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LIFE-LIMITING **ILLNESSES IN THE** **WORKPLACE**



**A TOOLKIT FOR MANAGERS
AND HR PROFESSIONALS**



ACKNOWLEDGEMENT

Palliative Care Queensland (PCQ) acknowledge the Traditional Custodians of the lands and seas on which we live and work, and pay our respects to Elders past, present and emerging.



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FEEDBACK

Palliative Care Queensland welcomes feedback on the content of this booklet.

Please contact us with corrections or suggestions, which will inform future editions.

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INTRODUCTION

We know from the work of the Grattan Institute in their report “Dying Well” and other research that, at a community level, Australians are not comfortable talking about death. We see this in the discomfort of many health professionals when discussing a terminal illness diagnosis with their patients and in how willing people are to plan for, and document, their end-of-life care wishes.

As Ashby et al note:



“...acknowledgement of the inevitability of death, and preparation for it, have largely lost their place in our culture. For many, an almost child-like faith in medicine and science has taken its place.”²

And yet the number of deaths in Australia is estimated to double in the next 25 years as our population ages¹. This means an increasing number of people will be impacted by terminal illness, referred to as a life-limiting illness, when still in the workplace. While some individuals who are working will be diagnosed with a life-limiting illness, a greater number will become responsible for caring for a loved one with such an illness.

Given death is such an uncomfortable topic of conversation in our society and for many individuals, dealing with it in the workplace is not easy either, whether for the affected employee, human resource professionals or managers and teams. Many people in the workplace find themselves out of their depth and uncertain of how to navigate a challenging situation.

This uncertainty impacts an employer's ability to provide information and practical support for their employees faced with a diagnosis of a life-limiting illness or caring for a relative facing such an illness.

Palliative Care Queensland acknowledges it is not an easy process and has developed this toolkit to provide managers, human resource leaders and team leaders with some best practice resources and information to help deal with these issues in the workplace. The toolkit should also initiate, and help develop, workplace policies and practices to support

employees in need.

Please use this toolkit as a basis for starting conversations and consultations within your organisation and to develop and implement policies and training to foster a caring and positive workplace that builds a supportive culture for employees involved in end-of-life care.

NOTE

Throughout the toolkit the person affected by the life-limiting illness is referred to as the 'affected employee'. The term 'staff' is used as the generic term for paid employees and other people working in the organisation, such as contractors and volunteers.

1. Swerissen, H and Duckett, S., 2014, [Dying Well, Grattan Institute](#)
2. Ashby, M., Kellehear, A. and Stoffell, B. (2005) 'Resolving conflict in end-of-life care', Medical Journal of Australia, 183(5)

Palliative
Care is

about the
whole
person



for the entire
dying journey



for every
age and
every stage



about the
community
of care



about
choice, autonomy
& dignity



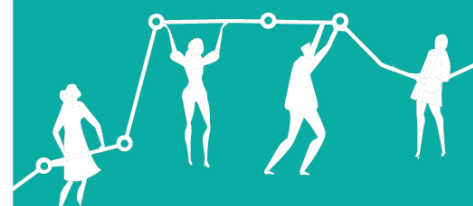
about
living



not
'one-size
fits all'



Everyone's
business



care for
the carer



a Human
right



Palliative
Care *It's more
than you think.*



WORKING WITH THIS TOOLKIT

WHAT YOU WILL GET FROM THIS TOOLKIT

This toolkit provides users with resources to:

- initiate and have helpful, practical and sensitive discussions about what can be an uncomfortable subject
- provide guidance and information to inform practice
- plan for dealing with life-limiting illness in the workplace
- encourage a caring and positive workplace
- improve understanding about serious illness, dying, death and grief

The toolkit will help organisations to:

- create and deliver a training program for managers
- develop a policy on supporting staff with a life-limiting illness.
- create a compassionate community in their workplace



PART 1:

DEVELOPING POLICY

A life-limiting illness diagnosis is not in anyone's plans, but as Alan Lakein, the well-known author on time management once said, "Failing to plan is planning to fail".

Few workplaces are set up for the very ill, which often leaves human resources (HR) professionals facing complex issues to consider on behalf of the organisation, such as:

- How long a person should be 'allowed' to work?
- What if an employee doesn't want anyone else to know they are ill?
- What supports are in place for staff faced with extra work and emotional distress when a colleague needs to be absent?
- What is the impact of this issue on managers helping the affected employee?

KEY CONSIDERATIONS AND QUESTIONS

Supporting an employee facing a life-limiting illness is a complex and delicate task.

Numerous issues and challenges may arise, impacting both the affected employee and the workplace. These challenges evolve as an illness progresses so, when developing a policy, organisations should reflect the need to revisit issues with employees during their illness.

When an employee has a life-limiting illness, the path from diagnosis, through treatments, to eventual death can take many months and even years. It is an individualised journey and the support needs of the affected employee will evolve, requiring proper management, ongoing monitoring and checking in with all involved.

The word 'communication' is used a lot in this toolkit. The HR professional, the line manager and others with managerial responsibilities for an employee with a life-limiting illness, or caring for a loved one with such

an illness, will need to demonstrate a tremendous amount of emotional intelligence and leadership.

