

A 10-step guide to hospice development in Queensland



**What to think about
before you start a hospice**



PalliativeCare
QUEENSLAND

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Acknowledgements

Palliative Care Queensland (PCQ) acknowledges the Traditional Custodians of the lands and seas on which we live and work, and pay our respects to Elders past, present and emerging.

This publication is an initiative of the Palliative Care Queensland Hospice Services Network, as part of the PCQ Palliative Care in Queensland program.

PCQ wishes to thank all of our stakeholders who have given their valuable time and provided their expertise to help guide the development of this publication. We greatly appreciate the contributions everyone has made in sharing experience, knowledge and time with us.

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To reference this document:
Palliative Care Queensland (2019).
A 10-step guide to hospice development in Queensland.
Published on website: www.palliativecareqld.org.au

Funded by



Palliative Care Queensland wish to acknowledge the generous support from the Queensland Government in funding this project.



We believe that the way we care for our dying is a significant indicator of the kind of society we are.



About Palliative Care Queensland

Palliative Care Queensland (PCQ) is the peak body for palliative care in Queensland. PCQ has been operating for more than 30 years, has over 400 members and is a founding member of Palliative Care Australia.

PCQ members include health professionals across all sectors of health, specialist and generalist palliative care services, aged care, disability care, peak bodies, as well as consumers and interested members of the Queensland community. Collectively, the PCQ membership body holds tremendous knowledge and wisdom about the challenges the sector faces and the opportunities those challenges can bring.

Our priorities are that:

- All Queenslanders are able to live every day until their last
- All Queenslanders are able to have a dignified death, regardless of their illness, age, culture or location
- All Queenslanders have access to a supportive social network at the end phase of life and have the choice of quality palliative care

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About this guide

In 2017, we established the PCQ Hospice Services Network with an aim to connect, promote collaboration and provide a collective voice for the eight existing Queensland Hospice Services.

In March 2019, this network facilitated the first National Hospice Symposium on the Gold Coast to bring the existing and interested hospices together. Following the successful Symposium, we have put together this small publication to guide community groups inspired to start a hospice.

This publication aims to provide a basic guide for people with a motivation to start a hospice in Queensland. It shares the wisdom from people who have experience in the area and provides a clear guide of key considerations to ensure all hospices are well thought-out and connected to existing services before the community is engaged to fundraise.

This guide is developed in collaboration with the PCQ Hospice Services Network. These hospice services have given their time, shared their stories and provided advice to support other like-minded groups to provide care to their community members at the end of life. Palliative Care Queensland has compiled this guide with the support of Queensland Health. At the time of writing this guide there are eight operating Queensland Hospice Services.

- [Karuna Hospice Service](#)
- [Cittamani Hospice Service](#)
- [Little Haven Palliative Care](#)
- [Ipswich Hospice Care](#)
- [Toowoomba Hospice](#)
- [Hopewell Hospice Services](#)
- [Hummingbird House](#)
- [Katie Rose Cottage](#)

In addition, two other hospices have secured funding either from the Government or community support to secure land to build a hospice.

- [Sunshine Hospice](#)
- [Fraser Coast Hospice](#)

Furthermore, we are aware of at least two other hospice groups in Queensland currently developing their models of care.

We also acknowledge the great work of Carolyn Mandashoot who helped to bring this guide together and to sincerely thank all the hospices who shared their wisdom to create this publication.

We hope this guide is useful and wish you all the best in the growth and development of your hospice.

