interventional treatments. We believe there is an urgent need to fully explore health policy development around the continuation of aggressive interventional treatment when a patient's situation is considered to be medically futile.

We also discuss a proposal for Ipswich Hospice to become the central point of palliative care co-ordination for the Health District and if Hospice was able to expand, the increased opportunity for us to care for patients for longer periods of time.

The future need for services, given the population forecast for the Ipswich area and increased longevity of Australians, is vast. On our current site in Eastern Heights, Hospice has the opportunity to increase our beds a further six clinical care rooms.

Barriers to effective palliative care focus around the industry's lack of funding and the need for an improved referral process from the referring Hospital or doctor to an in-patient palliative care facility.

We recognize that the vast majority of Australians, when asked where they would like to die, state they would like to die in their home. While consumers may prefer to die as home, the reality of this wish is that many obstacles prevent this from occurring, such as mobility issues, availability of carers and transport, management of complex symptoms, etc. We also recognize however that the home care has an important role to play in palliative care.

In terms of models of cost effective and quality service delivery, we believe Ipswich Hospice delivers both these criteria. We believe that by offering a 24 hour high quality palliative care service closely linked to a large Hospital, our service fills the gap that other service providers cannot, particularly with our ability to:

- Provider longer admissions required than an acute hospital;
- Provide care for patients who are not appropriate for an Aged Care Facility – either Care needs too high or not over 65 years of age or both;
- And, socio economic, family, substance abuse/ addiction, mental health issues and a variety of other reasons.

In addition to the high quality care, we can provide our services in a cost efficient manner.

Hospice generates a larger percentage of income every year from the community including through its enterprises, donations, fundraising and private health insurance.

This enables Ipswich Hospice to provide seven palliative care beds at \$660 per bed per day. Ipswich Hospital provides each bed at \$1100 per day (\$900 quoted by Palliative Care Queensland) and an Intensive Care Unit bed at \$4,000 per day.

We support the concept that greater involvement from the community based General Practitioners could facilitate an improved palliative service. We have discussed in our submission the influencing factors of why we believe GPs are not as involved in palliative care as we would like them to be, and offer comments regarding the importance of continuity of care and education in the palliative care specialty.

Introduction

The World Health Organisation describes palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

As the Queensland Health, Queensland Clinical Services Capability Framework¹ states palliative care is multidisciplinary care delivered by coordinated medical, nursing, allied health, pastoral care and social services. It integrates the physical, psychological, social, spiritual and cultural aspects of care.

Overview of Industry

o Australia

- o The number of Australian aged over 65 years is expected to increase by 50% over the next 10-15 years;
- o Over the next 40 years there is a projected fourfold increase of the population aged 85+ years;
- o International studies show that on average, providing palliative care in the last year of life has a cost saving of 30%; (*PCQ Fact Sheet – (15) RAND Corporation, 2008, The potential cost savings of greater use of hospital-and hospice-based end of life care in England, p37*)
- o 75% of people, who died in 2008/09 in Victoria, died in a healthcare facility (no stats available for Qld)².

o Queensland

- o Queensland and New South Wales are the only States in Australia that do not have a developed framework or State wide plan for the delivering palliative care services;
- o Ipswich Hospice Care is one of seven non-government palliative care services (receiving partial Government funding);
- o According to population modeling, Queensland requires more than 300 specialist palliative care beds. ²

o Ipswich and West Moreton District

- o Ipswich Hospice Care - 7 beds
- o Ipswich Hospital - 10 beds with further 3 beds to open by 2014
- o Laidley Hospital – 1 bed
- o Other Aged Care facilities

¹ Queensland Health, Queensland Clinical Services Capability Framework for Public and Licenced Private Health Facilities, Version 3.

² Palliative Care Queensland, Fact Sheet About Palliative Care in Queensland, February, 2012

○ Ipswich Hospice Care

Overview

- Ipswich Hospice opened in September 1994 offering home and respite care with patients being admitted to the Hospice to the six bed facility from 1995;
- From 1998 Ipswich Hospice has offered bereavement counselling and educational services;
- As demand for the bereavement services grew, Ipswich Hospice acquired the property adjacent to the existing building, and opened Hilda des Arts Community Centre in 2003 (now known as Hilda's House);
- In 2012 Ipswich Hospice expanded its beds to seven due to two successful grants;
- Services currently provided:
 - In-patient palliative care
 - Home Respite Service
 - Psychosocial support for patients and their families
 - Bereavement support for members of the community
- We employ 54 staff (18 full time equivalents) and supported by 270 volunteers;

In-Patient Palliative Care

- Located within one kilometer of two major hospitals in the Health District;
- We offer World Class standard of care: accredited by the Australia Council of Healthcare Standards (ACHS); participation in National Standards Assessment Program (NSAP) and Palliative Care Outcomes Collaboration (PCOC) in addition to holding a Private Hospital Licence and a contract with the Department of Veteran Affairs; Clinical Services Capability Framework (Queensland Health, 2011) Level 4 Palliative Care Service;
- Provide regular reporting to the Health Quality and Complaints Commission;
- On average we care for 80-90 patients per year;
- The average length of stay per patient is 19 days.

Patient Profile

- The average age of our patients is 73 years old, however 10% of our patients last year were aged between 20 to 49 years old;
- The vast majority of patients (92%) are admitted with a diagnosis of a malignancy;
- Over 70% of our patients are referred from the local Ipswich Hospital;
- Over 65% of our patients do not have Private Health Insurance or access to Department of Veteran Affairs funding;

- Many patients come to Hospice from a low socio-economic background, drug and alcohol abuse problems, dysfunctional family situation and no support system or means to care for themselves.