It is reasonable to anticipate that those involved (the affected employee or carer, their immediate team mates and supervisor, and senior managers) will need to be prepared to have clear and sensitive conversations about the extent to which the organisation can be flexible and what is fair and reasonable for all involved during what is understandably an emotional time.

Consider these questions when formulating a policy to support and manage employees with a life-limiting illness in the workplace.

Supporting an employee facing a life-limiting illness is a complex and delicate task

EMPLOYEE ENTITLEMENTS

- What are the organisation's legal obligations towards the affected employee?
- What are the entitlements for personal leave, annual leave, long service leave, miscellaneous and unpaid sick leave in the relevant industry awards, enterprise agreements or contracts in the state or territory you operate out of?
- How do these different kinds of leave interact, and are the staff who process leave requests familiar with those interactions?

[Appendix 1: Legislative Framework](#), which outlines relevant nationwide acts and workplace laws, is a good starting point on these entitlements, together with due diligence for examining the particular circumstances of your organisation.

ASSISTANCE FROM THE ORGANISATION

Consider what resources and / or assistance may be made available to employees with a life-limiting illness above and beyond the organisation's legal obligations. It is important to confirm what the organisation can afford, and the possibility of setting precedents that are not possible in the long term.

Resources or assistance might look like:

- financial and estate planning assistance for affected employee
- helping them access superannuation funds early or qualify for insurance
- counselling services for affected employee and staff
- gratuitous paid or unpaid leave
- encouraging creation of a compassionate community within the work place


CASE MANAGEMENT

- How will the affected employee's privacy be protected?
- How will communication about the situation between the affected employee and organisation be handled?
- How will communication to others (fellow staff, clients, etc.) be handled, and by who?
- Can the affected employee maintain full-time hours at their current work level and workload? Do they need adjustments to their work or workload to support their treatment regime?
- How will performance reviews, leave management, duty adjustments etc. be handled?
- How will other staff be supported in knowing how to appropriately approach and / or assist their colleague?

Typically, staff will go to their team leader or senior manager to break the news of their situation. It is important that those who hear the news first have the necessary training and guidelines to handle the situation and their personal response and feelings. Regular reviews should take place as this situation may go on for some time. Reviews should consider the affected employee, as well as other staff around them.

SUPPORTING THE MANAGER AND TEAM OF AN EMPLOYEE WITH A LIFE LIMITING ILLNESS

- How will the impact on other staff workloads be managed?
- How will the colleagues of the affected employee be informed? How much will they be told and who will tell them?
- Will the organisation offer counselling services to support the affected employee's manager and colleagues during this time?
- Will client, business contacts etc. be informed? When and by whom?

A woman with blonde hair tied back, wearing a dark blazer over a light-colored shirt, is seated at a desk. She is looking off to the side with a thoughtful expression. Her hands are resting on a spiral-bound notebook. The entire image is covered with a semi-transparent red overlay.

**STAFF WILL GO TO THEIR
TEAM LEADER OR SENIOR
MANAGER TO BREAK THE
NEWS OF THEIR SITUATION**

MANAGING A COLLEAGUE'S PASSING

- How and when will staff be notified of their colleague's passing?
- Will the organisation offer leave or arrange shifts to support funeral attendance?
- Will the organisation offer counselling services to staff who may need it?
- How and when will clients, business contacts etc. be informed?
- When and how will personal belongings held at the office be returned to the family?
- When and how will organisational equipment and other assets formerly in the deceased's possession be retrieved?

DEVISING POLICIES

When devising policies, keep the following advice in mind:

- Documents should be compliant with law and drafted in a way to afford business protection.
- Guidance should include advice for managers on benefit options for the person concerned, including early ill-health retirement and access to any support services such as an Employee Assistance Program (EAP) or occupational health services.
- Managers are central to discussions about work adjustment, work retention and workload, so it is important to include them when devising policies.
- HR and employment law support in managing an employee with a progressive illness is crucial. *Where is that support coming from and at what juncture will it be sought?*
- This subject may become a complex HR issue and your organisation is tasked with exploring reasonable adjustments. Individuals should be allowed to work as long as they wish, subject to medical advice and any health and safety factors. *Where is that advice coming from?*

- Many larger organisations have workplace health and safety professionals who can provide managers with information and support, including guidance on the affected employee's condition and how it might affect their work, advice on work adjustments and fitness for work. *Where is that support coming from and at what juncture will it be sought?*

Individuals should be allowed to work as long as they wish, subject to medical advice and any health and safety factors



PART 2: SUPPORT FOR MANAGERS

Line managers are central to the effective handling of employees with a life-limiting illness. They are usually the main point of contact for the affected employee and are also responsible for managing work adjustments and the overall performance and wellbeing of their entire team.

To provide the necessary support to the line managers within your organisation, equip them with the best possible information and provide new resources and training where necessary. This includes policies and training so managers can find and / or seek input and direction on the following key aspects of their role.

An employee's rights and access to leave – managers must have access to accurate information. They must communicate with HR regarding the provisions of any Enterprise Agreement or contract. Other resources, like the Chamber of Commerce and Industry or the Australian Public Service Commission, can support understanding of rights and obligations. You may also wish to seek legal advice.