Warm regards



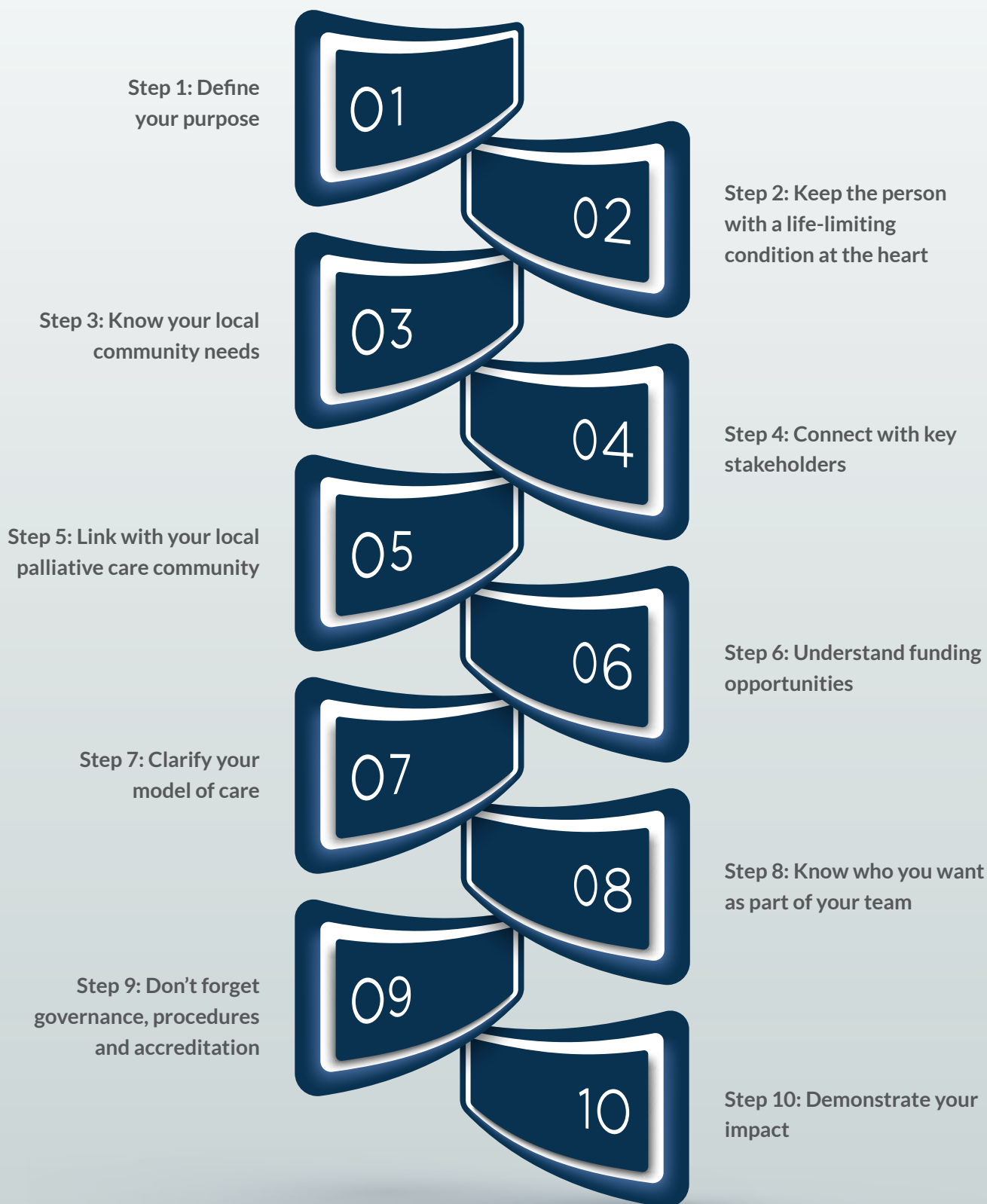
Shyla Mills

CEO, Palliative Care Queensland



A 10-step guide to hospice development in Queensland

This Palliative Care Queensland publication aims to provide a basic guide for people with a motivation to start a hospice in Queensland. It shares the wisdom from people who have experience in the area and provides a clear guide of key considerations to ensure all hospices are well thought-out and connected to existing services before the community is engaged to fundraise.



What is a hospice?

Hospice care is a style of care, rather than something that takes place in a specific building.

It seeks to improve the quality of life and wellbeing of adults and children with life-limiting conditions, by honouring the diversity and uniqueness of each individual, with a goal to help them live as fully as they can in the precious time they have left.

Hospice care can be carried out in the person's home or in a home-style facility so that all family members can be active participants in their care, and includes bereavement follow up. Some hospices provide a day respite model of care.

The hospice model of care is holistic, person-centred and specialises only in care at the end of life. The hospice model combines both medical and social domains of care, as hospices have strong links with their local community and have a particular focus on community engagement and community capacity building. Hospices are funded through a combination of Government funding and public donations.

Hospice teams provide comprehensive comfort care to their local community members who are at the end of life or are bereaved.

