

Sunshine Coast Community Hospice - Hospice Support House Model

Palliative Care Queensland and Palliative Care Australia believe that “people facing death need to be cared for in an environment of their choice”. It is generally appreciated within the palliative care professional community that we would want people to have as much choice as possible about the location or place they wish to die in. For most Australians this usually includes four locations:

- * their own home
- * a home-like hospice facility
- * a hospital (private or public), including palliative care beds or a palliative care unit attached to the hospital
- * or a residential aged care facility

For some people home is their preferred place to die, whereas others who may have complicated medical needs would be more suited to a hospital or PCU setting. It is important to recognise, however, that this choice of place to die is influenced by a great many things. This may include:

- * Past negative or problematic experiences of the dying process
- * The level of doubt or fear a family caregiver may have, and therefore what level of confidence they have in managing dying at home
- * Financial constraints
- * What support services are available in their own community
- * The accessibility and cost of equipment and prescribed drugs
- * The perceived safety of the hospital setting
- * The increasing societal medicalisation of dying

Thus, even though we talk of choice of place to die these considerable individual, community, medical and cultural aspects influence this decision. This is why, as a profession, what we need to do is make sure that these four options are viable and available for people to choose from and provide good quality supportive care in each of these locations.

There is currently, therefore, on the Sunshine Coast a gap in end of life care service provision. We do not have the second option of choice for a place to die – a home-like hospice facility. We certainly have other excellent hospice and palliative care services which partially meet the needs of the Sunshine Coast population, including the up in coming addition of a ten bed palliative care unit at Caloundra Hospital. In addition, we have primary and community care providers also doing what they can to provide end of life care. The Sunshine Coast, however, does not have a free-standing, purpose-built, home-like hospice facility.

Three years ago Terry Clarke-Burrows and Sue Story, two highly experienced palliative care practitioners and managers, decided to rectify this omission. These two dedicated women quit their jobs and worked tirelessly to raise funds to build a hospice on the coast. Since that time they have had successes, setbacks and a change of direction. Unfortunately, a purpose-built hospice building and service is extremely expensive to build and to provide ongoing staffing costs. Recognising the high costs involved in establishing a hospice facility has translated into an adapted model of care – A Hospice Support House. This document aims to explain this model to the reader and answer commonly asked questions about this innovative, flexible and cost effective way of providing hospice supportive care in the community.

Palliative Care Australia states that “most people with a terminal illness will be cared for by their general practitioner and community nurses ... [and] that most people with a terminal condition prefer to receive care at home, but this will depend on many factors”. We, too, believe that dying is “everyone’s business” and rather than replicating the excellent community and primary care services already providing end of life care we developed a new model of end of life care.

This Hospice Support House Model is similar to several projects which commenced in the early 1980s in the United Kingdom. These small care homes provided support to the terminally ill and their families by work-

ing in professional partnership with the local community palliative care providers and GPs. Like here in Australia, many people in the United Kingdom wish to be cared for in their own homes. When this is not an option, small care homes provided an alternative choice. These small care homes work collaboratively with professional colleagues in all settings and in partnership with the community palliative care services. These hospice homes and professional partnerships provided an excellent standard of palliative care to terminally ill people. They reinforced the right of choice to stay and die in their own community. In fact, the National Health Service funded patients to be cared for in these small care homes, which was seen by the government as a much cheaper option than a hospital admission. Furthermore, as we do here in Australia, the United Kingdom provide aged care for the over 65's in nursing homes. People under this age are not allowed into a normal aged care bed, but can be admitted to a palliative care bed within an aged care facility. Aged care facilities are allowed to have three palliative care beds in a separate area, but must work in professional partnership with community palliative care providers. The facility must have one registered nurse employed with palliative care experience to meet the Health Commission Standards.

We intend to pilot this type of small hospice care home by leasing a residential house, equipping and adapting it for caring for people with terminal illness and draw upon the local, community nursing services and GPs to provide the clinical care. This approach has, in many ways, paved the way for the long standing acceptance and community support of free-standing hospices in the United Kingdom.