Adjusting job responsibilities, managing absenteeism and return to work – managers may need to seek specialist advice when making adjustments to workplace responsibilities and work health and safety considerations for the affected employee. Managers should also communicate with HR about positively managing absenteeism (including staying in contact while the affected employee is on leave) and workload management for the individual and the team. If the affected employee returns to work following a long absence, care is needed when helping them re-enter the workplace.

Producing effective communication for all staff – communicating sensitive information about the health of the affected employee can be complex and certain details should only be shared with consent. When managers seek to identify and review processes before distributing any information, they may save a lot of heartache.

Staff morale and mental wellbeing – managers need to maintain effective communication throughout the affected employee's journey. They will also need to demonstrate emotional intelligence when gauging the mental wellbeing of staff within their workplace. Assistance in this area may be helpful and the involvement of HR and / or an EAP service provider is a good idea.

Managers need to maintain effective communication throughout the affected employee's journey

A BALANCING ACT

The role of the manager can be a complex one. There are three areas of focus that need continual consideration. The manager:

1. has core responsibilities for the ongoing performance of their business line
2. will need support and information on how to support the affected employee
3. has responsibility to other staff and will need to consider their own workloads and resilience in supporting the affected employee.

It is also important to acknowledge that it is not the manager's role, or responsibility, to be a counsellor. Managers should link in early with HR and / or an EAP service provider for this type of support.

Communication is key in successfully managing this process.

As an employer you have the right to know about circumstances that will affect any employee's performance. An employee needs to inform the organisation, as their employer, about matters that may impact upon their ability to work or cause a health and safety risk for themselves or others. In all conversations, managers must be mindful of the person's right to privacy. Therefore, questions posed must focus only on those matters related to their work performance and attendance. What an employee chooses to share with their employer beyond these matters is entirely at the employee's discretion.

Put simply, an employee does not have to divulge their diagnosis, prognosis or treatments being undertaken. That said, in relationships where trust is strong, employees are far more likely to divulge health and treatment details that better enable their manager and workplace to support their needs.

When in doubt, it is better to err on the side of caution. Even where an employer or manager has an established personal relationship with an employee, it is wise to think twice about asking for too much detail about the specifics of the situation.

STEP BY STEP

THE FIRST CONVERSATION

A serious or life-limiting illness is never planned, so how a manager handles that first conversation with an employee who announces the news is extremely important. Training managers and preparing them for this eventuality is vital. Building capability is key to successfully manage this conversation and the emotions and responses that are inevitable at this important moment.

This first meeting needs to take place in a private space without disruptions. Managers should aim to move the meeting should the conversation start in a less than ideal space.

People who have just received the worst news possible have said the most important thing others can do for them is to truly listen. This is also the best way for a manager to gather information without having to worry about what they can and cannot ask. A good listener encourages the speaker to elaborate and continue without having to prompt for specifics. Active listening will put the focus on the speaker.

Ahead are some tips for demonstrating active listening skills.

An employee does not have to divulge their diagnosis, prognosis or treatments

BE AN ACTIVE LISTENER

- Focus on the affected employee, pay close attention to what they are telling you and try not to interrupt.
- Acknowledge what they are saying and avoid agreeing or disagreeing with them. Instead, encourage them to continue by actively letting them know you are listening.
- Answer questions as specifically and as thoroughly as possible.
- Allow the affected employee to proceed with the conversation at their own pace.
- Provide reinforcement and reassurance to the affected employee. Don't try to interpret for them, just reflect what is being said.
- Be honest about what you don't know. Admit when you don't know the answer to a question and offer to investigate.
- Summarise the key points that have been raised by the affected employee at the end of the conversation so that you make sure both of you have a clear understanding of the situation.

Focus on the affected employee, pay close attention to what they are telling you



There will be some key pieces of information a manager needs to determine during the first meeting.

A clear understanding of the affected employee's wishes in terms of privacy. What do they want their colleagues to know, if anything? And how do they want to communicate news? In the first instance it is likely they would want very little to nothing communicated while they come to terms with the news themselves. This also may change as time passes. It may be worth letting them know that if news is shared with family or friends on social media, it is likely to make its way into the work place. There may also need to be communications with HR and senior management to ensure proper care for the affected employee, with due respect for their privacy.

Ask the affected employee what they need from you right now. Be prepared for any answer that comes your way. You may not be able to fulfil their requests. If you're not sure, say so and reassure them that you will get back to them quickly. Be clear and honest with your answers. Take notes to ensure you follow up on all matters raised. It is important that you do what you say you will do, as this will build trust and give the affected employee a level of certainty from the workplace.

Where possible, a request for immediate time off should be granted without hesitation. Assure the affected employee that taking time off is fine and you will take care of any work issues. Advise that you will get back to them as soon as possible with up-to-date leave entitlements.

Consider reassuring the affected employee of his or her continued job security. This is particularly important if he or she has delayed informing you of their diagnosis, as this may have been one of the reasons for that delay.

Action any work matters, projects, calls or communications pertaining to their work function. Try to relieve the affected employee's worry about letting their colleagues or the operations of the organisation down. People don't lose their sense of pride because they are ill, so it can really

help if you are able to reduce unnecessary stress and worry for them.