Based on patient data for January – June 2012:

- 95% of our patients pre admission were cared for by their family
- 95% of our patients were pensioners
- 21% lived in a rural area
- 50% did not have their own transport
- 57% of carers had medium to low availability to care for their loved one
- 50% of carers had medium to low physical ability to care for their loved one

Bereavement Support Services

- Hilda's House, an initiative of Ipswich Hospice Care, was opened in 1994, to provide bereavement support to terminally ill people, their families and members of the community. The service is largely run by specially trained volunteers, and provide one-on-one counseling and a variety of grief groups;
- Bereavement Support is a specialized area of expertise in the human services/counseling fields. Pre- and post- death bereavement support is a significant part of the Palliative Care Spectrum (Liverpool Care Pathway for the Dying Patient);
- Bereavement Support is also a Service Requirement in the Queensland Clinical Services Capability Framework, developed by Queensland Health, 2011;
- Over the past nine years, Hilda's House has seen significant growth in the number of community members accessing bereavement support as a result of the sudden, accidental or traumatic deaths of someone close to them;
- Hilda's House professionally facilitated peer support groups provide an opportunity to normalize the grief experience, build relationships of mutuality with others in a similar situation, to develop new skills and perceptions, and most significantly for many, to begin to articulate new ways of moving forward positively with their life;
- We offer World class children's bereavement support by the way of Kid's Grief Groups. This program runs over 7 weeks several times per year. Research by Dr Irwin Sandler et al, 2008, indicated that similar programs result in:
 - higher levels of self esteem in young people;
 - a decrease in externalizing of problems and challenges;
 - decreased prolonged grief related problems: e.g. intrusive and distressing grief thoughts, social detachment/insecurity.

Section 5. Capacity and future needs for palliative care and HACC services

5.1 Service Capacity

a) Current Capacity – Ipswich and West Moreton Health Services District

- **Ipswich**
 - Ipswich Hospice Care - 7 beds x 365 days of the year for inpatient care
 - Ipswich Hospital - 10 beds with further 3 beds to open by 2014
 - Laidley Hospital – 1 bed
 - Several Residential Aged Care facilities

- **Ipswich Hospice Care**

While 98% of all our patients at Ipswich Hospice Care have a diagnosis of a malignant illness, we have the capacity to care for non malignant chronic illnesses for both respite & end of life care for patients with chronic diseases, such as:-

- Motor Neurone Disease
- Muscular Dystrophy
- Chronic Obstructive Pulmonary Disease or other lung diseases
- Multiple Sclerosis
- Renal Failure
- Heart Failure
- HIV (AIDS)

We also have the capacity to provide Respite in the home for Carers. Ipswich Hospice Care has an established federally funded program - the National Respite Carers Program. This is a successful program in place supported by staff and volunteers who have been specially trained in respite, and we have the capacity for growth in this service

In addition, we have the capacity to care for patients of all ages and all special needs in a dignified and private manner, from adolescent upwards with:

- A peaceful physical setting on a acre gardens, fish ponds, memorial rose gardens with tranquil outdoor areas
- Single private rooms, with private ensuite and balcony, in a home like environment adapted to individual requirements
- Well equipped rooms with medical electric beds, pressure mattresses, nurse call system and medical equipment
- No restricted visiting hours

- Individualised meals freshly made
- Support people are invited to stay 24 hours
- Psychosocial support by experienced counsellor & social worker. Families supported through the Grief & Bereavement stages
- Families offered opportunity to be involved in the care
- Grief and Bereavement support services for after a loved one's death.
- High Staff and volunteer retention – including nine staff members wanting an increase to hours or to change employment status from casual to permanent.
- Clinical Placement provided to three Universities, two TAFE Colleges, two training institutes, Program of Experience in the Palliative Care Approach (PEPA) and Industry release training.

The current criteria for admission to Ipswich Hospice is as follows:

- Confirmed diagnosis of a life threatening condition/disease.
- Medically estimated prognosis of less than three months.
- No longer receiving active interventional treatment.
- No expectation of curative treatment and acceptance of a Not-for-cardiopulmonary resuscitation order.
- Consideration of facility limitations e.g. staff resources for manual handling & security.

The patient's condition is reviewed weekly. If there are no active signs of deterioration after six weeks of admission, alternative suitable places of care are explored.

If a patient is showing signs of active deterioration it is acceptable for patients to remain an inpatient for periods longer than 3 months.

b) Future Needs

Labour Costs

The biggest challenge for a health care facility of our size and structure is constant rising labour costs, primarily for our clinical nursing staff.

Nursing work force: Our initial recurrent funding from Queensland Health covered the vast majority of our 24 hour per day nursing costs. Our recurrent funding has not kept pace with the rapid increase in nursing wage costs. Our recurrent funding currently covers 61% of total nursing wages.

Due to the rapid increase in nursing wages from 2005 to 2008 by 16%, during the Beattie Government, Hospice has struggled to keep competitive in this labour market. Until 2009, Hospice kept pace with Queensland Health nursing rates, however this was not sustainable.

Hospice negotiated an Enterprise Bargaining Agreement in 2010 and now pays our nursing staff 9.6% under Queensland Health nursing pay rates;

Non-nursing work force: The impending Social and Community Services Award (SACS) increases will have a large impact on a number of staff employed by Ipswich Hospice Care.

Prudent financial management strategies are constantly deployed, seeking value for money, areas for cost cutting, and when required, decreased staff hours. Our large volunteer work force performs in almost every aspect of our service and provides a huge portion of our skilled labour.

Complex Admissions

Due to current funding limitations, we are unable to cater for all types of admissions. With additional funding for the appropriate equipment we would be able to care for Bariatric and Wandering patients.

1. Bariatric Care:-

We believe that we will see an increase in the demand for palliative care services for bariatric patients in the coming 5 to 10 years due to trends in overweight patients. There is currently a short fall in many non –hospital in-patient palliative care facilities & domiciliary nursing services to adequately care for these patients. This is due to the increased equipment, skills and staffing required to safely care for obese people.

2. Wandering Patients:-

Ipswich Hospice is limited to being able to manage confused and wandering patients, as it is not a locked, secure facility.

