

# The Katie Rose Cottage Model

## A Hospice Support House

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. 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 Palliative Care Unit 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 care giver may have, and therefore what level of confidence they have in managing dying at home
- Financial restraints
- What support services are available in their own community
- The perceived safety of the hospital setting
- The increased 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, we need to 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 addition of a ten bed palliative 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 resigned from 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 provide ongoing staffing costs. Recognising the high cost involved in establishing a hospice facility has translated into an adapted model of care – The Katie Rose Cottage Model.

**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.**

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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.

The Katie Rose Cottage Model is similar to several projects which commenced in the early 1980’s in the United Kingdom. These small care homes provided support to the terminally ill and their families by working in professional partnership with the local community palliative care providers and GP’s. 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. The support homes with 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.

We intend to pilot this type of small hospice support facility at Katie Rose Cottages, equipping and adapting it for people with terminal illness and draw upon the local community nursing services and GP’s to provide the clinical care. This approach has, in many ways, paved the way for 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 of all required modifications and first option to purchase.

Regional council planning approval from the Sunshine Coast Council has been given. 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 eg. 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 three beds, but once we have piloted this model we plan to lease a second property with at least another three hospice support 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.

[sunshinehospice.org.au](http://sunshinehospice.org.au)

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- 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. Katie Rose Cottage has particular admission criteria 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.
- Consent for support service to be given by Katie Rose Cottage is signed by the guest or carer.
- A Palliative Care 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 at the hospice support house includes:

- Hospice Co-ordinator
- A Registered nurse who is Cert IV Training and Assessment certified (2 days a week)
- A Registered nurse employed each day (7 days a week) from 08:00hrs to 16:15hrs.
- A Registered nurse will be on call evenings and overnight and if required will stay residential at Katie Rose Cottage to support the volunteer carers.
- Two part time Loss and Grief counsellors
- For out of hours PRN medication dispensing and in the case of no family or friends being available. a RN will be available.
- Hospice support volunteers will be rostered over 24 hours and trained to meet palliative care standards. Each volunteer holds a current Blue Card.
- Mandatory training to support workers includes Occupational Health and Safety, First Aid, Manual Handling, Infection control and Fire Safety

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.**



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Every Moment Matters

### **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 peoples 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.

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### **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 us how this is any different from the home setting. Well it is and it isn't. Let it be known, however, that if it is a person's first choice 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 to 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 registered nurse 7.6 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 counsellor each week which is again 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 eg. 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
- GP's 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
- Guest is required to have a 6 month prognosis
- Food, laundry and other amenities provided
- Hands-on 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
- Access to specialist treatments of care – hairdresser, beauty therapist and nail care.
- Guest is encouraged to live until they die
- Library facilities available
- 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 for 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 supported facility 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. 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 prognosis until death.

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 able to provide support to people who are terminally ill with no family or carers. KRC does also provide support and a place for terminally ill children and their families. What standards and guidelines will we be following?

The Sunshine Coast Community 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 SCCH does intend to work towards an accreditation process for Katie Rose Cottage.

### **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. 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 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 hospices have. That is a director of nursing salary. Our business analysis demonstrates

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to us that this model which will include the rental and general running costs of the house and the staff required is less than a third of what it costs to run a free standing hospice facility (based on figures provided by Toowoomba Hospice).

Importantly, this cost is reduced by the establishment of a second site as staff are 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 \$1,000 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 around \$200 per day per bed in a 3 bed setting, however with 6 beds this would then reduce to around \$150 per day. On top of this daily costing, the SCCH has other financial obligations including administration fees and ad hoc projects from time to time. SCCH has other financial obligations including volunteer and project co-ordination and administration 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 that 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, states 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 support and outreach hospice support volunteers. Grief and loss Support Groups will be commencing in February 2011 at Nambour. Katie Rose Cottage is adapted and totally equipped to provide care to three guests and their carers.
- The Co-ordinator and Registered Nurses are employed and have all undertaken orientation and mandatory training.
- The Memorandum of Understanding has been written and available for nursing services to read.
- The Medication Policy for Katie Rose Cottage is available for GP's and the nursing services to read
- Volunteer Support workers have been orientated and trained.
- Mandatory training undertaken by a Certificate IV trainer.
- A Registered Nurse employed each day (7 days a week) from 08:00hrs to 16:15hrs. The Registered Nurse will be on call evening and overnight and if assessed as necessary will stay overnight.
- The staffing ratio for Katie Rose Cottage will be two support workers on site 24 hours.
- Carer / family members are most welcome to participate in their loved one's care
- Katie Rose Cottage can provide various items of equipment to assist with the care of the terminally ill, free of any personal cost eg. Wheelchairs, shower chairs, wheely walker, over toilet chair and specialist recliner chair.
- Specialist Grief and Loss Counsellor is available to support the Guest, Carer and Katie Rose Cottage staff and volunteers.

***Katie Rose Cottage ... a Home for you, when you can't stay at home.***