Establish yourself as the point of contact for all communications. Provide the affected employee with a single point of contact so they don't have to discuss their situation many times over and to ensure their privacy is managed correctly. This also ensures a single source of information so they don't receive conflicting advice. In some larger organisations, a case manager may be assigned by HR. In those circumstances, it is important for the manager and case manager to discuss and agree their separate responsibilities and to communicate them to the affected employee.

Where possible, the affected employee should be offered counselling via an EAP. This offer should also be extended to immediate family members.

It is particularly important to document conversations with employees and follow up with an email summarising the conversation with them. When people have the burden of many different appointments and conversations it can be difficult to remember what was agreed.

[Appendix 2: Case Management Cover Sheet](#) provides a comprehensive check list.

COMMUNICATING WITH COLLEAGUES

It is rare for people diagnosed with a potentially life-limiting illness not to share the diagnosis with colleagues. In many cases managers are asked to communicate with colleagues, clients and customers in a way that is in accordance with the employee's wishes. Be sure to agree on a communication plan with your affected employee, including what you will—and will not—mention to others.

Acknowledge and thank your affected employee for consenting to the release of information. Their colleagues are more likely to be empathetic and understanding about absences, changes in workload and new assignments if they know what is happening.

Where your affected employee has agreed on what information others should know, it is important to:

- identify if they want to break the news themselves, or whether someone else should do so on their behalf
- establish what they would like other staff to do once they have been advised
- discuss whether they want to be present if someone else is breaking the news on their behalf
- decide on how the news should be communicated; for example one-to-one, in a meeting, by email etc.
- determine how much information should be shared and what should remain confidential.

In planning this communication, a manager also needs to be mindful of the impact the news may have on other staff. In preparing the communication:

- avoid personal details
- use positive language but be honest about what to expect
- don't dramatise
- outline known changes that will be made and the need for flexibility
- invite staff to speak to you or another manager if they are having practical problems with potential increased workload, or if they are feeling distressed.

The reaction of other staff to the news will vary.

It is best to arrange a private area such as a meeting room when communicating with the team so they can react to the news in private, ask questions and speak with each other or you. You can also leave them in the room to collect themselves if they are visibly upset. It is recommended to have tissues on hand, along with contact details for the EAP service provider.

This element, in terms of the impact on a manager's time and own emotional resilience, can be the most telling. People will respond to the stress of finding out about a colleague having a life-limiting illness in various ways. Remaining compassionate to everyone may test the resilience and composure of even the strongest of managers.

It can be challenging for the manager who is now dealing with a person with a life-limiting illness, with probably an unknown trajectory for work, workload management to accommodate them, the emotions of their entire team, plus their own emotions. Support should be offered to the manager through the HR team and / or the EAP.

Once the situation is communicated, the desire of staff to help a colleague may need to be addressed. Team members may also want to know what the organisation is doing for the affected employee. Part of that answer will be the flexible work arrangements you are putting in place and everyone's assistance to help their colleague. Any further information on personal agreements with the affected employee should be kept confidential.

Staff may also be feeling awkward and unsure about how to approach their colleague. Often the greatest benefit to the affected employee comes from the emotional support afforded through the social network within the workplace, rather than specific work-related assistance.

[Appendix 3: Useful Tips for Staff](#) Provides guidance on how staff can communicate with, and assist, their colleague.

SUPPORTING YOUR EMPLOYEE

In devising the workplace strategy that works for your organisation, be as generous as you can afford. As mentioned earlier, these decisions can either foster (when generous) or diminish (when not) workplace productivity and job satisfaction.

Agree on a communication plan with your affected employee early on, including what you will and will not mention to others.

Do not assume the affected employee should stop work immediately. Many people with a serious illness often report that continuing to work helps them focus on things other than their health and provides them with important social contact.

Be clear about the actual requirements of the person's job. Does their illness impact on their ability to do the job, or is it more about the fact that the affected employee is away on sick leave more, or is fatigued etc.

Provide support – emotional and practical – and document the support that is given.

Give the affected employee every opportunity to demonstrate they can still perform their role without over-managing them. At the same time, make sure you check in about how they are managing their workload.

Avoid making assumptions about what the affected employee can or can't do. With their permission, you may need to check with a work health and safety specialist, or the affected employee's doctor, to correctly formulate the job function.

Appreciate that it is difficult to know exactly how any treatment will affect an individual. Be alert to the need to change work schedules, at short notice if necessary.

Adjust work schedules in consultation with the affected employee and over the course of their treatment.

Make reasonable modifications / adjustments to enable the person to continue doing their job. Consider whether tasks that are particularly tiring can be reallocated (in consultation with the affected employee) or if equipment can be purchased to help the person do their job with greater comfort and ease.

At some point a finish date will need to be discussed. What the triggers for that date might be is worthy of discussion. Be mindful that leaving work will not be easy for some. A well planned and thought through departure is in everybody's best interest.


Suggested 'reasonable adjustments' to consider in your obligations as an employer:

- Allow an affected employee time off to attend medical appointments.
- Modify a job description, with the affected employee's agreement, to modify tasks that cause particular difficulty.
- Allow flexibility in working hours.
- Reduce / eliminate travel obligations.
- Allow extra breaks to help an affected employee cope with fatigue.
- Allow the affected employee to be restricted to 'light duties'.
- Adjust performance targets to take into account the impact of sick leave / fatigue on the affected employee.
- Move the affected employee to a position with more suitable duties (with their agreement).
- Allow and enable working from home arrangements.
- Change a meeting date / time so it doesn't clash with the affected employee's medical appointments.