Availability of Oncology Services in the Ipswich and West Moreton Health District

Oncology services in the Ipswich and West Moreton District are extremely limited, given the large population in the area.

We are led to believe that only 4% of all cancer treatments are currently delivered at the Ipswich Hospital to patients. 96% of patients from the area is required to travel to Public and Private Hospitals in Brisbane for their treatment.

This lack of local oncology services forces patients to seek a Consultant and oncology services in large Brisbane Metropolitan Hospitals, mainly attending the Mater Public and Princess Alexander Hospitals. In many cases, these patients then do not return to their local area for future treatment, their condition deteriorates and they often die in these Metropolitan Hospitals.

Often the Hospital environments are not ideal for Palliative Care. The dying patient may be admitted to a shared, mixed 4 bed room in a busy Medical or Surgical ward. This setting may lack dignity, privacy or the specialized palliative medical & nursing care needed to provide the best death possible.

c) Innovative ways to develop sustainable palliative care services to meet current and future needs.

○ **Relationship with the Ipswich District Palliative Care Service Providers**

Ipswich Hospice believes that a close working relationship with the local Hospital is key to the success for providing sustainable palliative care services to the community. It is imperative that Queensland Health continue to employ at least one full time Palliative Care Consultant, who is also contracted to provide this consultative service to Ipswich Hospice.

This close working relationship between Hospice and the Hospital ensures the availability of services is maximized to the serve the patients in the most efficient way. We believe however, that this working relationship could be improved by the issuing of daily electronic reporting from both the Hospice and the Hospital to key stakeholders in the district.

This daily reporting could include the current patient loads, available bed situation, including possible/planned separations and admissions to help plan the accommodation of patients that best utilizes the services available in the District.

In addition, we believe that we could offer the Hospital and other palliative care service providers in the District greater support in terms of palliative care specialized education for clinical staff, if appropriately funded. This could include domiciliary nursing services and Residential Aged Care Facilities who also care for dying patients.

○ **Rationalisation of Resources and Interventional treatments**

Ipswich Hospice fully supports the Queensland Government's review of best patient outcomes. We believe that there is an urgent need to fully explore health policy development around the continuation of aggressive interventional treatment when a patient's situation is considered medically futile. We are aware that there may be many cases where patients are being managed in such a manner in acute medical settings, including Intensive Care Units. The patient continues to be actively treated, when all medical staff are aware it is impossible for the patient's medical situation to result in a positive outcome.

For example, an 89 year old frail patient, with multiple other health problems and extensive metastatic disease continues to be offered treatments such as intensive chemotherapy. The chemotherapy may have severe adverse side effects – such as nausea, vomiting, fatigue & infections.

This leads to a very poor quality of life for this 89 year old. Another example of patients dying in an inappropriate environment might be the admission to ICU of a patient who has had an extensive and irreversible Cerebral Vascular Accident (Stroke). This patient may be on assisted breathing (ventilated) & connected to lines (monitored) for often extensive periods of time. The medical and nursing team are often aware that the patient will ultimately succumb to the body's catastrophic event, however all attempts are made to prolong the inevitable with artificial life prolonging techniques. Palliative care the most appropriate care for both these cases, either for longer or short term care.

Alternatively, The World Health Organisation description of palliative care should be introduced. This approach 'improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'

Ipswich Hospice recognises the sensitive & ethical dilemmas of medical treatment. However, we believe that education and support needs to be given to all people involved – Doctors, Nurses, the Patient and their Family, as to the many choices, the implications of these choices and what would be the best possible outcome. A peaceful death in dignified, private, individualised surroundings, provided by expert medical and nursing care – such as Ipswich Hospice - may end up being the preferred option.

The financial implications of treatment options cannot be underestimated. An ICU bed with Queensland Health is quoted to cost up to \$4000/day (Source Palliative Care Queensland). Ipswich Hospice can offer a bed for \$660 per day.

- **Central point of Care Coordination**

Ipswich Hospice Care is open to exploring the opportunity to being the District's conduit for palliative care services.

We believe that the Ipswich Hospital is best suited to provide the patient's 'acute' palliative care. This would include diagnostic tests, acute symptom management, interventional treatments – such as blood transfusions and intravenous antibiotics. Following some stabilization of the symptoms, the palliative patient would be discharged or referred to Hospice - either for respite care or end of life care.

There may be an extended period of time – from days, to weeks, to months, to even years, when a patient require ongoing palliative care, but is not deemed 'terminal' or needing end of life care. The patient is then managed very effectively by their GP and through the outpatient Palliative Care Clinic and domiciliary support services.

Home Services are of vital importance during this period of time. If patients and carers are well supported during this stage, the number & length of admissions to acute hospitals are reduced.

As the disease or condition progresses, several admissions to Hospital may be required to once again manage any symptoms arising. Ipswich Hospice Palliative Care Unit would continue to manage this.

Ipswich Hospice would continue to care for people deemed to be in the last three months of life. With an average length of stay of less than three weeks, generally Ipswich Hospice cares for people very close to the end of their life.

Ipswich Hospice would be function across inpatient and outpatient settings as necessary to maintain continuity of care. This will ensure that the patient is being cared for in the most appropriate environment – at home, in Hospital, in Hospice, a Residential Aged Care Facility or other alternatives.

This would include:-

1. Managing the Home visiting service called the 'Outreach Program' currently being run out of Ipswich Hospital. This Outreach Program will employ both a Palliative Care Nurse Practitioner (PCNP) & a Registered Nurse.
2. Employing a Nurse Practitioner in our work force to support the clinical work of our current medical staff - including the Palliative Care Consultant and GPs and the community. The Palliative Care Nurse Practitioner (PCNP) would receive Medicare consultation based funding.
3. A PCNP has:-
 - Advanced, independent triage and assessment skills with associated referral and admission to either Ipswich Hospital or Ipswich Hospice.
 - Advanced independent diagnosis plans implementation and evaluation of patient problems and needs.
 - Initiates diagnostic tests, treatment and prescriptions within endorsed scope of practice.
4. It is proposed that the Outreach service will be available from 8.30 to 1700 hrs Monday to Friday.
5. Telephone support to the other palliative care service providers will be offered.