Pastoral care may be inferred but not specifically included. They play a large part of our role and their role is very different from counsellors or therapists etc.

Hospice teams usually have formalised partnerships with their local hospitals, palliative care units and community nursing and package providers, which promotes smooth transitions between environments. While many hospices can provide complex care management, the hospice model allows for the hospitals/palliative care units to focus on the more complex care requirements which may require resources only available in acute hospital facilities.

Hospices aim to feel more like a home than hospitals or palliative care units do. They aim to meet their communities wish to 'die at home' or 'place of choice'.

They can provide individual care suited to the person who is approaching the end of life, in a gentler and calmer atmosphere than a hospital and can provide care closer to their own community.

Defined by the PCQ Hospice Services Network 2017, adapted from: <https://www.nhs.uk/Planners/end-of-life-care/Pages/hospice-care.aspx> and <https://www.hospiceuk.org/about-hospice-care/what-is-hospice-care>.

Key fact: It is important to know that there is no one definition of hospice care in Australia or internationally. In the USA hospice is defined as care provided to those with a prognosis of less than six months, while in the UK, Canada, New Zealand and Australia it does not apply. When reviewing hospice models and systems internationally, ensure you understand their definitions and care models.

Step 1: Define your purpose

When a group of people decide to start a hospice, it can be motivated by many reasons, some may include:

- personal experience of losing a loved one
- longing for a service which meets their needs
- a bad experience in a hospital/aged care facility/dying at home
- deep sense of community support to increase opportunity to help those at the end of life
- wanting to increase options of care at the end of life
- experience with other hospices and wanting to start one in another area

Understanding these motivations are an important first step and the second is to define your key purpose. This is essential to ensure your journey throughout hospice development is not swayed and your group has a collective vision that can be articulated to everyone on the way. Your key purpose needs to be inspirational, honest and focused.

“

“We had major sponsors and donors who believed in our passion and vision, so inspiring people was an absolute essential.”

Deirdre Hanna (Hopewell Hospice)

Brainstorming questions to assist you to define your purpose:

- Who are we?
- What do we want to achieve?
- Who do we want to benefit?
- Why do we want to do this?
- How does this help our community?

Step 2: Keep the person with a life-limiting condition at the heart

As the Greek Physician Hippocrates said, “it is more important to know the person who has the disease than it is to know the disease that the person has”.

Hospice development usually takes years and involves many people and processes; it’s critical that the person with a life-limiting condition is never lost in the process.

It’s important to clearly define your motivation from the very beginning and ensure this is used to benchmark your key decisions, plans and processes throughout the development and once your hospice is up and running.

“

“Our approach to palliative care ~ every patient will have different needs and care will be individually tailored to those needs.

At the heart of our mission is enhancing the quality of remaining life, so that those in the final stage of life can live as fully, independently, and comfortably as possible. Our model of care values early access to palliative care at any time in the disease trajectory.”

Sue Manton (Little Haven Palliative Care)



Step 3: Know your local community needs

“

“Gympie has engaged with our vision it ‘takes a village to care for their dying’ and the ripples of this vision have spread out into the community.”

“A compassionate community caring for our own.”

Sue Manton (Little Haven Palliative Care)

Hospices develop out of a community need. It is essential that you know exactly what your community needs and why. A hospice might not always be the answer to your community need when you delve down into it. Have an open mind and ensure you listen to your local community.

Before you conduct a community meeting/forum or a community survey, it is recommended to gain a fundamental understanding of the existing health services in your local community and what relevant plans are in place for the future; your community is likely to ask you this, so it is essential to be prepared.

You don't want your hospice to become an isolated pocket or be in competition with another service. You do want the hospice to be of benefit, work in collaboration and be an enabler for people with a life-limiting condition to receive the care that they need within their local community.

Once you understand your local health service, check in locally by doing your own community engagement research. Research and analyse the existing services and supports (search for both formal and informal supports) ie. local newspapers, Facebook community groups, churches, GP's, home care services, local hospitals, Specialist Palliative Care services, Residential Aged Care Facilities, local hospitals, service clubs, 24 hour supports (both close by and further afield).

Undertake some common journey pathway mapping – what are common stories/pathways for people in your community when they die, what is working and what is not working and why? Think about how your hospice will help this. It is important to note that your hospice will not be the only solution, it will be part of the bigger solution; it needs to be integrated as a whole of service model.