As an employer, consider several factors when deciding whether an adjustment is reasonable, including the effectiveness of the adjustment for people with medically imposed limitations. What is considered 'reasonable adjustment' will depend on many different things, including but not limited to:

- the cost of making the adjustment
- the amount of benefit for the affected employee
- the practicality of making the adjustment
- whether making the adjustment will impact the employer's business / service / financial situation.

If a manager is proposing to terminate the employment of someone with a life-limiting illness, they need to be very clear about the grounds for termination and need to ensure their reasons are lawful and not discriminatory or in breach of the relevant contract, award or agreement. An ill employee can make a claim against their employer under the relevant unlawful termination laws or discrimination laws.



The announcement that an employee has a life-limiting illness is the beginning of a situation that will bring up many emotions and practical challenges

ONGOING MANAGEMENT

The announcement that an employee has a life-limiting illness is the beginning of a situation that will bring up many emotions and practical challenges.

In larger workplaces the diversity of strengths, weaknesses, emotional intelligence and maturity is going to keep even the most seasoned HR professional on their toes.

HR and managers endeavour to foster a productive, caring and harmonious workplace. In managing and supporting an employee with a life-limiting illness you have the entire organisation or workplace to consider, not just the affected employee.

Below are some of the issues you can expect at different stages of supporting an employee with a life-limiting illness and some ideas for dealing with them.

Stage 1: The announcement

In the initial stages of finding out an employee has a life-limiting illness, or is the carer of someone with a life-limiting illness, the affected employee and other staff may find it difficult to know what to do. This can manifest in a number of ways.

Staff are awkward, uncomfortable and not sure how to react to the situation. Advise staff it is okay to just acknowledge their colleague's situation and to get on with their work. Staff are not required to become their colleague's best friend as a result of their illness.

Staff are upset. For some staff the news that a colleague has a life-limiting illness may bring up old memories of other experiences. These staff should be encouraged to seek support through the organisation's EAP provider or other counselling service.

Some staff make it all about them. A gentle reminder that everyone experiences different emotions and that there is one person that really needs our support right now and we need to manage our own feelings as best as we can.

Staff are eager to support their colleague and to help with workload sharing. This is a very positive outcome. Staff should be acknowledged and thanked. However, workload sharing is not sustainable over the longer term.

The affected employee takes on too much work load relative to their condition. If performance or quality of work is dropping, you need to step in. Adjust their work load so that quality and quantity are aligned on a reduced scale. Get a doctor involved if you need to. Encourage the affected employee to seek support from the organisation's EAP provider or other counselling service if they are struggling with the changes they are experiencing.

The affected employee does not wish to share any information about their illness. Help them understand that if you can't talk about their situation at all then, not only will they be ill, but

their workplace will not be the same either. Explain that their colleagues, with no explanation, may resent their absence and having to pick up extra work. Colleagues may also feel 'left out' of what's going on (they will know something has changed) and consequently leave them out. You can offer to speak on their behalf, using words like 'unwell' instead of cancer, disease or terminal.

Stage 2 - What's happening?

As the initial shock of the news fades and time passes, it is possible staff will become frustrated with the uncertainty of task adjustments and timeframes for how long these adjustments will apply. Staff may no longer be happy with the extra workload they initially accepted. Additionally, senior management may also be demanding certainty themselves and seeking more immediate change.

Throughout this period, it is important to receive regular updates on your employee's health and how they are coping with their work. It is during this time that the difficult but inevitable conversation about the right time to finish work will need to occur. It might be appropriate to identify milestones for that decision in advance. Hopefully, with the time passed, emotions will have settled and constructive and pragmatic conversations can be held.

You should also check in with other members of the team about their health and wellbeing within the workplace. Identify and discuss their concerns and alter directives to accommodate changing circumstances. Follow through by communicating progress and changes as per the agreed communication plan.

You will also need to communicate effectively with senior management about how the affected employee's circumstances are progressing and how you are managing them. It may be necessary to remind them that dismissing an employee with a life-limiting illness, while they are able to contribute to the workplace, may be unlawful.

Many people will have insurance cover under their superannuation policy for total and permanent disability and terminal illness. Before benefits are paid

certain thresholds need to be met. These policies need to be investigated, particularly the superannuation fund policies. As a matter of organisation policy you may wish to bring in, or pay for, a financial adviser to have a look at the affected employee's complete situation. This includes looking at all leave entitlements, insurance policies, debts, dependants, health insurance and government benefits to help the affected employee devise a financial strategy that is best for them.

It may be the case that, rather than the affected employee seeking to reduce work hours or alter job tasks, they resign as soon as 'normal' work becomes too much so as to trigger the start of qualifying periods and other income sources that would see the affected employee better off.

***Check in with other members
of the team about their health
and wellbeing***



Stage 3 – Death of a Colleague

After the death of a colleague, staff may have feelings of guilt or regret, possibly due to their feelings or actions during Stage 2.

