



Preparing for palliative care

The information sheet below talks about difficult topics like **death**.

Death means that a person's body has stopped working and their life has ended.

You can ask for help to read the information.

You could ask

- a family member
- a support person
- a friend.

You can talk to a person you trust about your feelings.

You do not need to read all the information at the same time.

Some words in this sheet are written in **bold**.

Bold means the letters are thicker and darker.

These words in **bold** are explained.

The first part of this sheet has information about **palliative care**.

Palliative care is help for people who have a serious health condition that they will die from.

The second part of this sheet has questions and empty boxes to write or draw in.

This sheet was made for people with intellectual disability and their **supporters** to help them **prepare** for **palliative care**.

Supporters are people that help a person with care or daily life.

Supporters might be friends, family or paid and unpaid carers.

To **prepare** means to get ready for something.

This sheet helps **prepare** people by helping them to

- Understand what **palliative care** is
- Think about questions they might want to ask.

About palliative care

Palliative care is help for people who have a serious health condition that they will die from.

When a person dies it means that their body has stopped working and their life has ended.

Palliative care helps people manage their **symptoms** so they feel well until they die.

Symptoms might be things like having pain or feeling sick.

Palliative care will not make a person's life longer or shorter.

Palliative care is managed by **health workers**.

Health workers might include doctors and nurses.

Other people can also help with **palliative care** like **supporters**.

Palliative care can offer different support depending on a person's needs at different times.

Support might also be called **treatments**.

Treatments are things that can help a person feel better.

Treatments can be **therapies** and **medicines**.

Therapies are activities that **health workers** use to support a person for example to feel less pain.

Medicine is sometimes called medication or drugs.

Medicine can be in

- A tablet
- A pill
- A drink
- An injection.

A person might get **palliative care** at the same time as other **treatment** and care.

What palliative care might help a person with

A family doctor and other **health workers** during **palliative care** might help with

- Pain
- Sickness
- Emotions such as sadness or worry
- Continuing everyday activities
- Support with movement
- Support with religious beliefs or cultural issues
- Support for family and friends.

Health workers will talk to the person getting **palliative care** about different **treatments** that might help.

The person getting **palliative care** or their **guardian** will have a choice in what services and support they have.

A **guardian** is a person who helps someone make decisions about parts of their life when they cannot make decisions by themselves.

Where palliative care might happen

Palliative care can happen in different places.

A **palliative care** team might ask the person

- Where they would like to get **palliative care**
- Where they might like to be at the end of their life.

Palliative care might happen

- **In the community**

Health workers that work in the community provide support to people in their homes or near their homes in buildings called clinics.

Palliative care in the community might also include a person's family doctor.

- **In a hospital**

There are different parts of a hospital that a person might get **palliative care**.

As an inpatient in a hospital

An inpatient **palliative care** unit is a special part of a hospital.

Being an inpatient means staying in hospital for one or more nights.

Inpatient units support people who need extra care.

As an outpatient in a hospital or in the community

An outpatient clinic is usually in or near a hospital.

A person getting **palliative care** sees **health workers** that they have been **referred** to.

To be **referred** means a person's doctor has sent them to another **health worker** for support.

An outpatient is a person who visits a clinic or hospital to get **palliative care** but does not stay overnight.

Palliative care might also happen

- **By virtual care**

Virtual care is when **health workers** meet a person using video or phone technology.

Virtual care can happen anywhere for example at a person's home using their phone.

- **In an Emergency Department in hospital**

When a person has an urgent health problem they might get help from an Emergency Department in a hospital.

The Emergency Department is sometimes called an ED.

People usually go to the Emergency Department by ambulance with a person they trust.

The person they trust can also take them to the Emergency Department.

A person does not need an appointment to go to an Emergency Department.

Doctors and nurses help people in the Emergency Department.

The sheet *Palliative care services* can be given to a person's **palliative care team** to complete with information about available services and support.

The people that might be in a palliative care team

Palliative care is managed by **health workers**.

A **palliative care team** might include

- A family doctor
- **Specialist palliative care health workers**

Specialist palliative care health workers are people that know a lot about **palliative care**.

- A **physiotherapist**

A **physiotherapist** helps a person with their movement.

- A **psychologist**

A **psychologist** helps a person with their thoughts and feelings.

- An **occupational therapist**

An **occupational therapist** helps a person to take part in their daily activities.

- A **speech therapist**

A **speech therapist** helps a person with their communication or when they have trouble with eating and drinking.

- Other **health workers**.

A person's **supporters** can also be involved in helping them during **palliative care**.

Questions a person might get asked in a palliative care appointment

The **palliative care team** might ask a person some questions to get to know them and how they feel.

The **palliative care team** might ask questions during a **palliative care** appointment.

It is OK for a person to ask the **palliative care team** questions.

It is OK for a person to let the **palliative care team** know if they do not understand something.

A person can prepare for a **palliative care** appointment by thinking about what they might say.

