

# Palliative Care


What is it and who is it for?



**Irish  
Hospice  
Foundation**


To die and grieve well wherever the place





The information in this booklet is written for people who have been diagnosed with a life-limiting condition and it is intended to provide information about palliative care as a holistic approach that aims to make you feel comfortable and supported throughout your illness.

This information will also bring useful insights for the people close to you.





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# What is palliative care?



Palliative care is holistic care that includes looking after your physical, psychological, emotional, and spiritual wellbeing. It aims to support you, and to improve or maintain your quality of life when diagnosed with or living with a life-limiting illness.

Palliative care also supports your family or significant people in your life by facilitating open and honest communication to ensure that treatment options and care decisions align with your preferences and values.

Palliative care provides excellent symptom control so you have the added reassurance of knowing symptoms associated with your condition can be managed in a timely manner.

Palliative care is supportive care offered throughout the progression of your life-limiting illness or at phases of your illness. It will help to improve your ability to participate in your daily activities and hobbies.



**Palliative care focuses on your best quality of life. It is comprehensive, compassionate and person-centred.**



## Does having palliative care mean I'm going to die soon?

This can commonly be the first thought for people when they hear the words 'palliative care', and it was possibly your first reaction too. However, palliative care is holistic care, and it is about improving quality of life for people and their families throughout their illness.

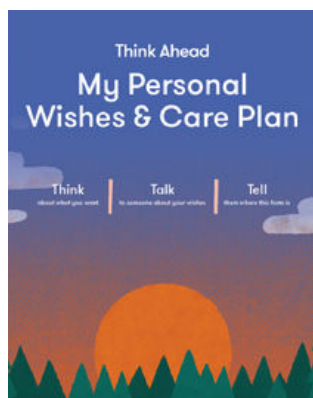
Thankfully, remarkable advancements in medicine enables a response that quickly and effectively manages your care needs to ensure you will live your life as well as possible.

A prognosis on life expectancy is very difficult to determine at the outset of any diagnosis, so whilst your illness may not be curative, it may be managed for a very long time.

Palliative care should not be synonymous with end-of-life care only as it is much more than this. Palliative care is about ‘living your best life’ and being involved with all aspects of decisions as your illness progresses.

Palliative care is about living and being able to plan for your end of life and your preferences and wishes for your future care. Irish Hospice Foundation’s ‘Think Ahead Planning Pack’ can help you discuss and record your wishes and preferences. Visit [thinkahead.ie](http://thinkahead.ie) for further information.

Palliative care support also includes your family and those special to you.





## Who provides palliative care?

Palliative care provision is the responsibility of an entire healthcare team using a multi-disciplinary approach to planning and providing care that is tailored to meet the individual needs of the person and their family. This team may include General Practitioners (GPs), Public Health Nurses (PHNs), Registered General Nurses (RGNs), Carers, Hospital-Based Healthcare Professionals, Pharmacists, Counsellors and many other allied health professionals; this is your Primary Palliative Care Team.

Specialist Palliative Care (SPC) teams become involved when complex symptom management is required. These teams can be hospital or community based. Many community Specialist Palliative Care Teams are based at your local hospice, which provide additional services like symptom control admissions or outpatient services or day-care services.

Different levels of palliative care are provided depending on the stage of your illness. More specialised palliative care will be needed as your illness progresses through a specialist team.

**Within a healthcare team, there are three levels of palliative care provision with increasing specialisation from Level 1 to Level 3.**

## **Level 1**

Level 1 is provided in any location - at your home, in hospital, in a nursing home - or while in respite by all healthcare professionals as part of their role using a non-specialist palliative care approach.

Care provision **at home** is often referred to as **primary palliative care**; this is provided by your GP/PHN/RGN/Carer/Physiotherapist/Occupational Therapist/Social Worker/Dietician/Speech and Language Therapist/Pharmacist. Care **in hospital** or respite will be provided by your medical team. This is a basic nursing and medical care needs approach. Level 1 includes managing basic symptoms and providing educational supports for you and your family.

Example: Being linked in with your Public Health Nurse will provide you with signposts to support groups, other healthcare professionals and information resources for you and those closest to you. A Public Health Nurse can organise family meetings where goals of care can be discussed as you move through different stages of your illness.

**“We cannot change the outcome, but we can affect the journey.”**

**Ann Richardson**



## Level 2

Level 2 is provided in any location - at your home, in hospital, in a nursing home - or while in respite using a non-specialist palliative care approach by your GP/PHN/RGN and Carer who have additional knowledge, training and experience of the palliative care principles and use this as part of their role.