Now that you have an idea of your model of care, build your profile up within the community with community engagement activities – ie. a forum or a survey to gain interest and give your community members a voice for them to tell you what they need. This will be critical information to demonstrate that your local community is behind you and will support your hospice.

Handy hints:

Understand local palliative care providers and services, scope the landscape and look at the following:

- What is already in place?
- What is not in place and is needed?
- Look at the demographics - what is happening with population trends?
- What do you want to do?
- Who is already doing it?

“

“We have to actively network in the community promoting the awareness of what services the Toowoomba Hospice provides. Also, we have a very positive working relationship with the three local hospitals as well as the medical fraternity ie. Physicians and GPs. Pastoral Care also plays a vital role with us in the delivery of very professional palliative and respite care.”

Graham Barron (Toowoomba Hospice)



Step 4: Connect with key stakeholders

Hospices don't function in isolation, they work in collaboration with existing health and community services, supports and groups. Therefore, identifying and building relationships with key stakeholders is critical.

Initial conversations with these key stakeholders should not focus on funding, they should focus on demonstrating your purpose, local need and collaboration opportunities.

“

“Education has been a major part of our journey – we advertised widely and had hundreds of people interested in training which spread the hospice word widely in our community. We passionately pursued Health Department Ministers and bureaucrats, sent out hundreds of newsletters in our area and got a lot of media coverage including front pages in local newspapers and TV. We wrote to all the local clubs and got speaking opportunities.”

Deirdre Hanna (Hopewell Hospice)

Potential key stakeholders may include:

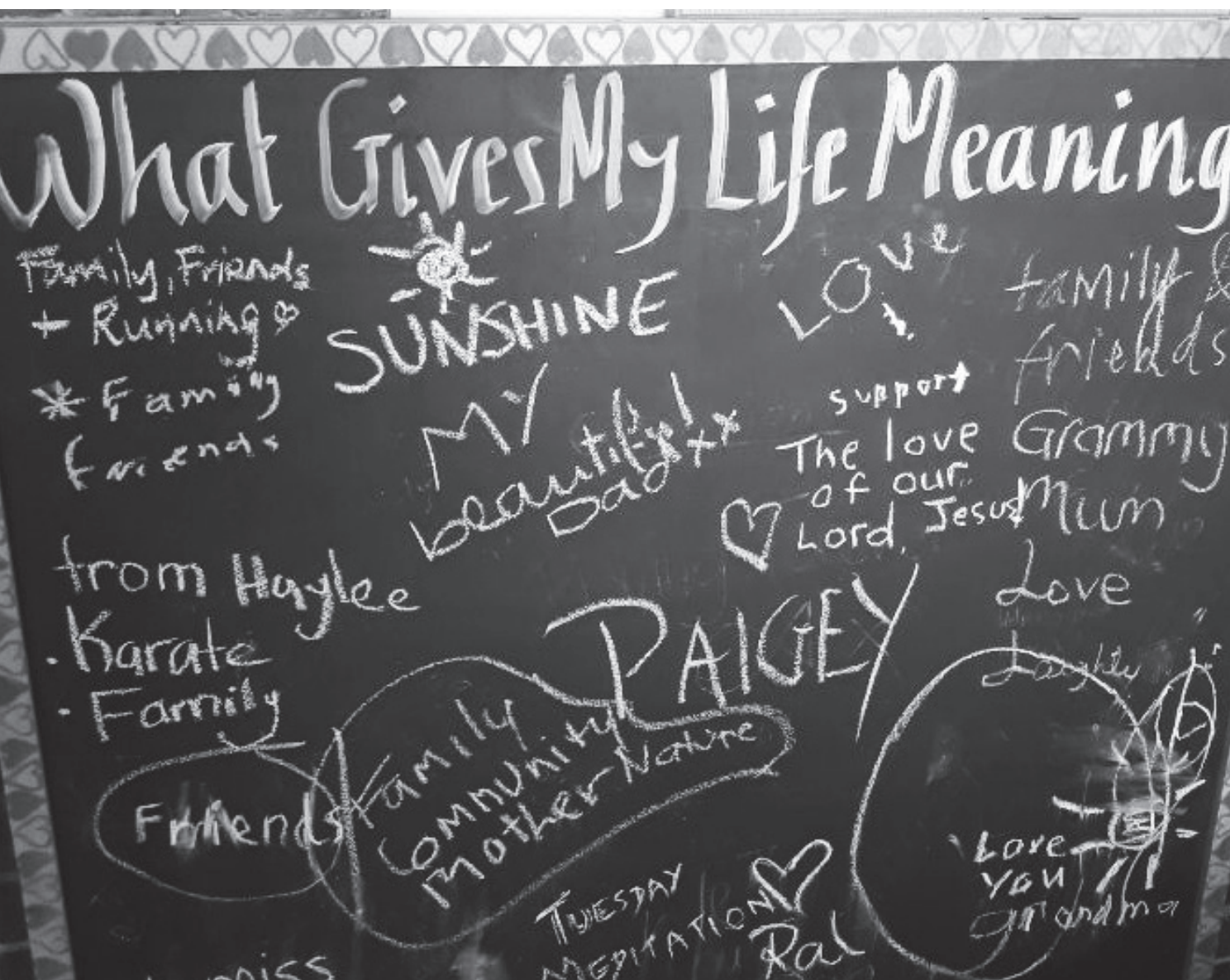
- Specialist palliative care services
- Primary Health Networks
- Federal, State and Local representatives of government
- Aged Care – both residential and home care
- General Practices
- Community Groups – service clubs, churches, other groups
- Palliative Care Queensland
- Community supporters/sponsors
- Media