We believe that the co-ordination of the Outreach Service may be better dealt with at a grass roots level rather than a large Hospital setting.

- **Expansion of Ipswich Hospice**

With increased funding & increased bed capacity, Ipswich Hospice has the potential to offer care for Palliative Care Patients for longer periods of time than the current three months time frame.

This would have several advantages:-

1. Patients aged less than 65 years of age, who are still requiring Palliative Care, but not end of life Palliative care, who are not suitable to be Aged Care Assessment Team (ACAT) assessed for transfer to a Residential Aged Care Facility.
2. Patients who require high levels of specialized palliative care that a Residential Age Care Facility would not be able to provide. For example, in patients with a diagnosis of Motor Neurone Disease or require intensive support and management of symptoms.
3. Ability to accept patients requiring palliative care for more than three months, but their personal circumstances limits their option of being at home. For example, housing situation, living on own, financial or personal safety concerns.

5.2 Future Need for Services – Aging Population

The pattern of life, disease, dying and death has changed dramatically in Australia both over the last century and over the last several decades. As discussed in Supporting Australian to Live Well at the End of Life, National Palliative Care Strategy, 2010³, in 1907 in Australia over 45,000 people died with a mean age of death of 41. Based on current mortality rates, a person born in Australia can now expect to live to 80 years old. According to United Nations estimates, Australia's life expectancy at birth is ranked among the highest in the world.

This change in the life expectancy could result in a cost burden for the health system and a potentially poorer quality of death, with inadequate palliative care services.

At a more local level, the population in Ipswich is the fastest growing area in Australia. Ipswich population is forecast to grow on average 5% annually over the next 10 years, compared to a growth rate of 1.8% for the rest of the State.

To care for our community in the future, Queensland Health has forecast that by 2026:

- The Palliative Care Unit at Ipswich Hospital will require 15 beds;
- Ipswich Hospice Care will require 9 beds.

³ Australians Health Minister's Advisory Council, Supporting Australians to Live Well at the End of Life, National Palliative Care Strategy, 2010

Ipswich Hospice Care has made some initial investigations as to the possible expansions to our bed facilities to our current site, and has developed architectural plans to include six further beds. Increased nursing and ancillary staff would be needed to support an expansion, however we believe no increase in governance and support services such as medical, pharmacy or management would be required.

Section 6. Effectiveness, efficiency and adequacy of palliative care and HACC services

a) Research on the effectiveness of palliative care services based on the experience of the consumer and service providers

Ipswich Hospice Care is an active participant in the National Standards Assessment Program (NSAP) since 2010. NSAP, which is funded by the Australian Government's Department of Health and Ageing, is a quality improvement program available for all specialist palliative care services across Australia.

It is a resource that enables services to engage in continuous quality improvement through self assessment against Palliative Care Australia's national palliative care standards, quality improvement action plan development and implementation, as well as peer mentorship.

NSAP has an overall aim of supporting palliative care services to move towards best practice, as set out in the agreed National Palliative Care Standards, through providing resources that support and enhance the ability of palliative care services to improve the quality of care within their existing quality improvement process and accreditation cycle.

As part of NSAP's recent activities, a client satisfaction mail out survey has recently been produced, called the Family Evaluation of Palliative Care Survey. Ipswich Hospice is in the early stages of utilizing this tool, and unfortunately at the moment we have not reached the sample size threshold where a report could be produced. In the future however, this client satisfaction tool will be most useful in guiding our services and continual improvement. The anecdotal comments that we have received to date however, have been extremely positive.

The second research/evaluation program that Ipswich Hospice Care participates in is the Palliative Care Outcomes Collaboration (PCOC) in which we have been involved with since 2007. PCOC is the only national voluntary program that utilises standardised validated clinical assessment tools to benchmark and measures outcomes in palliative care. Participation in PCOC enables palliative care service providers to improve practice and meet the *Standards for Providing Quality Palliative Care for all Australians*.

In addition to NSAP and PCOC evaluation, Ipswich Hospice Care undertakes ongoing internal patient feedback/surveys with the most recent results are as follows.

Summary of Patient Satisfaction Surveys January 2010 to December 2011

There were 156 separations for this two year period with 21 Satisfaction Surveys returned. Response rate was 13.5%.

Question 1) Are you satisfied with the services provided by Ipswich Hospice Care?

90.5% of respondents were very satisfied with the services. 9.5% (2/21) of respondents were satisfied with the services.

Question 2) Have you had adequate input into your care and treatment?

81% of respondents were very satisfied with their input into their care and treatment.

19% of respondents were satisfied with their input into their care and treatment.

Question 3) Have you been provided with adequate information (verbal and written)?

70% of respondents were very satisfied with the provision of information. 30% of respondents were satisfied with the provision of information.

Question 4) Do you feel that you have been given appropriate care, attention and respect?

90.5% of respondents were very satisfied with the level of care, attention and respect they received. 9.5% of respondents were satisfied with the level of care, attention and respect they received.

Question 5) Overall, how would you rate the facilities?

100% of respondents were very satisfied with the facilities at Ipswich Hospice.

Complaints Management – Ipswich Hospice Care is compliant with legislation reporting requirements from the Health Quality and Complaints Commission (HQCC). We have been keeping records of complaints for ten years and no complaints related to patient care have been received since August 2008. Since 2002 only one complaint was reported to the HQCC. This complaint was dismissed by the Commission.

b) Barriers to effective palliative care

Lack of Funding

Ipswich Hospice is under-funded and relies heavily on donations from the community to continue to offer its services. At times, the lack of resources and funding results in stretching our staffing resources to the limit. Many of our staff give hundreds of hours of unpaid work to be able to meet the required deadlines and ensure the quality of care is continued.

