



# **HOPEWELL HOSPICE SERVICES Inc.**

**A submission to the Legislative Assembly of  
Queensland, Health and Community Services  
Committee's inquiry into palliative care and home  
and community care services.**

**6 August 2012**

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## **Summary and recommendations:**

Hopewell supports a palliative care system for Queensland that:

- Provides comfort, pain control, dignity, respect and choice in respect to treatment, care and surroundings
- Meets individual needs and preferences
- Supports families through the dying and bereavement process
- Provides equitable availability of care
- Promotes healthy attitudes towards death and dying
- Provides considered care plans that has input by all significant family and care team members
- Provides a recording system that allows access to records for all who need to be involved.

To help facilitate such a system Hopewell recommends:

- 1. Funds be made available to fund at least two public beds at all accredited hospices.**
- 2. Life enhancing palliative care information sessions be offered as a matter of routine to all people with diagnosis of life ending conditions, so that they are informed early and in full control of when and how to access assistance.**
- 3. Where practicable support be given to developing an integrated suite of services to limit distress and discomfort for people with palliative care needs and their families.**
- 4. Funds be made available to appropriate agencies to assist parents and children manage the effects of the dying process on the children in families where a close member of that family is dying.**
- 5. Under-utilised capacity in Hospices be made available for emergency respite care.**
- 6. Appropriate Organisations be funded to provide respitecare beds that can be booked well in advance to assist carers with life planning.**
- 7. The current discharge system from both public and private hospitals be reviewed so that discharge procedures are streamlined and provide accurate information needed for the ongoing care of patient irrespective of where they are being discharged to.**
- 8. Weekend transfer of patients by ambulance be made possible.**
- 9. Reporting requirements be examined with a view to reducing workload for providers.**
- 10. A pilot study be conducted using a small Organisation that offers an integrated suite of services as well as having collaborative arrangements with**

**other providers to ascertain the impact of these arrangements on effectiveness, efficiency and funding.**

- 11. The current funding system to be reviewed and all funded organisations be funded on an equal basis.**
- 12. The concept of 'good practice forum' be implemented in palliative care.**
- 13. The Health System recognise and reward organisations that have substantial innovative outcomes through their continuous improvement strategies with financial and other incentives, such as promoting their expertise.**
- 14. When multiple providers are involved a lead provider be appointed who takes responsibility for managing that client's care and ensuring all providers involved have the information to complete their contractual agreements.**
- 15. Advanced (preferably electronic) plans for care to be the property of the client or their carer and held by them.**

## Introduction

Hopewell Hospice Services Inc. is an Incorporated Association (IA13351) and a Registered Charity (No. 1194) established in 1993. It provides for Gold Coast residents, a haven with practical, medical, emotional and spiritual support when they or a family member is facing one of life's greatest challenges, the end of life.

The service provided at Hopewell is comprehensive. Hopewell offers palliative care in a home-like environment eight bed hospice, respite care, as well as home based palliative care. In addition it offers services for children dealing with grief and loss, a holiday program for families with a child who has a terminal diagnosis, community training courses in grief and loss and palliative care, after death support services such as funeral/ remembrance services and grief support groups. It also operates a café on its premises.

Over 200 trained volunteers regularly contribute to Hopewell activities. This valuable contribution keeps the services relevant to community needs, caters for diversity, assists with stretching the budget, and supports the efforts of the professional paid staff.

The community also gains from this involvement. It receives training through multiple student placements for future practitioners, a venue for community activities and confidence in knowing that should there be a need, a quality service is available.

It is from the perspective of a small community based palliative care provider that endeavours to respond to its clients and the community's palliative and bereavement needs within a very small tight budget, that Hopewell offers this submission to the Health and Community Services inquiry.

## The capacity and future needs of these services (including children and adolescents palliative care)

Population growth will require additional services and creative use of existing resources to meet palliative care demands. For instance, the Gold Coast population continues to grow and age. The 'current population of 515,157 is expected to continue to grow by 13,000 to 16,000 people per year, so that by 2026 Gold Coast City will be home to over 730,000 residents. In 2009, people aged 65 years or over accounted for 13.8% (71,269) of the population. 10.7% of older people provided unpaid assistance to a person with a disability' or illness but this figure is believed to be understated<sup>1</sup>. Consequently, much planning and development needs to take place to meet future demands.

