

Caring for someone with a terminal illness



What is a terminal illness?

A terminal illness is a condition or illness which cannot be cured and is likely to lead to someone's death. It may also be called a life-shortening or life-limiting illness. Someone can live for years, months, weeks or days with a terminal illness following their diagnosis.

Someone may be living with more than one terminal condition, which can have different care needs that change over time.

What are palliative care and end of life care?

Palliative care aims to support a person to have a good quality of life. It can be offered at any time after a terminal illness diagnosis. Palliative care can involve:

- managing physical symptoms such as chronic pain, as well as different types of pain
- emotional, spiritual and psychological support
- social care, including help with things like washing, dressing or eating.

Palliative care can include end of life care, but they are different. End of life care offers treatment and support for people who are near the end of their life. It usually starts to be offered to those who are thought to be in the last year of their life. The aim is to help someone be as comfortable as possible in the time they have left, as well as making sure that practical things such as Wills or wishes are sorted out.

How do I know if I am a carer of someone with a terminal illness?

If someone with a terminal illness needs help and support because of their condition, and you offer that to them, you are a carer. This support might include the palliative care we mention above.

This leaflet

This leaflet is for people caring for someone with a terminal illness. It explains what a carer is, how to get an Adult Carer Support Plan or Young Carer Statement, and where to get more information and support.

Do you provide care for someone?



You may be a parent, a husband or wife, a son or daughter, a sister or brother or friend to someone who needs support as a result of their illness (physical or mental illness and substance misuse), condition or disability. **If you provide them with help and support to manage their life – you are a carer.**

You might be a family member, including a partner, or friend of someone who needs support because they have a terminal illness.

As a carer, you are entitled to an Adult Carer Support Plan or a Young Carer Statement to help identify what support you need in your caring role. You might need support more urgently depending on the person's terminal illness, which can be discussed with your local council.

What is an Adult Carer Support Plan or Young Carer Statement?

An Adult Carer Support Plan (ACSP) or a Young Carer Statement (YCS) starts with a conversation with your local council to discuss your caring role and what is important to you in your life.

It helps plan what support you might need if you wish to continue caring for someone who is terminally ill, and what support could help you to have a life alongside caring.

If you are looking after someone with a terminal illness, an important part of the conversation will involve identifying your needs for support, including any immediate or urgent needs.

What are the timescales for starting and completing an Adult Carer Support Plan (ACSP) or Young Carer Statement?

If you are caring for someone with a terminal illness, you may be able to get an Adult Carer Support Plan or Young Carer Statement more quickly. In this instance, a terminal illness is defined as a progressive disease where the person is not expected to live more than six months.

Your Adult Carer Support Plan, or Young Carer Statement should be completed within 10 days, with the timescales set out on the right-hand side of this page.

What is anticipatory grief?

Most of the time, we expect grief to start after a person has died. But grief can start a long time before the death, even beginning when the person receives a terminal diagnosis. This is called anticipatory grief, but it is often not acknowledged or talked about openly.

It is completely normal to experience anticipatory grief at any stage of a person's terminal illness while you are caring for them.

You might have feelings of sadness, anger, frustration, hopefulness, isolation, anxiety, guilt, depression. There is no wrong way to feel, and there is support available to help you, including Marie Curie's Check In and Chat service.

Where to get more information and support

Caring for someone with a terminal illness can be physically, emotionally and financially intensive. Here are some resources that may help.

- For more information visit www.mariecurie.org.uk/support or call Marie Curie's free Support Line on **0800 090 2309**
- If you want to find out more about accessing an Adult Carer Support Plan or Young Carer Statement, you can contact your local carers centre. Contact details can be found at: careinfoscotland.scot/topics/support-for-carers/carers-centres/

Timescales

Being offered an Adult Carer Support Plan or a Young Carer Statement

Day 1 is counted as the day that you **are identified by your local authority as looking after someone with a terminal illness.**

Or the day that you approach your local authority for support as a carer looking after someone with a terminal illness.

Once you are identified the local authority must offer you an Adult Carer Support Plan (ACSP) or a Young Carer Statement (YCS) **within 2 working days** (weekends and public holidays are not counted), unless there are **unforeseen circumstances**, in which case you must be offered an ACSP or a YCS as soon as possible.

Your ACSP or YCS – having a conversation

Your local authority must have a conversation with you to **identify your immediate or urgent personal outcomes (goals) and needs for support.**

They must do this **within 5 working days** of you requesting, or accepting the offer of an ACSP or YCS.

If you are not able, or do not want to, have this conversation within 5 working days, you can ask for a later date. This means it will take longer to complete your ACSP or YCS.

Light Touch ACSP or YCS

Following this conversation, your ACSP or YCS must be prepared **within 10 working days** of you requesting, or accepting the offer of an ACSP or YCS (unless you asked for a later date).

This may be a shorter version than usual. It is sometimes called a 'light touch', but must include information on your immediate or urgent caring role needs, and what support has been arranged for you.