A key stakeholder is your local community and how your local community accepts and respects your hospice. Rather than a stand-alone new venture, your hospice should be seen as something grown and owned by the community.

“

“Having earned the respect of the community, Little Haven in return receives enormous recognition and support locally. We are often told when employers poll their staff about where they would like sponsorship dollars/donations to be directed, Little Haven is unanimously the name put forward. NGO’s know if you want to draw from the community you need to be responsible with their money and serve that community.”

Sue Manton (Little Haven Palliative Care)



Step 5: Link with your local palliative care community

Hospices are part of palliative care services and supports offered throughout Queensland. It is critical that there is ongoing dialogue with the Queensland Health Specialist Palliative Care service in your region to ensure the hospice is seen as part of the strategic plan to support end of life within your region.

It is essential to be connected to the “bigger picture” of palliative care – the peak bodies and national projects which advocate for improved service systems and supports.

“

“As an individual or a service, I can make a difference with my patient or my community. But it is only when we join in with the collective voice of Palliative Care Queensland that we can collectively advocate for all Queenslanders.”

Matthew Cooper (Cittamani Hospice board member and PCQ Life Member)

Palliative Care Queensland

We recommend you becoming an organisational/individual member of Palliative Care Queensland – this is the statewide peak body for palliative care. Palliative Care Queensland supports you through providing linkages to services, supports, policies and education.

Palliative Care Australia

We recommend you sign up to the Palliative Care Australia e-news and review their relevant key documents, particularly:

- [Palliative Care Service Development Guidelines](#)
- [National Palliative Care Standards](#)

“

“Benchmark with other hospices in Australia and overseas to inform your grant writing and business proposals; demonstrating current costs of palliative care patients in the acute sector versus predicted costs of hospice and home-based palliative care to present to all stakeholders.”

Deirdre Hanna (Hopewell Hospice)

Standards, benchmarking and accreditation

As hospices provide a health service, it is essential that they are accredited. This ensures you are providing a quality service.

We also recommend that you participate in [Palliative Care Outcomes Collaboration \(PCOC\)](#) and [Palliative Care Self Assessment \(PaCSA\) Online Portal](#)

- We recognise these programs can be resource intensive, but participation from the beginning of your service delivery will ensure that you are able to demonstrate the quality of palliative care your hospice provides.



Step 6: Understand funding opportunities

Funding is always a critical component of starting a new initiative and ensuring its sustainability. Palliative Care Queensland recommends a multifactorial approach to funding in order to limit the risks as much as possible.

“

“Our new hospice will be purpose built. It will be licensed and accredited. Licensing will allow access to private health fund rebates and DVA. We will continue to run four op shops (and hopefully more), engage in ongoing and major fundraising campaigns, receive donations and hopefully receive some bequests; although bequests are not considered in any annual budget as they are an unknown quantity.”

