

Palliative Care Home Support Packages **FAQs**



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Palliative Care Home Support Program - FAQs

Why this service?

Surveys consistently show that up to three-quarters of Australians would prefer to die at home. The local reality is very different – only 16% of people living in Australia with a terminal illness die at home.

The aim of this new service is to increase the opportunity for people in NSW who wish to die at home to do so.

Three key points:

1. Packages comprise of up to **48 hours** of end of life care
2. Care workers delivering packages will undergo **palliative care training**
3. Packages will **enhance existing** local Specialist Palliative Care services under the direction of those services

Who can request a package?

Requests for Packages will be required to come from a member of a Specialist Palliative Care team, as agreed with participating LHDs.

What criteria will determine patient eligibility?

Access to Palliative Care Home Support Packages by patients who have expressed a wish to die at home will **only be** arranged through the local Specialist Palliative Care service. The patient's palliative care phase will be either deteriorating or terminal as well as meeting one or more of the following criteria:

- Family carer is physically/emotionally unable to continue caring at home without support
- There is limited family support
- There are specific cultural/spiritual issues necessitating extra support
- Carer stress is high
- Functional ability of patient is poor (AKPS of 40 or less, or RUGADL of 13 or more)

What support will be available under a Palliative Care Home Support Package?

Care support delivered under the package will be individually agreed between the patient or family carer and the Specialist Palliative Care team and may include assistance with activities of daily living, personal and domestic care support, shopping and household assistance - providing carers with vital support in end of life care. In consultation with the Specialist Palliative Care team and the patient's GP, it may also include basic nursing care.

How will care workers be introduced into the patient's home?

At the commencement of a package, care workers will be given the Patient Information Briefing Note by the HammondCare Package Manager. Wherever possible, care workers will be introduced to patients by the Specialist Palliative Care service representative and briefed at the patient's home by way of a handover at commencement of the package. It is acknowledged that in some remote areas this may not be possible and the introduction may need to be made by a generalist community nurse or a GP briefed by the Specialist Palliative Care team.

Will care workers be able to administer medication?

Care workers can only assist with medication from a blister pack. The palliative care specialist will provide medication advice to the informal care giver as required. In the event that a care worker is in the home of a patient overnight and a medication requirement arises, the care worker will be responsible for waking the informal care giver who will have the responsibility to manage the situation. If there is no formal caregiver, the care worker will be required to escalate to the after-hours on-call support.

How much support will be available in a package?

The provision of end of life packages is for up to 48 hours of palliative home-based care, day or night, by community workers trained for the task and working as part of existing specialist palliative care multidisciplinary teams. The delivery of the 48 hours of end of life care may be consecutive hours, or may be spread over days or weeks. It is anticipated that decisions not to admit patients to acute hospitals will greatly reduce costly and potentially distressing admissions into acute hospital beds. Package utilisation is to be decided by the Specialist Palliative Care team in consultation with the patient and family.

What if one 48 hour package is not enough?

A second package for patients needing more than 48 hours but unable to afford additional support may be requested at the discretion of the Specialist Palliative Care Team Leader.

What happens after-hours?

Care workers will have after-hours access to the Specialist Palliative Care provider's clinical on-call support. In addition, the Consortium remains committed to working with state-wide after-hours phone support systems once they are introduced.

How will these packages differ from existing general home and community care services?

These packages are unique – accessible across participating LHDs, they will provide specialised care worker support at end of life, reducing the need for patients to spend their final days in hospital. For the package period, care workers will join and be guided by the Specialist Palliative Care team, and will be supported by the team's clinical on-call back-up.

Will this service complement existing networks and primary health services?

Yes. The GP remains pivotal to the care of a patient choosing to die at home. The GP will continue to provide direct care and liaise with the Specialist Palliative Care team as appropriate. The Consortium is committed to working collaboratively with the Agency of Clinical Innovation (ACI), GPs, Medicare Locals and other relevant primary health organisations.

What will be covered in care worker training?

All care workers will have completed the Fundamentals of End of Life Care training modules listed below prior to working on the program.

1. Essence of palliative care and ethical issues in palliative and end of life care
2. Grief and loss and self care
3. Pain and symptom management and care during last days
4. Communication in end of life care

What about local health networks serving Indigenous and remote communities, particularly in rural LHDs?

The Consortium recognises the significance of local knowledge in rural areas of the needs of Indigenous people at end of life and will seek guidance from rural teams in this regard. In addition, Sacred Heart Health Service has appointed an Aboriginal Health Network Co-ordinator to oversee health care planning for indigenous patients and clients in rural and metropolitan areas. This Co-ordinator will be available for advice to participating Specialist Palliative Care teams.

How will packages be administered and governed?

Packages will be held and administered centrally by HammondCare, enabling package hours to be available for distribution to the point of greatest need. They will be governed by a Steering Committee which will include members from participating LHDs.

How will care workers be recruited and how will they be deployed, particularly in rural LHDs?

HammondCare will work with Specialist Palliative Care teams across participating LHDs to recruit and train care workers either through preferred providers or through HammondCare directly. This process will be outcome focused and guided by local intelligence and preferences. In some cases HammondCare will have an existing pool of staff available. In other cases brokered local staff may be engaged. In establishing these arrangements, it is expected that an understanding of local differences will be key to delivering successful package outcomes.

Will care worker travel time be taken into account in rural and remote areas?

HammondCare will work with each participating LHD and Specialist Palliative Care team to ensure remote patients are not disadvantaged due to additional travel time associated with greater distances. Accordingly, in principle it is proposed that an additional four hours per remote patient package would be funded out of the total annual package pool to achieve equity for rural and remote patients. Whilst an additional allowance of 4 hours would not cover all travel costs in every instance, the Consortium believes it will mitigate the impact of distance on the quantum of care delivered.