Need for Improved Referral Process

Ipswich Hospice Care receives 70% of its referrals from Ipswich Hospital. The other 30% of referrals come from other Public Hospitals, Private Hospitals, Aged Care Facilities, General Practitioners through a simple referral process. No asset testing is required, and patients can be admitted the same day of referral if the referral meets admission criteria and availability.

The communication between the referring doctor/ hospital and the in-patient palliative care provider however needs to ensure relevant medical history pertaining to the patient is consistently provided. This will enable the in-patient palliative care provider to establish effective pain management strategies soon after admission.

In addition, when an external agency chooses to refer a patient to Hospice, it would be most helpful if a full summary of the patient's medical and emotional history could be provided. This would better facilitate an efficient referral and decision regarding appropriateness of admission to the in-patient palliative care facility.

c) Consumer preferences – how and where

In survey results discussed in the Supporting Australian to Live Well at the End of Life, National Palliative Care Strategy, 2010, most healthy Australians, when asked where they would prefer to die, stated they would like to die at home. However the statistics on place of death indicate that this stated preference does not actually occur.

Place of death in currently Australia is listed below:

- 10% of people die in Nursing Homes
- 16% of people die at home
- 20% of people die in Hospices
- 54% of people die in Hospitals

For a small number of patients, care in the home until the time of death is possible. Palliative Care and death at home is achievable when the following is available:-

- Suitable place of residence: A dwelling which is suitable for disabled access e.g. no stairs, access for assistance & equipment aids in bathroom and toilet. Needs to be own property or able to make adjustments needed e.g. hand rails, shower hose, and is suitable for accommodating more than one person.
- Access to immediate private transport.
- Able bodied, responsible primary carer and at least two other people able to assist the carer twenty four hours a day. This could be for extended periods of time.
- The carer needs to reside in the house for the duration of the end of life care.

- Assistant carers may also need to reside in the dwelling or be available within a short distance. This may involve re locating, taking time off work – either paid or unpaid.
- Carer's/Assistant Carer's own family and financial situation allows for time away from their own home or financially time away from their own work.
- Excellent communication skills between the patient, the carer and those assisting the carer. No animosity or dysfunctional relationships.
- Patient's symptoms are able to be managed with a one hour visit from nursing support per day.

While consumers may prefer to die at home, the reality of this wish is that the following problems usually prohibit this from occurring:-

- Availability of a doctor to do home visits and be available on call for 24 hours
- Support provided to GP by a Palliative Care Consultant
- Patient Mobility issues
- Availability of a responsible carer with full mental capabilities for decision making related to care and symptom management
- Requirement for several carers to be available 24 hours a day
- Physical, emotional and availability capabilities of carers
- Access to appropriate medication 24 hours a day
- Transportation issues
- Ability to purchase and install required equipment.

Even with the highest level of home based care offered, it is not available 24 hours a day. Twenty four hour care and support is required for end of life to ensure all symptoms are managed appropriately and a humane death is achieved.

Complex symptoms in the terminal phase may include:-

- Pain
- Anxiety
- Nausea and vomiting
- Swallowing difficulties (unable to take tablets, nutrition or fluids)
- Confusion
- Restlessness
- Bowel and bladder irregularities, often with double incontinence
- Increased secretions leading to distressing noisy breathing (known as the 'death rattle').

All of the above symptoms often require intense, educated and expert medical and nursing care to manage effectively.

At Ipswich Hospice Care, we provide in-patient palliative care in a home-like environment. 24 hour a day high quality nursing care, with access to medical care is provided. We aim for maximum flexibility to accommodate individual preferences, rituals and personal situations.

d) Innovative service delivery

○ **Rationalisation of Resources and Interventional Treatment**

Ipswich Hospice fully supports the Queensland Government's review of best patient outcomes. We believe that there is an urgent need to fully explore health policy development around the continuation of aggressive interventional treatment when a patient's situation is considered medically futile. We are aware that there may be many cases where patients are being managed in such a manner in acute medical settings, including Intensive Care Units. The patient continues to be actively treated, when all medical staff are aware it is impossible for the patient's medical situation to result in a positive outcome.

For example, an 89 year old frail patient, with multiple other health problems and extensive metastatic disease continues to be offered treatments such as intensive chemotherapy. The chemotherapy may have severe adverse side effects – such as nausea, vomiting, fatigue & infections. This leads to a very poor quality of life for this 89 year old. Another example might be the admission to ICU of a patient who has had an extensive and irreversible Cerebral Vascular Accident (Stroke). This patient is intubated, ventilated and monitored for often extensive periods of time. Palliative care the most appropriate care for both these cases, either for longer or short term care.

Alternatively, The World Health Organisation description of palliative care should be introduced. This approach 'improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.'

Ipswich Hospice recognises the sensitive & ethical dilemmas of medical treatment. However, we believe that education and support needs to be given to all people involved – Doctors, Nurses, the Patient and their Family, as to the many choices, the implications of these choices and what would be the best possible outcome.

A peaceful death in dignified, private, individualised surroundings, provided by expert medical and nursing care – such as Ipswich Hospice - may end up being the preferred option. The financial implications of treatment options cannot be underestimated. An ICU bed with Queensland Health is quoted to cost up to \$4000/day (Source Palliative Care Queensland). Ipswich Hospice can offer a bed for \$660 per day.

- **Central Point of Care Co-ordination**

Ipswich Hospice Care is open to exploring the opportunity to being the District's conduit for palliative care services.

We believe that the Ipswich Hospital is best suited to provide the patient's 'acute' palliative care. This would include diagnostic tests, acute symptom management, interventional treatments – such as blood transfusions and intravenous antibiotics. Following some stabilization of the symptoms, the palliative patient would be discharged or referred to Hospice - either for respite care or end of life care.

There may be an extended period of time – from days, to weeks, to months, to even years, when a patient require ongoing palliative care, but is not deemed 'terminal' or needing end of life care. The patient is then managed very effectively by their GP and through the outpatient Palliative Care Clinic.