In any given workplace, it is impossible to know what will happen. Key considerations include:

- How long was the affected employee with the organisation?
- How strong were their relationships with staff?
- How long did their illness last?
- What position did they hold in the organisation?

When an employee dies there are some practical elements to be considered:

- Inform the workplace. Sensitive communication is required.
- Inform clients, suppliers and customers to avoid embarrassment should they call to contact the deceased.
- Appoint someone to act as liaison with the family and also to organise the organisation's expression of sympathy, cards, flowers etc.
- Advise colleagues of funeral arrangements. The family's wishes must be respected in terms of what involvement they want from people at work. Managers should, where possible, allow staff time to attend the funeral.
- Recover work property from the family. This may be a car, laptop etc. Sensitivity around the timing is required here.
- Return belongings to the family and settle any monies owed as soon as possible. These may be paid to the estate, so seek advice as appropriate.
- Remove the person's name from distribution lists, email lists, phone message banks etc.
- Let some time pass before making office / work space changes. Colleagues need time to grieve and immediate changes may cause staff to react badly to decisions in this regard.
- Consider having a minute's silence, a candle, letting go of a helium balloon, or other memorial ritual at your next staff meeting to honour and respect your employee who has died.

The timing of the employee's death will have a bearing on the management of these issues.

GRIEF AND BEREAVEMENT

There is no easy way to deal with the death of an employee and colleague. It is an emotional time for everyone concerned. As previously mentioned, most people will have given permission to divulge at least some information about their illness, so colleagues can prepare for the inevitable. The reaction of staff will be somewhat influenced by whether the person was at work yesterday or had been absent for some time.

The effects of grief and how it is expressed varies from person to person. Each person's experience of loss is unique. It may interfere with thought processes, concentration and interrupted sleep patterns. Fatigue, anxiety and mood swings are common, in addition to feelings of sadness, guilt, anger, betrayal, anxiety, tension and loss of confidence.

Being a supportive employer can help ease stress levels and minimise periods of sick leave. If your organisation has an EAP, make sure your staff know about the service and how to access it. If your organisation doesn't have an EAP, consider making counselling services available. It may be appropriate to arrange for the EAP or a grief counsellor to visit the workplace so staff can meet as a team, or individually, for support.

When a colleague dies, each person's reaction to the loss will be different. Below are some tips to help staff deal with grief:

- Don't tell people you know how they feel. You don't, nor does anyone else.
- Be prepared to spend time listening, and to just be there for them.
- Do not use platitudes, for example, "They've gone to a better place" or "They had a good innings".
- Encourage people to take time out during the day to clear their heads and gather their thoughts.
- Do not avoid them.
- Ask if there is something they need, rather than how are they feeling.
- Be patient. People who are grieving will often not know themselves what is helpful.

- Understand that grief can have an impact on a person's work performance.
- Don't be afraid to use the name of the person who has died, to share memories and stories.
- Be mindful of any cultural sensitivities.

Understanding grief is particularly relevant when it comes to supporting an employee who was a carer.

Grief does not have a timeframe, however, most people with the support of their family and friends, gradually learn to live with their loss and do not need to seek professional help.

In handling the death of an employee, be mindful of setting precedents that the organisation will be expected to follow should this circumstance arise again. The important thing is to be consistent and offer the same amount of support to all employees.

RETURNING TO WORK

When an affected employee is returning to work after an extended period of absence, during treatment or after being a carer, these tips may help:

- Meet with the affected employee before their return to discuss their work plan and facilitate a smooth transition back to work.
- Ask the affected employee about their first few days back. The team may want to hold a morning tea to welcome them back, but the employee may not want the attention.
- Be there to welcome the affected employee back and if you can't be there, phone in. If policies, practices or arrangements have changed in their absence, take the time to provide an update.
- Advise staff that their colleague is returning so they are prepared to welcome them back to the team. Communicate the return-to-work plan at the macro level to ensure everyone knows what it is and expectations are clear.

- Check that logistics, such as building and IT access, are in place as they may have lapsed.
- Check regularly with the affected employee on how they are going and identify any concerns early.
- Offer your affected employee the services of your EAP.
- Where the affected employee has medical restrictions, a change of job function and a range of work health and safety considerations may need to be discussed. The return to work process can be quite involved and will require careful planning and regular evaluation.

[Appendix 4: Return to work checklist](#) is provided to assist managers.



IF YOUR EMPLOYEE IS A CARER

The emotional journey of a carer can be similar to that of the person they are caring for. In fact, research has shown they are more likely to suffer from depression than those suffering the illness.

Assisting an employee who is a carer is similar to the processes described above, as they support the person facing a life-limiting illness, and they should be afforded the same privacy provisions. Carers are also required to notify their employer of an inability to work as soon as practicable. As the employer you are entitled to request evidence to substantiate the reason for the leave (e.g. a medical certificate or statutory declaration).

An employee may not wish to advise their employer of their carer responsibilities; a common concern is they do not wish to be discriminated against or lose out on promotional opportunities. Although a carer is not obliged to advise their employer that they have caring responsibilities, where an opportunity is presented, managers should welcome this and work with the affected employee to provide time off to attend to and support their loved one.

