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## Managing work and employment with a life-limiting condition

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### Summary

- After being diagnosed with a life-limiting illness, it is a good idea to take some time off work to consider your options.
  - Talk with your family and think about how you need to prepare for what lies ahead.
  - Have an open and honest discussion with your manager or the human resources department about your situation. Get their advice on the best way to talk to your colleagues and how to restructure your responsibilities.
  - If you have to care for someone with a life-limiting illness, organise a time to meet with your manager or human resources representative and talk about how your new role may affect your ability to work.
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When you or a family member is diagnosed with a life-limiting illness, it can be difficult to decide what to do about work. Most families will be quite overwhelmed by the news and need some time to adjust and think about their priorities.

It is a good idea to take some time off work to consider your options. Talk with your family and think about how you need to prepare for what lies ahead. How much time you can take off work at short notice will depend on your role and your employer's sickness or carer benefits.

### Advantages and disadvantages of continuing to work

Most people who are diagnosed with a life-limiting illness choose to leave work so they can spend their remaining time with their families and friends. However, depending on your family and financial situation, the type of illness you have and your emotional response to being ill, you may need or want to stay working for longer.

After being diagnosed with a life-limiting illness, you may feel a lack of control and a loss of independence or any chance of a normal life. For some people, work can play a positive role in providing a continued sense of identity, independence and ongoing financial security for their family.

If your partner or another member of your family is diagnosed with a life-limiting illness and they have to stop working, you may be the only money earner in the household, which means juggling your role as carer with your job.

### Talking about your illness at work

It can be hard to know how to talk about your life-limiting illness with your colleagues. You may want to keep your health situation private at first, but if you need regular time off or your appearance begins to change, you may need to consider talking about your illness.

Everyone will have a different response to news about your illness, depending on their personality, life experience and cultural background. Some people may be shocked or very upset, and this may be difficult to handle at first. However, it is important that you do what feels right for you and give people time to get used to the new situation.

Talk to your manager or human resources representative if you are not sure about the best approach to take.

### Issues you may face if you keep working

The personal experience of illness becomes a public one when work colleagues are informed. Your illness will affect not only you but also the people that you work with. This is the same if your carer continues to work.

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If you decide to remain in your job, it is a good idea to keep in mind some of the common issues that arise when someone with a life-limiting illness continues to work. You will be aware of the way your illness is affecting you, but it is important to remember that everyone in your workplace will respond in different ways. Your work colleagues may be unsure of how to respond, which can lead to communication problems. Some people will avoid talking about important issues, while ignorance may cause people to feel awkward and distance themselves from you. And some colleagues will know exactly what to say and how to be supportive of your situation.

The seriousness of your illness needs to be acknowledged and talked about. This may avoid emotional stress within the workplace and for you.

### **Getting support to stay in your job**

It is a good idea to have an open and honest discussion with your manager or the human resources department about your situation if you decide to stay in the workforce. Questions you will need to ask include:

- How do I tell my colleagues about my illness?
- How do I educate my colleagues about my illness?
- Can I rearrange my workspace to suit my changing needs?
- Is it possible for me to work more flexible hours?
- Can I reorganise my work schedule and share the workload?
- Are there counselling and support services for me and my colleagues?
- How will I arrange my attendance at staff meetings or functions?
- Is it possible to have extra rest breaks?
- What is the best way to ensure a smooth transition when it is time to leave?

### **Getting support in the workplace while being a carer**

If you are going to be caring for a loved one with a life-limiting illness while continuing to work, you will need support from your work colleagues.

Organise a time to meet with your manager or human resources representative and talk about how your role of carer may affect your ability to work. Discuss what arrangements you might need to make and get their thoughts on how to maintain a good work/life balance.

Some useful questions to ask include:

- What is the best way to tell my colleagues that someone I am caring for is ill?
- How can my colleagues learn more about my role of carer?
- Is it possible for me to work more flexible hours?
- How will I arrange my attendance at staff meetings or functions?
- Are there counselling services on offer through work?

There is also a wide range of carer support services available across Victoria. By getting support from your colleagues and seeking help through community services, you will be able to find the right balance for you and your family.

### **Where to get help**

- Your manager
- Your human resources representative
- Your doctor
- Your palliative care provider
- Palliative Care Victoria, call (03) 9662 9644

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