As the disease progresses, several admissions to Hospital may be required to once again manage any symptoms arising. Ipswich Hospice Palliative Care Unit would continue to manage this.

Ipswich Hospice would continue to care for people deemed to be in the last three months of life. With an average length of stay of less than three weeks, generally Ipswich Hospice cares for people very close to the end of their life.

Ipswich Hospice would be function across inpatient and outpatient settings as necessary to maintain continuity of care. This will ensure that the patient is being cared for in the most appropriate environment – at home, in Hospital, in Hospice, a Residential Aged Care Facility or other alternatives.

This would include:-

- Managing the Home visiting service called the 'Outreach Program' currently being run out of Ipswich Hospital. This Outreach Program will employ both a Palliative Care Nurse Practitioner (PCNP) & a Registered Nurse.
- Employing a Nurse Practitioner in our work force to support the clinical work of our current medical staff - including the Palliative Care Consultant and GPs and the community. The Palliative Care Nurse Practitioner (PCNP) would receive Medicare consultation based funding.
- A PCNP has:-
 - Advanced, independent triage and assessment skills with associated referral and admission to either Ipswich Hospital or Ipswich Hospice.

- Advanced independent diagnosis plans implementation and evaluation of patient problems and needs.
- Initiates diagnostic tests, treatment and prescriptions within endorsed scope of practice.
- It is proposed that the Outreach service will be available from 8.30 to 1700 hrs Monday to Friday.
- Telephone support to the other palliative care service providers will be offered.

We believe that the co-ordination of the Outreach Service may be better dealt with at a grass roots level rather than a large Hospital setting.

e) Models of cost effective and quality service delivery

At Ipswich Hospice Care we believe that our model delivers a cost effective, high quality in-patient palliative care service. We work consistently within the relevant standards and exceed these in many cases.

In reference to the Clinical Services Capability Framework (Queensland Health, 2011) Ipswich Hospice Care has been classified as a Level 4 Palliative Care Service. We believe to be able to deliver high quality palliative care services, a Hospice or any palliative care facility should be a Level 4 or above, and closely linked to a large functioning Hospital, offering supervision from a Palliative Care Consulting on a regular basis. This includes external service agreements with pharmacy, pathology and Ipswich Hospital.

A palliative care service should also ensure consultation and access to a multi-disciplinary team of experts including medical, nursing, allied health, pastoral care and social service. Ipswich Hospice Care holds weekly multi-disciplinary meetings involving medical personnel, undergraduate medical & nursing students, and pharmacy and pastoral care providers. An average of twelve people attends this Case Conference on a regular basis.

In addition, we believe that any in-patient palliative care service should be:

- Accredited with the Australian Council of Healthcare Standards
- Participate in PCOC and NSAP
- Provide accurate regular reporting to Health Quality and Complaints Commission
- Hold Service Agreements with local pharmacy and pathology providers
- Have a visiting Palliative Care Consultant to oversee medical care and provide advice where required
- Ensure all visiting General Practitioners must apply for Credentialing Privileges
- Ensure all nursing staff must have specific palliative care experience and training
- Have a second Registered Nurse available either on site or on call at all times as backup

- Provide evidence based care only
- Offer a Teaching environment – student nurses (Certificate III Aged Care, Diploma Students, Bachelor Students).
- Offer pastoral , social and bereavement support
- Participate and conduct research where possible
- Provide education to other palliative care professionals and the community
- Hold Weekly multi-disciplinary meetings with Palliative Care Consultant, medical staff, social worker and pharmacist.

We believe that by offering 24 Hour high quality palliative care that fills the gap those other service providers cannot, particularly with our ability to:

- Provider longer admissions required than an acute hospital
- Provide care for patients who are not appropriate for an Aged Care Facility – either Care needs too high or not over 65 years of age or both.
- Socio economic, family, substance abuse/ addiction, mental health issues and a variety of other reasons.

In addition to the high quality service we can provide with our current model, Ipswich Hospice Care also provides its services in a cost efficient manner.

Hospice generates a larger percentage of income every year from the community including through its enterprises, donations, fundraising and private health insurance.

This enables Ipswich Hospice to:

- Provide seven palliative care beds at \$660 per bed per day;
- Ipswich Hospital provides each bed at \$1100 per day (\$900 in PCQ info for Queensland), and Intensive Care Unit bed at \$4,000 per day;
- This model is currently saving the Queensland Government \$1.22 m (\$440/day x 7 beds) per annum;
- If Hospice were to close, it will cost Queensland Government an **additional \$2.1m**, total of \$2.81m per annum;

The Ipswich Hospice model also assists Queensland Health in several other ways:

- Hospice assists Ipswich Hospital to clear their intensive, acute and sub acute beds to ensure the availability of beds;
- Ipswich Hospice can care for patients who are difficult to place. There are often challenges regarding placement of younger patients who fall under the care of the Disability Services Queensland. Historically disability services have been inadequate due to long waiting lists. Our younger patients have remained in Hospice for prolonged periods or died whilst waiting for even assessment from Disability Services Queensland.

- Socially and culturally disadvantaged patients can also be a challenge to find places of alternative care. Ipswich Hospice Care can adapt our care according to the patient's specific needs. For example we have maximum flexibility to adapt our care to accommodate patient individual preferences, rights and rituals along with open visiting hours.
- Hospice is supported by a large Volunteer Team, (270 current active volunteers). We have been informed that Ipswich Hospice may have the largest number of volunteers involved in a Palliative Care Service in Australia. Two research projects are being conducted by the University of Newcastle as a result of this achievement.

Section 7. Improving integration, collaboration and co-operation between palliative care, HACC, disability services and other health services

a) Consumer-directed care

Ipswich Hospice Care's Symptom Management involves consumer involvement on a daily basis for optimal holistic medical and nursing care provision (PCOC scoring, weekly symptom assessment, pain charts, progress notes, clinical pathways).