### Access to services:

Currently access to palliative care is conditional on location, income, age, diagnosis, ethnic background and the knowledge and preferences of referring doctor.<sup>2</sup>

<sup>1</sup>Gold Coast City Council (2012) "Social Research Report" <http://www.goldcoast.qld.gov.au/thegoldcoast/default.html>

<sup>2</sup>Palliative Care Australia (2011) "Submission to the Australian Senate Standing Committee on Community Affairs Inquiry into Palliative Care in Australia" <http://www.palliativecare.org.au/Portals/46/Policy/Submissions%20and%20reports/PCA's%20Submission%20to%20Senate%20Inquiry%20into%20Palliative%20Care%20in%20Australia%20Final.pdf>

In the future, not only will more beds and services be required, but consideration must be given to where they are located. On the Gold Coast there are 18 public palliative beds available in a new hospital at the southern end of the coast and an eight bed hospice predominately for privately insured people at the north end of the Coast. Unfortunately Hopewell, the hospice, cannot afford to operate without taking residents with private health insurance, even with the huge contribution of over 100 volunteers. Hopewell, as a charity, does take the occasional public admission but this puts enormous pressure on the budget, and is unsustainable in the long term.

The current system discriminates against public patients having access to a Hospice beds. Public palliative beds are only available in a hospital setting. Let's make no mistake, hospice services are very different to hospital services. In a hospice there is far more flexibility, both for the resident and their family. Services are 'resident focused' and tailor made according to individual need and wishes. Residents are actively encouraged to shape their end of life experience in the way that suits their lifestyle, whilst receiving the best professional care and attention. Hospital services are run on a medical model and are far more regimented.

### **Recommendation:**

**Funds be made available to fund at least two public beds at all accredited hospices.**

### **Entry to Palliative Care System**

Entry to the current system relies heavily on the diagnosis and the information the referring practitioner knows about the available services. A cancer diagnosis is more likely to result in a referral to palliative care, and indeed this is a requirement for admission to some hospices. Such a system excludes persons suffering from alternative life ending diseases from this option.

In addition, the referral system is premised on the referrer's knowledge about what is available and their own preferences. On the Coast, a centralised regional system has taken control of the referral process with all palliative patients being referred to a central office that is in touch with the up to date capabilities of all providers. The efficiency of the system depends on the responsiveness of this office. As well work still needs to be done to promote palliative care as 'life enhancing' rather than focussing on the 'life ending' aspect of the journey.

### **Recommendation:**

**Life enhancing palliative care information sessions be offered as a matter of routine to all people with diagnosis of life ending conditions, so that they are informed early and in full control of when and how to access assistance.**

Age also discriminates against getting admissions. Aged care looks after the over 65s and young care looks after adults up to the age of 40. As Governments have moved many of their systems to

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age based entry criteria the 40 – 65 year old seems to have been overlooked. For this group to get any permanent care, let alone palliative care, it is time consuming and complicated. Hopewell opens its service to any in need and is currently admitting more in this age group who have had distressing experiences finding any care to meet their needs.

The future will require integrated services, high community involvement and a funding model that is a mixture of Government and donor sponsorship.

Hopewell is investigating the New Zealand's Nurse Maud concept for provision of palliative care. This integrates Hospice, Respite Care, Home Outreach Services, Family Support Programs with community participation through volunteerism, education and funding support. This model has many advantages. Palliative care is seen as integral to the community and to living. Hospice stay tends to be shorter, because with case managed outreach services meeting nursing needs, pain control, physical, emotional and spiritual needs is done predominately in the home, with the backup of respite care when required. Nurse Maud is so well known and respected in the community that it is seen as a charity of choice (akin to the Red Cross) and receives donations that finances much of its operation – thus saving the public purse.

Hopewell knows that palliative services are expensive and funding is not limitless. Better value for the public monies is gained if it builds on provision of integrated services some of which are conducted by trained volunteers. Hopewell Hospice could not exist without its 8:1 ratio of volunteers to paid staff and a substantial donor list.

### **Recommendation:**

**Where practicable support be given to developing an integrated suite of services to limit distress and discomfort for people with palliative care needs and their families.**

### **Meeting the needs of children in families where palliative care is occurring.**

Children's needs are often neglected when a family member is dying. Hopewell noticed this oversight and devised a comprehensive suite of programs to meet individual family needs. They include: a holiday program for the whole family including the child with the terminal diagnosis; groups, where children are assigned a 'buddy' as a mentor, to look at grief and loss in an age appropriate way; individual child counselling and or play therapy. These services are operated through Paradise Kids a subsidiary of Hopewell Hospice.

An area of great need in palliative services is how to tell a child that their parent or sibling is dying. The memory of this traumatic news often stays with the child for life. Such news must be delivered sensitively in an age appropriate way. Access to timely assistance and information on how to handle this delicate matter can limit the trauma associated with this event.

Contrary to popular opinion, a child's recovery and resilience commences when their fears about losing a parent are confirmed – not when the loved one has actually died. It is essential that a significant parental figure understands how to handle this troubling time early as significant life limiting patterns of coping can be formed before the actual death.