The Hospice Support House Model has, so far, progressed in this way:

The first house has been located and leased on a long term basis in a suitable environment. Katie Rose Cottage is a large, family home in a semi-rural location set on acreage. It is set back from the road and has plenty of privacy. It has a lovely garden and suitable facilities. The atmosphere is one of peacefulness. The owner has approved all required modifications and first option to purchase;

Regional council planning approval was, and continues to be sought;

Each room is set out with a hospital bed and mattress and other necessary equipment. In fact, we have an extensive array of equipment which would normally be difficult for people to obtain at home. In addition, suitable accessibility modifications have been made also i.e. ramps, bathroom changes.

This is the location or place that we have established. It is essentially a home away from home – or a home to die in when you cannot stay in your own home. Certainly it is only a small start with two beds, but once we have piloted this model we plan to lease a second property with another three hospice beds.

Our purpose is to provide hospice support services to people who are terminally ill and their family and friends. This care will be in line with Palliative Care Queensland's primary objectives:

- * to be as free as possible from unnecessary suffering (physical, emotional or spiritual);
- * to maintain their dignity and independence throughout the experience;
- * to be cared for in the environment of choice and
- * to have their grief needs recognised and responded to, and
- * to be assured that their families needs are also being met.

How does the hospice support house work?

Referrals to stay at Katie Rose Cottage can be made by a GP, a palliative care professional, Queensland Health, a community nursing service, the ill person themselves or a family member. We have a particular admission criterion which includes:

- * The guest has been diagnosed with a terminal illness;
- * A full assessment of needs to ascertain suitability for the facility will be undertaken;
- * A clear assessment and understanding of the guest's dependency level will be undertaken;

- * A community nursing service is in place;
- * An out of hours contact number available for the Nursing Service;
- * A GP prepared to assist and make house visits;
- * A Do Not Resuscitate (NFR) or Allow Natural Death (AND) order, signed;
- * Oral medications are in a Webster Pack.

The paid and unpaid staff available at the hospice support house includes:

- * A full time Hospice Coordinator - a Registered Nurse with palliative care community experience (Monday to Friday);
- * A casual Hospice Coordinator – a Registered Nurse (Saturday and Sunday);
- * A full time Hospice & Grief Counsellor-Coordinator, with specialist palliative care qualifications (Monday to Friday);
- * Casual and on-call nursing staff available for evenings, overnight and weekends;
- * For out of hours PRN medication dispensing, in the case of no family or friends being able to do so, a RN or EEN will be made available
- * Hospice support volunteers, who are trained to meet palliative care standards and who each hold a current Blue Care Card and First Aid Certificate.

We are not a nursing service, but rather will be working with the existing, local community nursing services. Thorough dependency assessments will be undertaken on all guests admitted and a written guideline will be followed for an appropriate carer ratio. The service will be provided free of charge.

How is it to be funded?

The Sunshine Coast Community Hospice has a vibrant and hardworking fundraising and public relations team. Just like any other charity organisation on the coast we are raising funds to make this hospice service a reality. This is not an unusual thing in that we understand that so many registered charities in Australia are vying for people's donations; a difficult thing to do in this economic climate. We do certainly hope that we will be considered for State Government funding at some point also.

What are the benefits of a hospice support house?

Many people have asked us what the benefit of this type of facility is, especially those who hold onto the dream of a purpose built hospice building. People often ask how this is any different from the home setting. Well it is different and it isn't. Let it be known, however, that if a person's first choice is to die at home, then this is optimal. However, we in this profession know that many people cannot stay at home and they do not wish to go into a hospital setting. Thus, we provide the next best option. Katie Rose Cottage sits somewhere between a private home and a hospice on the continuum. The benefits include:

- * A home environment, including a large yard, gardens, a dining and lounge room and all the other things you would find in your own home. Importantly, each of our guests will have a lovely view;
- * A coordinator available from Monday to Sunday – 8 hours daily and on call after hours. This is different in that at home a terminally ill person would normally receive up to one hour per day from a community nursing service;
- * An available and on-call counsellor which again is quite unique given the scarcity of specialised hospice and grief counsellors in the region;
- * Hospice support volunteers, during the day and overnight, who will provide companionship and other duties as needed;
- * The family, friends and siblings can stay with the dying person if they wish;
- * The facility is adapted to meet the needs of the terminally ill i.e. rails, ramps, and wheelchair access;
- * On site medical equipment is available including oxygen concentrator, suction machine and manual handling equipment. This type of equipment is often challenging to acquire in the home setting;
- * Allied health professionals (physiotherapist, speech pathologist, dietician, occupational therapist) will

be made available if needed;