There is space at the end of this sheet to draw or write things to share with the **palliative care team**.

The **palliative care team** may ask how the person likes to **communicate**.

To **communicate** is how a person understands and shares information.

For example

- Using pictures
- Talking with simple words
- Using a communication device.

The **palliative care team** might ask the person

- What they like
- What they do not like
- What is important to them
- What they enjoy doing.

The **palliative care team** might ask questions about

- If the person has any pain
- How the person is feeling
- Their health
- If they take any **medicines**.

The **palliative care team** might also ask questions about the person's future preferences

- Who they might like to bring to appointments
- Where they would like to have **palliative care** in the future
For example, at home or in a hospital.
- Where they might like to be at the end of their life
For example, at home.

The **palliative care team** will use this information to make a **care plan**.

A **care plan** is a list of things to help a person including the things they want or do not want for their care.

It is important for a person to tell their **palliative care team** how they are really feeling.

These conversations can be difficult and may make the person feel sad.

It is OK to feel sad. The **palliative care team** is there to help.

Who can join a person's palliative care appointments

A person can bring a **supporter** with them if they want to their **palliative care** appointments.

People can bring more than one person with them to their **palliative care** appointments.

Some people might like to bring a

- Family member
- Carer
- Support worker
- Friend
- **Guardian.**

A person's **supporter** might help them to **communicate** with the **palliative care team**.

The **palliative care team** can help everyone work together to support the person.

If a person wants to tell their **palliative care team, supporters** and other **health workers** how to work together, the sheet - *Working together with my team* can be filled out and shared with everyone.

The sections below can be given to a person's **palliative care team**.

Add answers below.

Who I would like to join my **palliative care** appointments

Name/s:

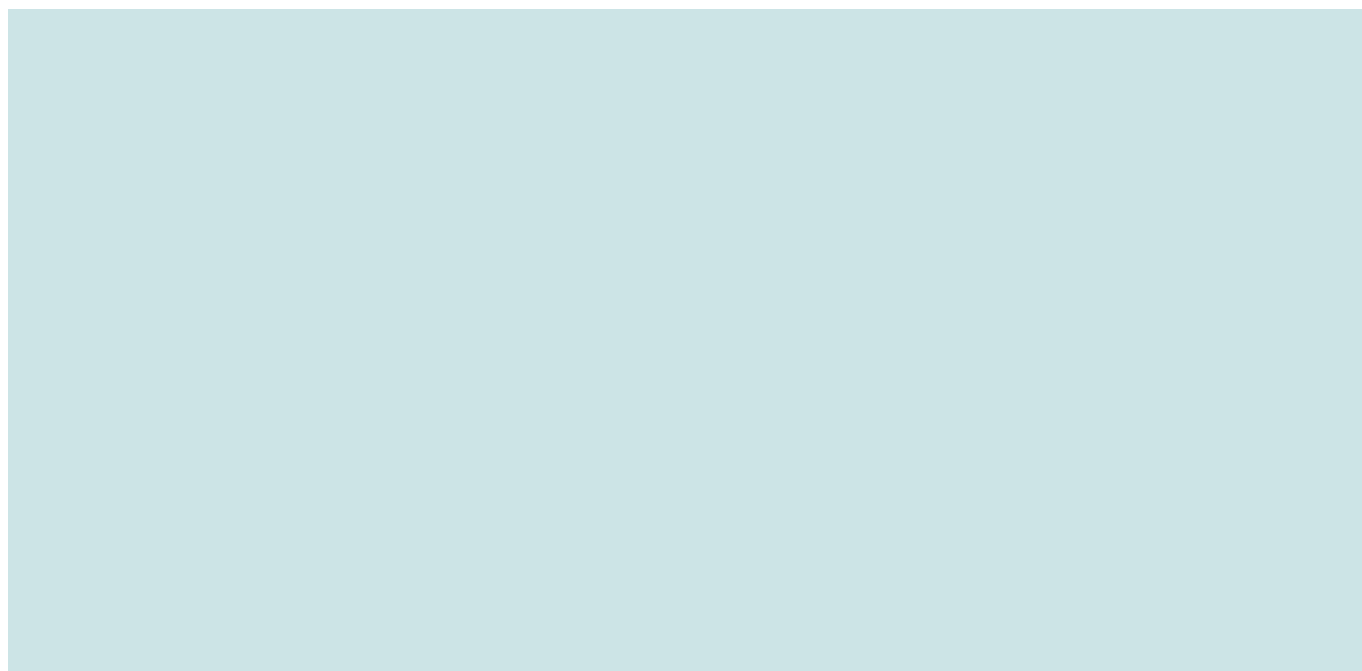
Who are they to me? For example, my brother.

Their phone number or email

The sections below can be given to a person's **palliative care team**.

Add answers below.

Questions I want to ask my **palliative care team**



Things I want to tell my **palliative care team**