### **Recommendation:**

**Funds be made available to appropriate agencies to assist parents and children manage the effects of the dying process on children in families where a close member of that family is dying.**

## **The effectiveness, efficiency and adequacy of palliative care services**

### **Palliative Care**

Palliative care delivers results. PCOC, 2011 results, shows that 75% of organisations participating in their research delivered above the baseline national average standard in SAS pain relief, symptom relief, psychological/spiritual assistance and family care.<sup>3</sup> Hopewell is part of this research. However not every Organisation that treats palliative patients delivers the same results and reports indicate that obtaining comfort, pain relief and information can be a tortuous route for newly diagnosed persons. Evidence shows that Hospice pain relief is far superior to home based care or hospital care.

### **Regional palliative health care centres**

As palliative care is unique for each individual no blanket solution will provide comprehensive cover for any given area. It is therefore essential that each health district maps out its provision deficiencies and has a forum to address how these can be best rectified.

The current system of having a regional palliative care administrative centre has merit with co-ordination, deleting duplication and assisting planning, but it also has deficiencies. The system rises and falls on the ability of this central office to know its' providers capabilities and capacities, coordinates well and distribute clients equitably. Service provision can be inadequate, and resources can be under- utilised if this is not done well.

### **Home careover- night nursing services**

A major deficiency with home based palliative care is lack of overnight nursing services. Day based home nursing services do not have the means to provide this expensive option. Some home based careproviders attempt to meet this need by employing specialist nurses for short periods of time, but it appears once families are unable to cope with night nursing needs hospital stay becomes the only option.

### **Under- utilised resources**

Future arrangements for palliative care have to make better use of under-utilised resources. The unpredictable nature of when a resident in a hospice dies, often means, that those on the waiting list can predecease the availability of a bed. Unfortunately this can lead to spare bed capacity. Because Hopewell has both an Outreach service and a Hospice, it can 'value add' to the Outreach service by making empty beds available overnight for respite care to people needing palliative care whose carers need a break.

This flexibility has many advantages. It offers relief to the most stressed carers; familiarises the patient with what the Hospice has to offer; gives carers a break, cuts down the expense of overnight nursing bills and allows public patients access to a service that would not normally be available to them.

### **Planned Respite care**

However planned respite in a Hospice is more problematic. Scheduling a bed for a carer's planned holiday limits bed availability, and would inevitably lead to underutilisation of capacity, thus limiting service to people who are in need of end of life care. Hopewell favours a system where designated

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<sup>3</sup>PCOC (2011) "Benchmark Measures and Care" <http://www.pcoc.org.au/>



beds are funded to be used for respite care only. This allows the whole palliative care community to plan breaks that are conducive to the carer's needs.

### Recommendations:

- **Under-utilised capacity in Hospices be made available for emergency respite care.**
- **Appropriate Organisations be funded to provide respitecare beds that can be booked well in advance to assist carers with life planning.**

An area which needs streamlining and which would gain immediate efficiencies is in admissions. Admissions to Hopewell can take up to two days to track down all the required information to complete the process. Difficulties with the system have resulted in many providers both in the Aged Care Sector and in the Hospice Sector taking the decision not to admit over the weekend. This situation is compounded by the fact that the ambulance service rarely will transfer hospital patients on a weekend or public holiday. The only option and often not feasible is for family to conduct the transfer. This leaves beds vacant. Clearly, if ambulance transfer could occur on weekends and hospitals both public and private have a uniform discharge procedure then many of the difficulties could be overcome.

It has been mooted that e-health recording system could overcome lack of information but e-health recording has its problems. It requires computer access; training for staff; has the potential to allow breaches of privacy; and is expensive for small operators.

### Recommendation:

- **The current discharge system from both public and private hospitals be reviewed so that discharge procedures are streamlined and provide accurate information needed for the ongoing care of patient irrespective of where they are being discharged to.**
- **Weekend transfer of patients by ambulance be made possible.**

Reporting requirements are onerous for providers. Hopewell Hospice helps 80 - 100 residents a year but has to complete annually, over 100 contractual, and other reporting obligations to 18 different entities, plus find the equivalent of 52 plus days annually preparing documentation for accreditation, just to meet funding and good practice requirements. This figure does not include resident records. Clearly this is an added cost and consumes a huge amount of time that takes from resident services.

Much of the same information is required by the eighteen entities but each requires it in their own slightly different format. The Palliative Care Outcome Collaboration (PCOC) is useful compilation of outcomes and could be more widely utilised by the system to save providers time effort and money.

### **Recommendation:**

**Reporting requirements be examined with a view to reducing workload for providers.**

The system provides little incentive to improve operations, but has big expectations.

