

Living with Life-limiting Illness

When you have a life-limiting illness there are things to consider. These can be for you or those close to you.

You may want to think about your quality of life, what is important now, whether you continue to work, and how things are likely to change. How you prepare yourself is important and you can receive support.



Changes over time: Changes may occur in all aspects of your life. This includes physical changes such as pain and other symptoms like tiredness or loss of appetite. You may also have to deal with changing feelings and emotions. You may feel overwhelmed.

Changes in your mobility or independence can be challenging but can be supported by health and allied health professionals.

Changes that may affect your quality of life include:

- Being uncomfortable or in pain
- Being unable to socialise or spend time with loved ones
- Loss of independence
- Feeling that you are a burden.

Certain changes can be expected and care planning can be useful in adapting to these.

It is useful to understand your illness and your prognosis. This is whether your disease can be cured or only stabilised for periods. You should also be told the goal of any treatment.

For example, whether it is to slow progress of your disease, to treat a symptom or to improve your ability to do the things you enjoy or need to do.

Emotional challenges: It is normal to have changing feelings and emotions. This is especially true if you or someone close are seriously ill or facing the end of life.

Sometimes the worry is so great that you may develop symptoms of anxiety. This can include feeling edgy or restless. You may have difficulty concentrating, feel tired, or have difficulty in falling or staying asleep.

If you feel sad, moody or low for a long period of time you may be experiencing depression.

It is natural for anyone facing a serious illness to feel depressed and need time to adjust. Talking to others about the adjustment may help. Your treating doctor or a psychologist may be able to help you understand your feelings and address any emotional problems.

Learning to manage stress can also be helpful:

- Use relaxation techniques, slow breathing exercises
- Get enough sleep and exercise
- Maintain social contact
- Reduce alcohol and other drugs
- Make time for activities you enjoy.

Symptoms: A symptom is physical evidence of a disease or illness that you experience. This can include nausea, pain, breathlessness, tiredness and loss of appetite.

These may not be the same from person to person. They may be mild in some cases or more severe in others. Symptoms are likely to change over time.

Talk to your health professional about any symptoms that you are experiencing. There may be ways to help manage your symptoms to reduce their impact on everyday life. Let them know if any of your symptoms get worse or if they improve. This may affect your medications or other therapies.

Communication: Being able to communicate is important. There will be different people to communicate with. This includes family and different health professionals.

Talking openly is important. It might be helpful to tell health professionals that you have a carer that looks after you. Do not be afraid to ask questions or to include a carer or family members in appointments or care discussions.

You may not want certain people to be aware of what is happening. Let health professionals know who they can and cannot share your information with.

Financial challenges: Most palliative care services are free, but there may be some costs associated with hospice and hospital care. You may need to pay extra for medications and equipment. Do not be afraid to ask questions.

Continuing to work: Work can represent a sense of identity and self-reliance in an uncertain world. Your illness will affect not only you but also the people that you work with. The seriousness of the illness needs to be acknowledged and talked about.

Planning for the future: You may just want to live as well as possible within the limitations of your illness. There may be conversations that you need to have or issues you want to resolve. Think about the choices that matter to you. Consider preparing an advance care plan, a will and even your funeral.

Spirituality: Spirituality is not the same as religion. However, religion may give you spiritual expression or a spiritual community. Your idea of spirituality could involve dignity, hope, joy, love or humour. It could be where you find your strength in difficult times. Spirituality can help people make sense of their lives. Pastoral care workers and chaplains can offer spiritual support.

CareSearch is a website that has been developed to provide trustworthy information about palliative care. For more information on this topic visit www.caresearch.com.au