Even though your quality of life may be more affected by your condition at Level 2 palliative care, often your primary care nursing team may refer to other healthcare professionals to assist with planning and supporting you for now and into the future. You should continue to speak with your GP/PHN/RGN and Carer about managing your symptoms and issues that affect your quality of life.

Example: Your primary healthcare team will support you in learning how to manage symptoms you may experience, focusing on reducing distress to increase the amount of comfort and control you feel.



### Level 3

Level 3 is provided in any location - at your home, in hospital, in a nursing home - or while in respite by specialist palliative care teams that are made up of healthcare professionals who work solely in palliative care and have extensive knowledge and skills in this specialty. As with Levels 1 and 2 palliative care, this can be provided to you at home, in the community or in a hospital. It is not uncommon to be discharged from a Level 3 specialist care if your needs become less complex; you can be referred again should you need it.

Example: The Specialist Palliative Care Team will visit you in your place of care and complete a symptom control assessment. They will then link in with your GP or medical team regarding any changes to medication or treatment that is needed and will do a follow-up assessment to determine their level of involvement at this stage.

**Most of your palliative care needs will be met at Levels 1 and 2.**

**End-of-life care can be provided at Levels 1, 2 and 3.**



## Who can access palliative care?

Palliative care is for anyone, at any age, who is living with a life-limiting illness. The term 'life-limiting illness' refers to any disease, condition or illness that is progressive and cannot be cured. Palliative care focuses on improving and maintaining quality of life for people who are facing the challenges associated with all life-limiting illnesses.

If you have been told you have a life-limiting illness, you can access palliative care in Ireland, and you can have palliative care at any stage of your illness at the level required. Ideally, **non-specialist palliative care** should be offered to you and begin at the time of your diagnosis and continue throughout your life-limiting illness.

In the past, palliative care was connected with the treatment of patients who had a cancer diagnosis. However, it is also available if you have other types of advanced life-limiting illnesses such as Parkinson's disease, motor neuron disease, dementia, heart failure, stroke, renal and respiratory conditions.

Palliative care can be integrated into care plans early in the course of your illness and can be provided in conjunction with other therapies and treatments intended to prolong life, such as dialysis, chemotherapy, and medication.

Providing palliative care at an early stage in a person's illness can support better management of symptoms and complications as well as in planning for future care.

## Do you have to be in a hospice to access palliative care?

**No.** As well as being available in hospices, palliative care can be accessed in hospitals, in residential centres, nursing homes and/or your home.



- If you are in hospital, your medical team may refer you to the Specialist Palliative Care Team. This initial consultation will determine your future care needs whereby you may be referred for ongoing specialist palliative care follow-up in hospital, or the team may write to your GP and PHN to support your needs when you are being discharged.
- If you are living in a residential care centre or nursing home, the staff there and/or your GP can provide palliative care to you and refer to the Specialist Palliative Care Teams to be involved in your care should your symptoms deem it necessary.
- If you are in your own home, your hospital-based medical team (if you're seeing one), your GP and/or Public Health Nurse can arrange for a referral to the community-based Specialist Palliative Care Team to involve them in your care should your symptoms require specialist input. This might involve you attending day services at your local hospice or a visit from the Palliative Care Team. These visits often happen more regularly as you near end of life. The Specialist Palliative Care Team will arrange, if possible, **free nursing care** for you at night in your final

days. This will also provide reassurance and respite for your families and loved ones caring for you at home. See [hospicefoundation.ie/nnc](https://hospicefoundation.ie/nnc) for details.





## How much is palliative care?

Primary palliative care and specialist palliative care services are **free** for all patients and their families in Ireland. Where people have private medical insurance, their insurer may be asked to contribute towards the cost of their care.

Depending on the stage of your illness, you may be entitled to a **medical card**, which is applied for by your consultant, GP or social worker, who facilitate the application process to the HSE.

Be sure to check in with your GP and local primary care team about what other free services may be available in your local area.

## Is palliative care the same as end-of-life care?

**No.** End-of-life care is an important part of palliative care provision and usually commences when a person is in their last year of life, whereas palliative care is much broader and can last for longer. Having palliative care doesn't necessarily mean that you're likely to die soon – some people receive palliative care on and off for years.

End-of-life care offers treatment and support for people who are near the end of their life to ensure their comfort and dignity. The aim is to allow someone to be as comfortable as possible in the time that they have left and making sure their preferences or wishes are respected as part of the care that they receive.

Palliative and end-of-life care also includes supporting your family, carers and those who are important to you.



This information booklet has been collated by healthcare staff in Irish Hospice Foundation who have combined expertise in the delivery of people-centred care through their nursing, social work, specialist palliative care, and health promotion background spanning over many years. All are advocates for compassionate and holistic care for patients and families.

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