We also utilize a patient centered model of care. Each guest-family unit is unique and Ipswich Hospice strives to accommodate their specific needs. We help people live their lives whilst dealing with the effects of a terminal illness; choices are encouraged and are creatively employed by team members. Different cultures and religions with associated traditions are honoured wherever possible.

In addition, as Ipswich Hospice Care will be participating in the National Safety and Quality Health Service (NSQHS) commencing in 2013. National Standard 2 Partnering with Consumers and Standard 6 Clinical Handover will be relevant to consumer-directed care. Ipswich Hospice has already commenced developing policies & protocols around these new Standards which will include bedside Hand Over and forming a Consumer Representative Committee to be involved in many Governance decisions & publications.

Consumer directed care is also evident in the management of Ipswich Hospice Care. As part of our Management Committee, we have appointed a nominated Consumer member who provides feedback from the community regarding Hospice performance and policy.

b) Use of multi-disciplinary teams

Case Conference

Ipswich Hospice Care key medical and non medical team members gather together for a weekly meeting to discuss each patient in care at Hospice and potential new admissions.

These meetings are a teaching tool for all attending thus improving patient outcomes, management and safety. Each individual patient is discussed, outlining history, past symptoms and family situation. Current symptoms are discussed and addressed to ensure optimal outcome for the patient. Pain assessment and PCOC scoring ensure accuracy of the information shared. Emotional and spiritual concerns of the patient and their family are also addressed, ensuring a holistic and individualized approach to total patient care.

The weekly Case Conference/Multi –disciplinary meeting is very well attended by:-

- The individual GPs caring for the patients. There may be seven different GPs attending at any one time
- Palliative Care Consultant (Chairs meeting)
- Medical Students accompanying Palliative Care Consultant
- GP who replaces weekend call for Palliative Care Consultant. Also has an interest in Palliative Care and would be considered an expert GP in this area.
- Pharmacist (External Service Agreement ensure weekly attendance).
- Psychosocial Support Coordinator
- Director of Hospice Services (Registered Nurse, Post Grad Dip in Cancer Nursing)
- Registered Nurse on duty on that day
- Student nurses doing Clinical Placement on that day
- Allied Health students or PEPA students on clinical placement
- Visitors – Palliative Care Doctor’s and academics.

Interagency meetings

Ipswich Hospice representatives regularly attend the monthly district Palliative Care Interagency meeting. These are held at Ipswich Hospital and the Palliative Care Consultant chairs these meetings. Interagency meetings run for over two hours, whilst every Palliative Care patient in the community is discussed.

This includes rural districts, domiciliary services, Outreach service, in patients (public & private), outpatients, and Hospice. Each patient’s management, prognosis, progress and suggestions for change to care or intervention are discussed. All attending are aware of possible admissions and smooth coordination of future care can be communicated.

c) Expanded Hospital into the Home services

As stated in **Consumer Preferences – how and where**, it is understood that many Australian wish to die in their home however the reality of this wish is that the following problems usually prohibit this from occurring:-

- Availability of a doctor to do home visits and be available on call for 24 hours
- Support provided to GP by a Palliative Care Consultant
- Patient Mobility issues
- Availability of a responsible carer with full mental capabilities for decision making related to care and symptom management
- Requirement for several carers to be available 24 hours a day
- Physical, emotional and availability capabilities of carers
- Access to appropriate medication 24 hours a day
- Transportation issues
- Ability to purchase and install required equipment.

Even with the highest level of home based care offered, it is not available 24 hours a day. Twenty four hour care and support is required for end of life to ensure all symptoms are managed appropriately and a humane death is achieved.

Complex symptoms in the terminal phase may include:-

- Pain
- Anxiety
- Nausea and vomiting
- Swallowing difficulties (unable to take tablets, nutrition or fluids)
- Confusion
- Restlessness
- Bowel and bladder irregularities, often with double incontinence
- Increased secretions leading to distressing noisy breathing (known as the 'death rattle').

All of the above symptoms often require intense, educated and expert medical and nursing care to manage effectively.

Even with the highest level of home based care offered, it is not available 24 hours a day, which is in most cases is required towards the end of life to ensure pain symptoms are managed appropriately.

Other limitation we believe existing for patient's dying in the home is that the team of medical and carers are not collaborating on a frequent, regular basis regarding the patients care.

In taking into consideration all the requirements to manage patients at home until death, there may be only a very small minority of families and situations able to do this – even with increased services to the home.

d) Greater involvement of GPs

GP Availability

There is currently a severe shortage of Doctors – both Consultant’s and GPs willing and able to do home visits.

From our observation, there is a growing trend for GPs who choose to:-

- Work Part time (decreased availability)
- Live in a different area to work place
- Not available to be contacted after hours
- Not interested in the specialty of Palliative Care
- Not provided with sufficient education either undergraduate or post graduate, on advanced symptom management
- Not willing to write scripts outside of their practice
- No colleagues willing to cover their call in periods of absence
- Contracts that do not allow GPs to do home visits (e.g. GP Super Clinics)
- Relocating frequently, thus losing continuity and longevity of long term patients
- GPs believing that they are not sufficiently financially remunerated for the time and effort that needs to be invested in a home visit
- The population is trending towards the public having either no regular GP (Medical Centre type practices) or several GPs for different health problems
- Changing trends in population migration, so new GPs sought when people re locate.

Continuity of Care

Once a patient has been diagnosed with a serious illness, their care is often transferred from the GP to a referred Consultant and larger hospital for interventional treatment. The GP may lose contact or communication with the patient during this time (sometimes months/years). If the patient’s disease progresses or relapses and then moves to requiring Palliative Care, the GP may not have reviewed this patient for an extended period of time. Communication between the specialist treatment centres back to the GP could be improved to ensure the GP is aware of the patient’s current progress and condition.

It would be ideal if patients could stay connected to the General Practitioner throughout their terminal illness, to ensure continuum of care particularly entering the terminal phase of the patient's life.

