

Emotional Distress

Although this was written for healthcare providers at the Marie Curie palliative care organization, the information may be helpful for the dying person or their family and friends.

Emotional distress is when someone's feelings become overwhelming. It is common in people with a terminal illness and those important to them. Both you and your person will feel a range of emotions with there is a terminal diagnosis.

Counsellors, therapists and other specialists can be helpful for people in emotional distress. But you too can provide emotional care for someone by sensitively encouraging them to express their feelings, listening without judgement, and accepting and respecting them as a unique individual.

When someone finds out they have a terminal illness, it's normal to feel some, or all, of the following at different times:

- shock
- fear
- anger
- resentment
- denial
- helplessness
- sadness
- anxiety
- frustration
- relief
- acceptance

People might also feel isolated and alone, even if they have a strong support network. They may feel more accepting over time as they come to terms with their diagnosis. But it's common for any, or all, of these feelings to become stronger when someone is approaching the last few weeks and days of their life.

These feelings can be very difficult to live with, but they are part of a normal response to having a terminal illness. There are also things you can do to help support someone with these feelings.

What is emotional distress?

Emotional (or psychological) distress is when someone is overwhelmed by their emotions and thoughts. Emotional distress can present as depression, anxiety or panic.

Lots of different factors can contribute to emotional distress including:

- physical symptoms such as pain or nausea
- social isolation or difficult relationships
- loss of independence
- fear of dying
- spiritual or existential distress

Emotional distress is common in people living with a terminal illness, as well as those important to them such as partners, family members and close friends.

How can I assess someone's emotional needs?

It can be difficult to assess how well someone is managing. Encourage them to talk about how they're feeling and listen without judgement. Some services use screening tools including questionnaires. Asking the person to rate how distressed they are feeling from 0-10, with 0 being no distress and 10 being the worst distress imaginable can help to identify how someone is feeling.

It's helpful to be aware of your local support services before you assess someone's needs. This will help you to find the best help as quickly as possible.

How can I provide emotional care?

It can feel daunting to start a conversation with someone about their emotions. There are things you can do to help you both feel more at ease. Activities such as listening to music, massage, looking at photos, or anything the person enjoys doing, could help them to feel more relaxed and able to talk about their emotions.

All emotions including anger and denial are valid and can be useful for the person at different times in their illness. You might find it helpful to share our information for patients on emotional and spiritual pain.

Taking time to get to know the person and understand their experiences and individual circumstances helps to build a strong relationship. This can be challenging if you are working shift patterns or don't see the same patients regularly. If it's appropriate and the person consents, giving them a hug or holding their hand can help them to feel safe and supported.

Encouraging them to talk about their fears and worries can help them to feel less anxious. It can be helpful to keep a positive attitude, but don't dismiss how the person is feeling. You can ask the person how they prefer to be supported emotionally – some people prefer a more 'upbeat' approach, while other people may prefer you to just be there and listen to them.

It's common for someone with a terminal illness to feel sad and anguished about the people they are going to leave behind when they die. Encouraging them to prepare a memory box is a way to help them to know that they'll still be part of their loved ones' lives after they die. A memory box can be a place to hold objects, letters and gifts for their loved ones. They can also prepare videos or sound recordings to be stored digitally on a memory stick or online.

People might be worried about losing control as their illness progresses. Encouraging someone to express their wishes about their care in advance can help them feel more in control.

Adapted from: <https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/individual-needs/psychological-needs#family>