Sue Mason-Baker (Sunshine Hospice)

Current funding methods of Queensland Hospices include:

- Service Level Agreement with Queensland Health
- Service Level Agreement with the Commonwealth Department of Health
- Private Health Insurance
- Department of Veterans Affairs (DVA)
- Scripting funding from Hospital and Health Services
- Medicare rebates
- Fee for service
- Fundraising
- Sponsorship
- Bequests
- Donations
- Grants

“

“Talk with government at all levels to determine ‘support’ for your venture – focus mostly on State and Federal to determine the degree of support, in every respect, more importantly funding for set up and recurrent funding to contribute to operational costs.”

John Gabrielson (Katie Rose Cottage Hospice)

Step 7: Clarify your model of care

A model of care broadly defines the way health services are organised and delivered. It outlines best-practice care and services through core components (the components describe who delivers which particular intervention, when, where, how, to whom, and for what purpose) and principles that sit within a framework that provides the structure for the implementation and subsequent evaluation of care¹.

Aspects to consider in relation to models of care include:

- Eligibility criteria
- Service delivery
- Care pathways
- Referral pathways

You will need to consider what skills, systems, processes and resources are required to fulfil this model of care. We recommend, rather than ‘reinventing the wheel’ completely, new hospices start with a similar model of care to an existing hospice.

“

“We believed strongly in ‘the model’ - creating a loving space that feels very much like home, hence the ‘cottage hospice’ model. That service is underpinned by strong clinical skills, significant palliative care experience and our team operates in an environment of quality, care, love, respect and compassion.”

John Gabrielson (Katie Rose Cottage Hospice)



¹From Palliaged website: downloaded on 21 May 2019 from <https://www.palliaged.com.au/tabid/4501/Default.aspx>

Step 8: Know who you want as part of your team

Model of care is important, and staffing is an essential aspect.

You will need to think about - what staffing structure do you want, what is essential and what is ideal?

Once this is decided you will need to cost it out and look at developing a workforce plan – particularly for regional areas where it can be more difficult to attract qualified and experienced staff.

It is also essential to remember that Palliative Care is a holistic model of care, not just medical. It is important to consider staffing requirements for social, emotional and spiritual care as well.

“

“Karuna’s staff and volunteers are of diverse faiths and spiritual traditions, but united in values and how to serve others with compassion and kindness. Karuna provides a trusted source of knowledge and compassion.

Backed by a modern business structure, our nurses, counsellors, educators and volunteers provide much needed services to thousands of people in any given year.”

Tracey Porst (Karuna Hospice Service)

Volunteers are commonly referred to as the “backbone of palliative care”. They are a great way of engaging the local community and promoting death literacy. However, it is essential that they are screened, trained and coordinated.

“

“Little Haven has a very high volunteer retention rate with 140 trained volunteers contributing over 13,000 hours annually. Many of our volunteers come with a personal connection and a deep sense of gratitude to the service, wanting to “give back”. In turn they report gaining strength, a renewed sense of purpose and develop skills and friendships they never dreamed possible.”

Sue Manton (Little Haven Palliative Care)

It is also important to ensure you consider how you are going to care for your staff and volunteers – the philosophy of care that you provide to your clients should also be mirrored with your staff and volunteers. This is an essential component of hospice care and this assists to attract and retain staff.

Examples of different positions at other Queensland Hospices:

- **Medical staff** – Specialist Palliative Care Nurses, Nurse Practitioners, Assistant Nurses, GP's, Specialist Palliative Care Doctors.
- **Allied Health** - Social Workers, Occupational Therapists, Physios, Pharmacists, Complementary Therapists, Art and Music Therapists, Counsellors, Psychologists, Spiritual carers.
- **Office and Management** – Business Managers, Administration Staff, Accountants, Legal, Committee members.
- **Volunteers** – Volunteers, Respite, Fundraising, Cleaning, Equipment maintenance.



Step 9: Don't forget governance, procedures and accreditation

A hospice is a business, therefore you will need to ensure everything is in place to operate effectively within the legal and health systems.

“

“We wanted the community involved in the culture of caring, and invited all to be part of the Hopewell gathering. We wanted a very inclusive culture of hospitality and teamwork (including our residents) we wanted the buildings and gardens to be serene and hospitable but we struggled with one part of an integral worldview - finance and governance.”