- * Our guests can keep their own GP, rather than having to change doctors;
- * GPs can be supported by specialist Palliative Care Services, Queensland Health;
- * Care and support is provided at no personal cost to the terminally ill person and their family;
- * No limits as to time of stay or required six month prognosis;
- * Food, laundry and other amenities provided;
- * Hands-on and as-needed training for the family and friend caregivers which will increase their confidence in caring for their dying loved one;
- * An enhanced relationship between hospice care staff and community nursing services and other primary care providers;
- * Bereavement counselling and support groups are included, as well as the opportunity to maintain an important and ongoing connection with the place where their loved one has died;
- * A place for resources and referrals;
- * Access to alternative therapists including massage therapist, bower therapist, reiki and aromatherapy;
- * An animal friendly location;
- * Relaxing gardens which are wheelchair friendly;
- * Social work support can be provided;
- * Assistance with questions and answers from guests and extended family and friends;
- * Access to spiritual and religious support also available;
- * Be welcomed no matter what belief system, lifestyle, race, age, religion, culture or sexual orientation;
- * To be supported and cared at the last phase of their life within a community.

This is certainly quite a lot of benefits. We suspect also that as time goes on we will better understand what other benefits might be apparent. The other benefit of the SCCH charity is that we will be providing outreach services. This includes end of life and grief counselling, the establishment of support groups and hospice support volunteers for the local community. It is important to reiterate, we are not attempting to replace the home setting, or replicate other palliative care services, but simply setting up another important place of choice for people in the community – a home-like hospice which is comfortable and conducive, in a cost-effective and innovative way.

Who might stay at the Hospice Support House?

The answer to this question is quite simply anyone who is facing the end of their life. This includes people with terminal cancer, motor neurone disease, end stage heart failure and any other life-limiting illness. As we are a flexible, community based service we are able to accommodate and care for people who might normally not be able to access other services; people who do not have a six month till death prognosis. For people wishing to discharge from hospital, but the home setting is not appropriate, they can come to the cottage. Think also of the family caregivers who may not feel confident about caring for their loved one at home and who could come in for a week and then go back home again after having gained some confidence in their caring abilities. We can provide respite for short or long periods and then end of life care for a day, a week or longer. We are also looking into the legalities of supporting people who are terminally ill with no family or carers. We are also hoping in the future to provide a place for terminally ill children and their families.

What standards and guidelines will we be following?

The Sunshine Coast Community Hospice has been, and will continue to, establish professional standards and guidelines for the hospice support house. These include:

- * The Standards for Providing Quality Palliative Care for all Australians – according to the criteria for primary care (PCA, 2005)
- * The National Standards Assessment Program (NSAP)
- * The Palliative Care Volunteer Standards (State Government Victoria)

Working in partnership.

We at the Sunshine Coast Community Hospice have always been, and will continue to be passionate about working with other services as much as we can. This intention to work in partnership led to the merging with the Integrated Youth and Family Service (IFYS) – a reputable community service on the coast. This community organisation provides us with governance, support and administrative services. By its very nature, this model relies upon services working together. To this end, Terry and Sue have sought meetings and conversations with key community and palliative care services located on the coast. We have received many letters of support over time, including a letter from Queensland Health, Stephen Robertson MP, stating that they “support the concept of the hospice facility and recognise the need in palliative care services for patients who do not require acute care services, but are not well enough to live at home”.

How much will it cost and why is it cost-effective?

