
Maintaining your quality of life during a life-limiting illness

Summary

- End of life and palliative care is based on person-centred and holistic care.
 - Talk with your family, close friends, doctor and your palliative care team about what they can do to help you to make the most of each day.
 - Having a creative outlet and sharing memories with friends and family can be very helpful.
 - Looking after your emotions and dealing with stress helps you maintain quality of life.
 - Pastoral care workers at a palliative care service, and supportive therapies, can help you.
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While you receive end of life and palliative care it can be important to try to continue your life as normally as you can. Simple things such as following a routine, connecting with family, eating well and being physically active where possible will help you feel more positive, enjoy each day and keep doing the things you enjoy for longer.

End of life and palliative care is more than just medical treatment and relief from pain or discomfort. It is care that aims to enhance your overall sense of wellbeing. With this in mind, it is important to look after yourself, stay connected with the people around you, and do things that provide meaning to your life. You can do some of these things on your own, but for others you may need the help of your family and friends, your doctor, the palliative care team and other healthcare professionals.

Person-centred and holistic care at the end of life

End of life and palliative care is based on 'person-centred care', which means you are treated in the way you want to be treated. You are involved in the planning and decision-making in relation to your care, according to your preferences.

Holistic care means the care team responds to you as a whole person, taking into account your physical, psychological, social, emotional, spiritual and cultural needs. This includes the needs of your family or friends and those around you.

Talk with your family, close friends and your palliative care team about what they can do to help you to make the most of each day. A care plan should include a range of emotional and spiritual supports as well as medical treatments for your symptoms. Therapies such as massage, art and music therapy can help you to do what you enjoy and make the most of your time.

Eating and exercise at the end of life

If you are able to, it's good to make eating a range of healthy foods, being physically active, getting some fresh air, and maintaining good personal hygiene a part of your day-to-day routine. By taking care of yourself as best you can, you will feel more positive, have more self-confidence and lower your chances of getting any new illnesses or complications.

Depending on your illness, you may feel that eating foods that you enjoy (even if they are not the most healthy foods) is more important to you than eating well.

Sleep and rest at the end of life

Maintaining a balance of rest and activity that works for you will help you enjoy good quality of life. You may need more sleep at certain times or it may suit you to have naps in the daytime.

Maintain good **sleep hygiene** when you can. Difficulty with sleep may become an issue depending on your illness or medication you are taking. If sleep problems are concerning you, talk to a palliative care team member or your

GP.

Setting personal goals at the end of life

It is up to you how you choose to spend your time. It makes sense to spend your days doing what is meaningful and important to you. This may involve sharing more time with family, finishing a project you have been working on, or getting back to nature. By setting personal goals you can continue to look towards the future.

Share your ideas with your family and friends so they can support you in achieving your goals. You may need help with things like transport and activity materials. The members of your palliative care team, such as your nurse, speech therapist, physiotherapist or music therapist, are all there to help you achieve your goals, so talk with them about how they can help.

Maintaining personal interests and hobbies at the end of life

Doing what you enjoy is the best way to keep your spirits up and your mind active. If you already have a hobby or particular interest there is no reason to stop just because you are receiving palliative care.

Whether your interests are sport, history, collecting stamps, yoga or working on craft projects, your palliative care team will do what they can to support you in your pursuits. Talk with your family and friends about what you are working on, and ask them to bring you materials if you need them.

Being creative at the end of life

Having a creative outlet can be very helpful in processing your feelings. Being creative is a great way to reduce stress, express your feelings and stay positive.

It does not matter whether you have always been creative or whether you are trying something for the first time. Your family and palliative care team can help you get started. Attend group music sessions, make artworks and gifts to give to your family members, or just enjoy your favourite songs, poems and paintings in your own way.

Sharing memories at the end of life

Sharing memories with family and friends is a great way to spend quality time together, stay positive and reflect on your life. By sharing stories or looking through photos, you can think about your lives together, make new memories and enjoy a happy time.

Recording your family history at the end of life

Writing down or recording your life story can be a wonderful gift for your family and a lovely way for you to reminisce about your time together. How you choose to document your life is up to you. You may want to write everything down, use photographs and clippings, or you may want to make an audio or video recording.

You may think your life 'won't be very interesting to anyone else', but you may be surprised at the joy that sharing adventures from your past can bring to you and members of your family and friends. Ask your family or friends to get you set up with the devices or materials you need. Many residential homes and hospitals have in-house services or can recommend professional services for you to use.