Some practical points for discussion:

- Does the affected employee want colleagues to know about their situation and, if so, how should that be communicated?
- What are the known caring activities and timing, so time off is planned. This may facilitate practical management of work and absences so that half days or hours off are incorporated into the affected employee's calendar.
- Discuss workload management and whether some responsibilities require assistance, or could be diverted. This may be on a temporary or ad-hoc basis, or something more permanent until caring responsibilities have ceased. Put any arrangements in writing, including a review date.

Management should also:

- be aware of the unpredictable nature of caring responsibilities and the need for unplanned time off at short notice
- anticipate that the carer may be struggling emotionally, and encourage counselling. If you have an EAP this is a time its services should be promoted
- regularly check in with your affected employee to see how any altered job arrangements are panning out. It is also a time to see if the carer's responsibilities are changing
- know that the *Disability Discrimination Act 1992* protects carers of people with a life-limiting illness from workplace discrimination. The definition of disability in the *Disability Discrimination Act 1992* is as broad as possible. It includes: "...the presence in the body of disease causing organisms." Unlawful discrimination under this Act includes discrimination because a person is an associate of a person with a disability. Associates include partners and families, friends, and carers.

There are many community resources available that may assist a carer with practical issues, such as getting people to a doctor's appointment, and helping the carer's work / life balance.

A carer may also take compassionate and bereavement leave when their loved one contracts a life-limiting illness and when their loved one dies.



IN SUMMARY

Developing a Working with a Life-Limiting Illness policy is a MUST for all employers. The policy will help managers support staff through a particularly difficult time in their lives, lead to greater retention of employees and their accumulated knowledge, and improve job satisfaction. It will also help managers through one of the more harrowing supervisory experiences.

Positioning your organisation to develop and implement workplace policies associated with supporting employees with a life-limiting illness, and those with caring responsibilities for others, will:

- provide employees with a life-limiting illness with information and certainty around how the circumstances of their illness and employment will be handled
- support employees with a life-limiting illness to access resources, advice, and tools to assist them at a difficult time in their lives
- give guidance to managers to work with their teams to support employees with a life-limiting illness
- support staff who are caring for loved ones with a life-limiting illness
- create leaders who understand how to best support and manage an employee dealing with a life-limiting illness
- contribute to the promotion of a caring culture where all leaders can deal with such situations with empathy, compassion and respect e.g. give them or facilitate access to the Life-Limiting Illnesses In The Workplace - A Toolkit For Employees.

CASE STUDY 1

WHAT NOT TO DO

For over 25 years I had worked for a large professional services firm and was in a senior role. I approached my CEO requesting three months leave, to commence urgently, due to the unexpected news my partner had been diagnosed with a life-limiting illness and needed full-time care.

Although my CEO was certainly empathetic at the time, he said he would need to put a few things in place and it may take him a few days to get back to me. What I thought should have taken three days to get in order, actually took three weeks. That was three weeks of precious time I no longer had with my partner.

So, when the CEO finally told me he had worked things out, I told him I had too. I had worked out that I no longer wanted to work for that CEO nor that company and I immediately resigned, taking my company knowledge, insight and experience with me.

That was three weeks of precious time I no longer had with my partner

CASE STUDY 2

A POSITIVE OUTCOME

Palliative care. I thought I knew what that meant. My grandfather went in to the local hospice, for the last two weeks of his life. But my next encounter taught me much more.

Some years after my grandfather's death, my mother was diagnosed with motor neurone disease in her early sixties. I hadn't heard of the disease at the time—it was before the 'ice-bucket challenge'.

The disease started in her right hand and she learnt to write with her left hand and found a few 'tools' to help do other things. As the disease progressed the 'tools' became more serious—a wheel chair, a mechanical lifter, a hospital bed at home, breathing support, and even a feeding tube when she was unable to swallow. Mum didn't like hospitals and my sister and I were lucky enough to be able to share in her care with our father—in a large part because of the support from our employers.

In the latter stages of this cruel disease, 'living angels'—palliative care staff and volunteers—visited regularly. At first, Mum was a little uncomfortable with having 'strangers' in her house doing things for, and to, her. But, these angels provided services we, as her immediate family, could not. Medical advice and interventions, counselling, and the type of care that enabled her to stay at home until the end.

Mum didn't want to die in a hospital and, thanks to the gentle, skilled and vital care provided by in-home palliative care, she didn't have to. The other partner in providing this end-of-life care was our employers. During this journey, we both had the complete support and understanding of our workplaces. We were each granted two days' carers leave each fortnight and with this support we were able to help our parents in their greatest time of need. It meant so much to us all during a very difficult time.