We understand that not only the building costs, but much more so the ongoing staffing costs at the community based hospices here in Queensland are quite substantial. Financially, it is difficult to sustain non-government specialist hospice and palliative care services. For this reason, and including the general economic climate at present, this hospice support house model does not have some of the high costs that other community based hospices have i.e. a director of nursing salary. Our business analysis demonstrates to us that this model, which will include the rental and general running costs of the house and the staff required, is less than half of what it costs to run a six-bed free standing hospice facility (based on figures provided by the Toowoomba Hospice). Importantly, this cost is reduced by the establishment of a second support house as the staff is shared over two sites. It certainly is the case that this model offers a cheaper and viable alternative to expensive hospital beds. Given also that funds need to be generated through the community this lower costing means that this model is much more sustainable. Consider Premier Bligh’s comments about many people in acute care beds, costing up to \$1000 per day, who do not need to be there or could be medically cared for in other settings at a cheaper price. We are such a setting, with our hospice beds costing approximately \$100-150 per day. On top of this daily costing the SCCH charity has other financial obligations including volunteer and project coordination and administrative fees. Overall, this is a much more cost effective way of providing end of life care services for those people who do not need to be in our costly acute care settings.

Is there a gap in service? Are we duplicating services?

We maintain that there is currently a gap in services for people who are dying here on the Sunshine Coast. One reason for this is there is not that second option of a hospice bed for people to access. Our staff, just like other palliative care and community staff, has to turn people away who are in need. This is simply not acceptable in our affluent society. We are definitely not duplicating services, but rather are merging with the local primary care and community services that provide excellent end of life care. This is especially important given that PCA, as mentioned above, state that most people who die generally need the primary care services from their local community and may occasionally have need for a specialist palliative care service. Our hospice support house model provides a balance between the two. We think that this then moves us closer towards a population-based approach as advocated by PCA.

What we are doing at present?

Currently the services we are offering include outreach hospice and grief counselling, education to primary health and community care providers about end of life care and loss and grief, and outreach hospice support volunteers. We are planning to pilot our first hospice support house in early 2010 and until that time we will continue working on setting up the facilities and compiling our standards. Of course, a lot of our time is also spent on fundraising and public relations activities. Finally, we are currently in negotiations to establish a grief and loss education centre on the coast.

We’ve certainly been in the media!

We have had a lot of media attention. This has been both a blessing and a curse. The blessing has been that so many people have been talking about the care of the dying, which is a wonderful thing, especially at the start of national palliative care week. The curse has been that the media, of course, write what they wish to write and there has been a lot of misinformation in these accounts. In fact, quite a bit of misunderstandings and assumptions have surrounded us for the last few months. One of them is that the residents of Doonan are against the hospice support house. This is simply not true. The vast majority of them are in support of the hospice. The few that have concerns have been addressed at informal meetings over the last two months. This is, in part, the reason for the creation of this document - so that an accurate understanding of what we are trying to achieve here at the Sunshine Coast Community Hospice can be provided to anyone who wishes it. To this end, please do not hesitate to contact Sue, Terry or Monika if you have any questions, concerns or suggestions. Please contact Katie Rose Cottage at 5471 1793 or the Sunshine Coast Community Hospice administration office on 5478 8153. Also, we would be more than happy to organise for you to visit the premises if you wish.

The final word from our Patron – Peter Wellington, MP.

In addressing the Queensland Parliament recently (3rd June, 2009), Peter was quoted as saying:

“On the issue of building the health system, I use this opportunity to flag that I believe Queensland Health can do more in supporting the not-for-profit community hospice sectors in our community. For the record, I am patron of the newly formed Sunshine Coast Community Hospice Centre on the Sunshine Coast. Only last month we officially opened our very first hospice, Katie Rose Cottage, at Doonan. I can see the possibility of one day a new, real partnership developing between the community and Queensland Health in making sure that people can always pass away with dignity and without pain in a place of their choice. When I look at the services that can be delivered through not-for-profit hospice services, I believe there are some real financial advantages for the government and the Treasurer. Where volunteers are involved, I think there are some real win-wins for our not-for-profit hospice sectors and Queensland Health and the government”.

- A Home for you, when you can't stay at Home –

Sunshine Coast Community Hospice

PO Box 56

Cooroy Qld 4563

Telephone: 61 7 5471 1793

CH: 1684 ABN 59 111 950 924

www.sunshinehospice.org.au

admin@sunshinehospice.org.au