

Easy Read

End of Life Care in Wales

How services in Wales should look

Information for services, patients and loved ones



October 2025

How to use this document



This is an Easy Read version of: **National Service Specification for Wales: Palliative and End of Life Care Services.**



You might need help to read it. Ask someone you know to help you.



Where the document says we, it means **National Programme for Palliative and End of Life Care and NHS Wales Performance and Improvement.** To find out more contact:

Email:

nhswe.nationalpeolcprogramme@wales.nhs.uk



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About this document



This a guide to help improve end of life care services in Wales.



It was written by **NHS Wales**.



It shows what you should expect from end of life care services.



End of life care is also known as **palliative care**. This is pronounced **pa – lee – uh – tiv**.



End of life care is for people living with serious illnesses. It is also for people who are getting older and weaker.



People think of it as being about the final days of life. But it is much more than that.



It is about supporting people to live as well as possible for as long as possible.



It is about supporting people to have dignity, comfort and some control.



It is about supporting family, friends and carers during some of the most difficult times.



This booklet will help guide staff and services to give the best possible care.



We have listened to people, families, and organisations to make this guide.



We want services to check what they are doing already. And work towards achieving what is in this guide.



We want patients and those closest to them to get care that is right for them.



Care should be based on their needs and wishes. This is called **person-centred care**. It means care that focuses on the person, their needs and choices.

Goals for end of life care

We want services to:



1. Give person-centred end of life Care.



2. Support families after someone dies.

To achieve this, services must:



- Work well together.



- Be well managed and work to improve quality.



- Provide staff with the right skills.



- Give support at the right time.



- Make sure everyone can get the same standard of service.



- Think about the needs of each person and what they want. Not just their illness.

End of Life Care in Wales



Health and social care services work together to give people end of life care.

It is provided in lots of places, including:



- Where you live.



- In hospital.



- In hospices - specialist places where people can go for end of life care.

All health and social care teams are at some point, involved in end of life care. This includes:



- Urgent care – like NHS 111, Minor Injury and A&E and out of hours doctors.



- Primary care – like your GP and Pharmacy.



- Care homes.



- Hospital teams – like surgery and cancer teams.



- Other professionals - like therapists, dietitians or occupational therapists, may also support you.



- Social care – like home care, social workers, and personal assistants.



- Charity and volunteer groups.



People may need care from lots of different services at the same time.



Services **must** work well together to give patients the right care for them, at the right time.



We want end of life care to be available 24 hours a day, 7 days a week. Things need to be improved in some areas.



Teams use safe computer systems to share information. This means you do not have to keep repeating yourself.

How End of Life services are run in Wales



Services for adults and children are run by different organisations, often working together.



For example, the NHS has different services providing specialist care.



They may also work with charities to run services.



Sometimes different Health Boards work together to get people the support they need.



We have a network to support children and young people. It is called **The All-Wales Paediatric Palliative Care network**.



Other support is not equally available across Wales. It depends on funding. For example, counselling services is different in different parts of Wales.



Services are not equal across Wales. Patients who live in countryside areas, and those living in poorer areas can find it harder to get services.



This needs to be changed. Services must be able to meet local needs.



We aim to respond to people needing care within 24 hours. We aim to respond to people needing urgent care within 2 hours.



To achieve this, we need to put time and money into getting more staff with the right skills.



Unpaid Carers play a large role in supporting people with end of life care.



It is really important that carers are supported well too.



This includes making sure they get a break.



This is really important for parents of children who have serious illnesses.



More people are going to need end of life care.



There is a growing number of people, and we are living longer.



We need to plan end of life care earlier.



Often people are given end of life care late in their illness. This means we miss the chance to improve the care they get.



There are also more people living with more than 1 serious health condition.



A lot of planning is needed to make sure the right services are provided earlier.



This will help us avoid the high cost of providing unplanned care, later in someone's illness.

Children and Young People in Wales



There are just under 4000 children and young people living with serious illnesses.



There are gaps in the services that are needed in parts of Wales. Especially in North and Mid Wales.



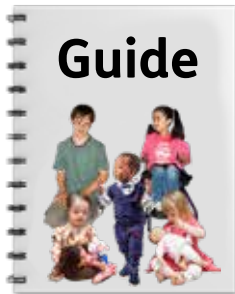
A lot of the care children need is given by unpaid carers and families.