Deirdre Hanna (Hopewell Hospice)

Below are some recommendations of websites and links to visit:

State and Local Government

Starting a Business – Business Types and Legal structures

- Start ups
- Setting up your business
- Business Legal structures
- Registering a business name
<https://www.business.qld.gov.au/starting-business/types-legal-structures>
- Queensland Health – [Care at the end of life](#)
- Commonwealth Department of Health – [National Palliative Care Strategy](#) and [other programs](#)

Licensing, Registrations and Legal Obligations

- Legal obligations for business
- Australian Business Licence and Information Service (ABLIS)
- Codes of practice
- Business rights and responsibilities
- Register a business name
<https://www.business.qld.gov.au/starting-business/licensing-obligations>

Australian Business License and Information Service (ABLIS)

- A comprehensive guide of what will be needed both locally and state. <https://ablis.business.gov.au/>
- Accreditation requirements <https://www.achs.org.au/>

“

“Ask what funding is available. Align with regulated industries – it is not a cottage industry any more. There are now enormous amount of laws and regulations, financial and burecratic hurdles.”

Elizabeth Davis (Ipswich Hospice)



Step 10: Demonstrate your impact

The productivity commission, Reforms to Human Services (2018) provided recommendations into end-of-life care particularly focusing on community care and highlighting that many people would chose to die at home in their community. Hospices are an enabler to meeting this community need; enabling community members to receive their care choice to die at home or in a home-like environment close to their community.

"Hospitals play an important role in the delivery of end-of-life care. Hospital accreditation standards will, from 2019, prescribe a range of best-practice elements for end-of-life care. This should drive the changes that are needed to improve hospital care. However, dying in hospital is not the preferred outcome for most Australians. Too many people who, with appropriate support, could and would choose to die at home or in their aged care residence, die in hospital. Providing end-of-life care for these people where they live would better meet their clinical needs and reflect their choices."

Productivity Commission, Reforms to Human Services (2018)

But how do hospices demonstrate this? How will you know you are making a difference and how do you share this with your community? Demonstrating your impact is critical.

“

"Over the years we have grown into the Gold Coast Community and have become asset rich because of our social impact and the generosity of donors and sponsors, while still struggling for operational funding. Consumer (family) feedback is important. Family is considered to be the unit of care in our care plans, choices available about where to die, and employee feedback surveys for sense of belonging to our community.

Bereavement follow up care, and annual memorial services are important as accountability to patient, family and community – keep everyone involved and your volunteers and the whole area will grow in number and in death literacy and awareness. The medium IS the message."

Deirdre Hanna (Hopewell Hospice)

In 2019, Palliative Care Queensland launched a new program, Ambulance Wish Queensland – sharing the simple story of Betty, a 92-year old lady receiving her last wish to have a passionfruit icecream. This simple, relatable story went global, with a reach of more than 147 million worldwide in more than 15 different countries and multiple languages. Relatable stories are important and help you demonstrate to your community and potential funding bodies how your hospice is making an impact on people's health and social wellbeing.

“

“[A hospice is a] brand in the local community that is trusted and loved. Families keep coming back and keep supporting. A family member was quoted ‘can I come here when it is my time?’ People coming back as Volunteers.”

Elizabeth Davis (Ipswich Hospice)

“

“Story telling is important – the stories can provide great insights in relation to the impact on the patient and those around them. Cost saving to government is a quantitative measure. By comparing public hospital bed day costs to hospice bed day costs, an argument can be made for better use of resources.”

Elizabeth Davis (Ipswich Hospice)

Some final thoughts to share

Have absolute belief in your success

Be prepared for set backs

Be driven and unrelenting in pursuit of your vision

Be in it for the long haul – this is a marathon, not a sprint

Be prepared to give up a lot of emotional and physical energy along the way

Have a strong and skilled governance team

Your group needs to define your purpose, believe in them and have the above qualities

“

“Future hospice groups may be lucky enough to breeze through the process, but this has not been our experience.”

Sue Mason-Baker (Sunshine Hospice)

“

“When we started Hopewell in 1994, there were no other community facilities offering hospice care. If there is a vacuum in the market, fill it – if it is your passion and the culture of the community calls for hospice. If there are already too many palliative care beds in your culture or community then start with hospice in the home.”

Deirdre Hanna (Hopewell Hospice)

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