Hopewell has had to self-fund over 30% of its operations to meet the systems, client, family and community needs. Once these resources have been achieved (such as the training of, and work done by volunteers, courses for children etc.) they are integrated into contractual expectations and the ongoing offerings of the Organisation - thus locking Hopewell into a cycle of ongoing and escalating fund-raising just to maintain its standard of service.

It would make sense to investigate the implications of integration of self- funded services innovations onefficiency, effectiveness and funding using a small operation such as Hopewell.

### **Recommendation:**

**A pilot study be conducted using a small Organisation that offers an integrated suite of services as well as having collaborative arrangements with other providers to ascertain the impact of these arrangements on effectiveness, efficiency and funding.**

## **Opportunities for reforms to improve collaboration and cooperation between chronic, disability and other health services**

Government Department have exacerbated competition.

Competitive funding, albeit unintentional, fosters competition. Ironically, funding for the entry of new ideas and services into the system is by way of competitive grants, with a service agreement that requires collaboration. This in turns produces larger competing groups.

Historically, Government funds (governed by service agreements) have awarded differing amounts to hospices required to provide similar amounts and quality of service. Those lucky enough to get the bigger grants also benefit when extra funding is available as this additional funding is given pro-rata of the recurrent funding. This situation puts more pressure on the least well-funded Organisations, as it locks them into continuous fundraising just to keep up. For instance, Hopewell the 8 bed Gold Coast hospice receives only 25% of its funding from Q-health, theseven bed hospice in Ipswichcites in its annual reports grants contributing 49% of its income. <sup>4</sup>

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<sup>4</sup>Ipswich Hospice Care Inc. (2011) "Annual Report" p21.

## **Recommendation:**

**The current funding system to be reviewed and all funded organisations should be funded on an equal basis.**

It is also popular for Government Departments to require innovative services for new funding rounds. This means service providers have to submit untested ideas to secure new funding. All services that are continuously improving get disadvantaged by this scenario. Sometimes it is a more prudent use of scarce resources to provide more funding for well utilised services and make sure these satisfactory providers evolve their provision by testing and coming up with new ways of providing service that they then must share with other providers.

## **Areas for collaboration**

The key to fostering collaboration is to give those involved a common goal that will advance the interests of all. There are four key areas where collaboration between sectors can produce capacity gains: sharing policy development strategies; sharing clinical tools and research data; cooperating on the development and delivery of patient and provider education; and cooperating on providing information on research efforts, from grant application to dissemination of findings. The practice of 'good practice forums' is well utilised in other disciplines as a means to foster sector development, collaboration and co-operation.

## **Recommendations:**

- **The concept of 'good practice forum' be implemented in palliative care.**
- **The Health System recognise and reward organisations that have substantial innovative outcomes through their continuous improvement strategies with financial and other incentives, such as promoting their expertise.**

## **Client choice and client focused service**

Providing outreach palliative care inevitably invites providers to give services that would normally come under HACC. It makes no sense to have demarcation between Palliative services and HACC services, as this has little significance for the client. They just need the services provided.

The important point to retain in the forefront of all stakeholders' endeavours is that clients get the services they need when they need them. It should go without saying that when jurisdictions cross over or make changes that this principle is the first consideration.

Who then becomes responsible for the care? The way to make this work is to appoint a lead provider for each client. Leader provider role will be to:

- co-ordinate the care in consultation with the recipient and their carers
- negotiate on behalf of the recipient with other providers to contribute to the care plan

- keep records and statistics up to date and make sure each provider involved has the information they need to fulfil their reporting obligations.

### **Recommendation:**

**When multiple providers are involved a lead provider be appointed who takes responsibility for managing that client's care and ensuring all providers involved have the information to complete their contractual agreements.**

### **Care plans**

Accessible and comprehensive care plans are the key to getting best outcomes for the client. This must be co-ordinated by one Organisation but the records made available to all. Personally held, electronic advanced care plans facilitate information being available to all who need it when they need it. It also gives the client and or their carer a sense of being in control of their own journey.

### **Recommendation:**

**Advanced (preferably electronic) plans for care to be the property of the client or their carer and held by them.**

### **Conclusion**

Providing palliative care is both a privilege and a headache. Every recipient requires a unique package of services that demands flexibility, diligence and careful planning. However, many aspects of the system are rigid, paper orientated, and tunnel visioned. Such a situation results in resources being syphoned away from patient care to meet regulatory and contractual obligations.

Providers, caught in the middle of great need and regulatory requirements struggle to make good decisions that will satisfy everyone. They are forced into self-funding many of their operations but once acquired, these additions to their operations are subsumed into the system without recognition that they are subsidising the public purse.

However, the provision of an integrated suite of services is user friendly, cost effective, efficient and provides more value for money.

Hopewell would like to see a system that maximises palliative patient choice, offers integrated quality assured services and gives recognition for innovative and cost effective management.