Reaching out to friends and family at the end of life

After you receive a diagnosis of a life-limiting illness you may feel the urge to reach out to people you have not seen in a while. This is perfectly normal. Seeing old friends and sharing your history with the people you see every week is a good way of connecting and processing your feelings about dying.

Dealing with stress

You may have mixed emotions and feel stressed when dealing with having a life-limiting illness. As a way to de-stress, consider including the following in your daily or weekly routines, if possible:

- physical activity
- relaxation exercises
- keeping up social contact with friends and family

- a hobby or pastime you enjoy.

For more information about managing stress, see the Better Health Channel's [Stress fact sheet](#).

Looking after your emotions

Everyone has times where they feel a bit low or flat. When dealing with a life-limiting illness you might become concerned about what is happening or feel a sense of helplessness or fear the unknown. This is very common and can lead to anxiety, depression and negative emotions like feeling sad or frustrated.

Talking things over can help you and your family cope. You can talk with a trusted friend or family member, your GP, a palliative care team member or one of the counselling helplines listed below.

Depression usually means you feel sad, down or miserable most of the time, or have lost interest or pleasure in your usual activities, for a period of at least two weeks.

While there are many types of **anxiety disorders** and the symptoms for each disorder are different, some general signs and symptoms include:

- feeling very worried or anxious most of the time
- finding it difficult to calm down
- feeling overwhelmed or frightened by sudden feelings of intense panic or anxiety
- experiencing recurring thoughts that cause anxiety, that may seem silly to others
- avoiding situations or things that cause anxiety (such as social events or crowded places)
- experiencing ongoing difficulties (such as nightmares).

If you have these feelings, contact your GP or the palliative care team. An assessment can be undertaken so that appropriate things can be done to try and lessen the depression or anxiety.

Better Health Channel's fact sheet on **depression** provides more information, including a list of services that can provide further help.

Counselling helplines

You can arrange counselling through your GP or the palliative care team. However if you need immediate support from a trained counsellor you can contact one of the following helplines:

- **beyondblue** – Tel. 1300 22 4636 for free support for issues relating to anxiety and depression.
- **Kids Helpline** – Tel. 1800 55 1800 for free counselling and advice for children, teenagers and young adults between the ages of 5 and 25.
- **SANE Australia** Helpline Tel. 1800 187 263
- **Australian Psychological Society** – Find a psychologist service Tel. 1800 333 497 (outside Melbourne) or (03) 8662 3300 (in Melbourne)
- **Mind Australia** Tel. 1300 AT MIND (1300 286 463)
- **youthbeyondblue** – Tel. 1300 22 4636 for free telephone counselling or visit their website for information, resources and support.

Being 'at peace' with dying

After being diagnosed with a life-limiting illness, you may find that you are worrying about what lies ahead, wondering about the meaning of life, or thinking about what really matters to you. Having these feelings is normal and part of the process at the end of life.

You may find meaning in your religion if this has been a part of your life. Or you may choose to focus on your relationships with family and friends, or activities that are meaningful to you.

The palliative care team are there to talk with you about what to expect as you approach the end of life and answer any questions you may have.

Spiritual, religious or cultural care at the end of life

If you are dealing with a serious life-limiting illness that may lead to the end of life, it is important that your cultural values and needs are respected. You are entitled to be treated with respect, whatever your cultural background, religion or sexual orientation.

Pastoral care workers (also known as spiritual care workers) are available as part of your palliative care team. They are trained professionals who can help you work through your feelings – whether you are religious or not.

Pastoral care workers can arrange visits from spiritual leaders such as reverends, priests, rabbis and imams. If you are not religious, you might prefer to focus on creating a 'life review', being part of a support group, enjoying nature or just spending time with family and friends.

For more information visit Better Health Channel's Emotional, spiritual and cultural care [link to page] fact sheet.

Individual needs

If you have a hearing or speech impairment, ask your palliative care provider about getting extra help or translating services, or consider the following services.

The **National Relay Service** (NRS) is available to help callers with a hearing or speech impairment:

- TTY users, call 133 677, then ask for (03) 9662 9644 (for Palliative Care Victoria)
- Speak and Listen users, call 1300 555 727 then ask for (03) 9662 9644
- Internet relay users, connect to the **National Relay Service**, then ask for (03) 9662 9644.
- Palliative Care Victoria has an interpreting service for callers who speak other languages. Call (03) 9662 9644 and ask for the language you need.

Where to get help

- Your GP
- Your palliative care provider
- **Palliative Care Victoria** Tel. (03) 9662 9644
- **beyondblue** Tel. 1300 22 4636

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