GP Education

We would also like to see more GPs undertaking continuing education in the area of palliative care, to prepare for their patients being admitted to in-patient palliative care facilities such as Hospice where they can be intimately involved in their end of life care. GPs availability and prioritization of their end of life care patients however would need to improve for more GPs to be involved in this process.

e) Potential improvements

As stated in the Part 5.0 Capacity and Future Needs, our close working relationship, between Hospice and the Hospital, ensures the availability of services is maximized to the serve the patients in the most efficient way. We believe however, that this working relationship could be improved by the issuing of daily electronic reporting from both the Hospice and the Hospital to key stakeholders in the district.

This daily reporting could include the current patient loads, available bed situation, including possible/planned separations and admissions to help plan the accommodation of patients that best utilizes the services available in the District and should be discussed in detail at the monthly Interagency meetings.

Also in terms of admissions, we feel it would be most useful to have access to the Ipswich Hospital's patient database to enable electronic access to patient history and discharge summary information.

CASE STUDY

FEMALE PATIENT AGED 35 YEARS OLD

CONGENITAL POLYCYSTIC KIDNEY DISEASE AND HEPATIC FIBROSIS

Overview

We have provided the following Case Study using a patient who stayed at Hospice recently to demonstrate, what we believe to be, was a perfect example of a seamless referral process. Following admission, maximum flexibility and accommodation of the individuals needs and desires for her last days were met. The time between the first contact from the PAH consultant and admission to Hospice was only 2 hours. This prompt admission was a result of integrated communication between palliative care and PAH renal treatment team.

Natalie's view on staying at Hospice was that she was going to live until she died. She was going to make the most of the time she had, and enjoy it the best way she knew how. On two occasions Natalie left Hospice for outings and held a large family gathering for thirty of her closest friends and family the night before she died.

Natalie did not wish to be cared for in her own home. She lived with her sister and her niece who was four years old in Ipswich, and Natalie wanted to protect her niece from seeing her die. In addition, once Natalie ceased dialysis, it was anticipated that she would deteriorate very quickly. It was not possible to coordinate equipment and resources to ensure appropriate palliative care could be provided. Alternations to the home were not possible as the home was a rental property.

Past Clinical Summary

Natalie was diagnosed by her Ipswich family GP at the age of six months with Congenital Infantile/Juvenile Polycystic Kidney Disease & Hepatic Fibrosis. In 1995 Natalie received a kidney transplant from an unrelated donor. Unfortunately Natalie chose to withdraw from medical care for a number of years. During this period at times she refused to take her anti rejection drugs and her kidney transplant failed.

Natalie's denial of her diagnosis and subsequent complications also lead to a period of time where she used illicit drugs and had several large tattoos applied to her body. Through either the IV drug use, the tattoos, or multiple blood transfusions during the mid 1990's, Natalie contracted Hepatitis C.

In 2000 Natalie agreed to accept traditional medical care again for her renal failure and commenced regular hemodialysis treatments.

Over the following years Natalie developed many further complications, including Grade 1 oesophageal varices, Portal hypertensive gastropathy, Anterior ischemia optic neuropathy with vision lost in left eye and right eye infer medial quadrantoanopia, Caroli's disease, recurrent life threatening sepsis, tuberculosis, VRE, genital herpes, positive pap smears.

Recent Clinical History

June 2012 Natalie was admitted to the PAH renal unit with yet another septic shock secondary to Klebsiella bacteraemia and associated encephalopathy. Natalie recovered from this and returned to Ipswich. However over the next 6 weeks, Natalie's condition continued to deteriorate. Her quality of life diminished as she struggled with multiple symptoms.

23rd July With extensive medical advice, Natalie decided to withdraw from having any further dialysis.

26th July After Natalie's consultation with her Renal Consultant at the PAH, the Doctor made contact with Ipswich Hospice's Palliative Care Consultant regarding possible admission for end of life care for Natalie. The Palliative Care Consultant made contact with Ipswich Hospice Director. As a bed was available, transfer was organized for that day. **Two hours later Natalie was admitted to Ipswich Hospice.** That evening, Natalie was seen by her family GP and Natalie's Mother was able to stay with her throughout the night in a sofa bed by Natalie's side.

27th July Natalie reported as having a 'happy day' spent with family. A hairdresser and makeup artist attended to Natalie in the Hospice as her request was 'to get dressed up and gorgeous' to the Brisbane Casino that evening. Lots of photos were taken of Natalie, but unfortunately Natalie became increasingly confused and unsteady on her feet as the evening progressed and she was not able to go out as hoped that evening.

28th July Natalie had pain in the bones, particularly in her knees therefore a syringe driver was commenced. She then went out from 11am – 2pm with her family to the local Club with a portable syringe driver in a shoulder bag to provide ongoing pain relief. Natalie's Mother and boyfriend stayed overnight at Ipswich Hospice where her symptoms well controlled and Natalie had a comfortable night sleep.

29th July Thirty of Natalie's friends and family came to Ipswich Hospice and held a BBQ gathering on the Hospice Family Patio area. Natalie is now unable to leave bed so her bed was wheeled to the Patio area to participate in family gathering.

That evening Natalie's breathing changed, and became like a "rattle". Natalie's father, mother, sister, and boyfriend all stayed overnight at Hospice. Several breakthrough medications were given for end of life symptoms – pharyngeal secretions causing 'noisy breathing' and restlessness.

30th July 7.10am – Natalie died with all family members present. The family GP attended and the family were counseled. Later that morning Natalie’s body transferred to the funeral directors with 2 rings right eyebrow, 4 rings in right ear, 2 rings abdomen and 6 rings left ear and a soft dog toy.

The family will now be followed up with counseling and support via Hilda’s House Bereavement Service. They will be offered one on one counselling and/or the Adult Grief Group.

Natalie’s family will also be invited to attend Ipswich Hospice Care Annual Rose Planting Ceremony to honour Natalie and all the other patients who died at Hospice during the year.