Local health staff support as well, but they may not have end of life care skills.



The **All-Wales Paediatric Palliative Care Network** is trying to make sure they have the right skills.



We believe there needs to be a guide like this one, just for children.



But we also must make sure the main goals for end of life care are in place for all age groups.



End of life care for children and young people covers over 300 serious illnesses and health conditions.



Many children have severe disabilities and many health needs.



They may need specialist care at different stages of their lives.



Care for children and young people should be planned early. This helps them move smoothly into adult services when they are older

What future services need



There needs to be larger community teams. This will support care at home and help take the pressure off hospitals.



Out of hours services need to have more specialist staff. These are services that run evenings and weekends.



Funding needs to be fair and last a long time.



There needs to be more support for patients with complex needs and lots of conditions.



There needs to be better online services.

Support for services



We need to support services to help them run well.



For example, the role of admin staff is really important. Also good computer and online services.

What End of Life Services should look like

1. Equal care for everyone



It is important for people and their families to get well planned care. It must be right for them and given at the right time.

What patients and families should expect:



- No waiting for care because of where you live, the time of day.



- Health staff will understand when you need end of life care and act quickly.



- If things change you will get a fast response from the right team. Whether at home, in hospital or somewhere else.



- Children and young people's needs will be met.

2. Person-Centred Care



End of life care must be right for each person's needs, wishes and values.



It is about treating the whole person and not just their illness.



Care teams must work together to provide the right support.

What patients and families should expect:



- Your care will be about your values and choices.



- You will be supported emotionally and socially. Not just medically.



- Care plans will be made with you, not for you. They will be reviewed as your needs change.



- There will be support for your family. Including breaks, counselling, and help with day-to-day life.



- We will not leave loved ones to deal with everything on their own.

3. Services working together

What patients and families should expect:



- You will not need to keep repeating yourself.



- Everyone involved in your care will share information well.



- If you need help in an emergency, it will be clear how to get it.



- If you need to change teams it will be planned well. For example, moving from children's to adult services.

4. The right skills for staff



Staff should have the right skills to provide the best care. This means ongoing training and keeping improving.

What patients and families should expect:



- You will be supported by staff who are trained, confident and kind.



- Everyone involved in your care will have the right skills.



- Staff will listen to you, whatever needs you have.



- Training will include supporting children, disabled people, older adults and complex needs. And those caring for them.



- If English or Welsh is not your first language, staff will do their best to support you.



- We will ask for people's views and keep improving.

5. Well managed, high quality services



It is important that services are managed well and have strong leadership.



We must check services are high quality, safe and planned well.

What patients and families should expect:



- You can feel confident that your care is safe and good.



- There are leaders in every Health Board who are responsible for high standards.



- We will listen to people's experiences and keep making improvements.



- We are looking to follow the best examples in the world. Not just raising standards in Wales.



- You will get the best possible care wherever you are in Wales.

On **page 7** we talked about wanting services to achieve these things:



1. To provide person-centred end of life Care.



2. To provide family support after someone dies.



We will now talk more about these important goals.

Giving person-centred end of life Care



We want people to get expert care and support.



Staff will be able to manage emergency situations and complex needs.



We want people to get care to support all parts of their life. For example, your body, feelings, beliefs and what matters to you.

What patients and families should expect:



- You will be able to see or speak to staff with high level training in things like managing pain, symptoms, emotional support.



- Support wherever you are by the right staff.



- Hospice specialist care available 7 days a week.



- Children and young people will be cared for by staff who are specially trained.

Providing family support after someone dies



Everyone experiences grief at some point in their lives.



It is a natural response to loss, but it is very personal for everyone.



Although it is normal it can have a huge effect on someone.



We want people to have the support they need, when they need it.

What patients and families should expect:



- Support will be available for you and your family before someone dies. This can help you prepare.



- Support will also be available for you and your family after someone dies.



- You will not be left alone to deal with grief and loss.



- Support can start before someone dies and carry on after.



- Services will offer counselling, peer support and advice. Peer support is support from people who have gone through something similar.



- Support will be available for everyone including parents who lose a child, loss of pregnancy or baby loss. And children who lose a parent.



- You will be treated kindly and with respect.