PART 3:

CREATING A COMPASSIONATE COMMUNITY IN YOUR WORKPLACE

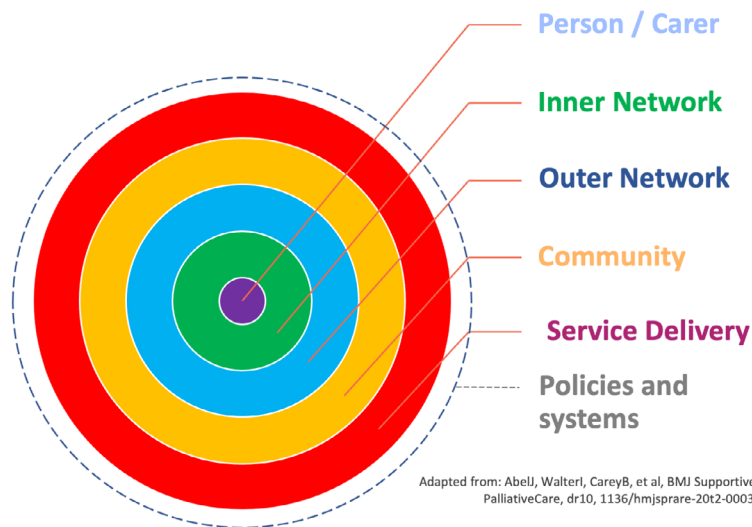
Compassionate communities are networks of support around people who are experiencing loss, ageing, dying, grief, and bereavement. This includes formal and informal health, social and community service, as well as informal supports including families, friends, groups, religious/faith/spiritual communities, social clubs, networks and workplaces.

Below is the Circle of Care diagram this explains the different circles of support around the person who is affected by the life limiting illness or their carer.

Your company may want to consider what role your staff can play in the person's circle of care. For example you may have some employees who are in someone's inner or outer circle, therefore may need more flexibility to provide their care support role or they might like to be your 'company liaison' - an informal conduit between the person and your company (note this is different to the HR and Manager role).

Your company also falls into the community circle of care for all people in your local community. For example could your company hold a local fundraiser each year to support palliative care or could the company offer a free service each year to support local people in your community experiencing a serious illness, dying, death or grief?

Circles of Care



CASE STUDY

I'm a Partner at a local law firm. After my secretary's husband died, our firm decided that each year we would donate ten free Wills and Estate sessions to local community members so they are more prepared in relation to palliative care.

I now actually volunteer my time as a Board member for our local hospice.

CASE STUDY

I work at a landscaping business. One of our landscapers died so our company decided that each year we would donate two free landscaping sessions to local community members experiencing a serious illness, dying, death or grief.

We have met such lovely people doing it tough.

SOME COMPASSIONATE IDEAS TO CONSIDER

- offering to set up a 'meal train' or other regular supports to engage employees in useful help (e.g. see Gather My Crew app)
- facilitating help to the other layers of the circle of care, e.g. could your employees help a family member, so they have more time to be with the loved one dying.
- offering public education about palliative care to your staff (e.g. PalliLearn or Last Aid), just as many do for mental health first aid.
- hosting a fundraiser to support palliative care in recognition of your employee or during National Palliative Care Week.
- building in flexibility into your policies for staff to gift accrued personal leave to other staff
- encouraging staff to complete an Advance Care Plan (ACP) e.g. by offering an additional half day leave during National Advance Care Planning week every year to complete or review their own Advance Care Plan or that of a loved one
- volunteering skilled employee time to support a palliative care initiative in your community; e.g. can your marketing team offer a few hours to support your local hospice or Palliative Care Queensland?



APPENDICES

APPENDIX 1

LEGISLATIVE FRAMEWORK

To manage the issues raised in this toolkit and to protect and promote good relationships with employees, organisations need to strike the appropriate balance between obligations and good policy.

There are three main elements of legislation that organisations should be mindful of when managing employees dealing with a life-limiting illness:

- the *Privacy Act 1988* regulates how personal information is handled. The Australian Privacy Principles, contained in schedule 1 of the Privacy Act, outline how most Australian Government agencies, all private sector and not-for-profit organisations with an annual turnover of more than \$3 million, all private health service providers and some small businesses must handle, use and manage personal information.
- the *Disability Discrimination Act 1992* prohibits discrimination against people with disabilities in employment, education, publicly-available premises, provision of goods and services, accommodation, clubs and associations, and other contexts. Discrimination is defined to include failing to make reasonable adjustments for the person.
- the *Fair Work Act 2009*, a law on the industrial relations system in Australia, governs the employee / employer relationship. It provides a safety net of minimum entitlements, enables flexible working arrangements and fairness at work and prevents discrimination against employees. Division 7 of the Act outlines employee rights with respect to personal / carer's leave and compassionate leave.



APPENDIX 2

CASE MANAGEMENT COVER SHEET

Employee Name		Date	
Employee's immediate manager:			
HR manager assigned to the case:			
Date commenced with organisation			Employee advised
Current Leave entitlements	Annual leave		Yes Date
	Personal leave		Yes Date
	Long service leave		Yes Date
Date of first notification of illness and who was present:			Date
Reassured employee of their job security at this time Notes:			Yes Date
Immediate time off offered or other time off discussed: Notes:		Dates	Yes Date
Agreed main point of contact for communication will be:			Date
Privacy requested Notes:			
Agreed communication plan is: Email / Meeting / Word of Mouth / Other Notes:			
Immediate work load, tasks etc. that need attending to	Action plan:		
EAP or other counselling services offered			Yes Date
Changes to work load / duties / hours discussed Notes:			Yes Date
Work health and safety concerns arising from treatment discussed Notes:			Yes Date

Is there a need for an independent medical report as to what functions / duties are permissible and not permissible Notes:	Yes Date
Changes to duties to be implemented with employee's consent Brief description:	Yes Date
Documents detailing work duty changes signed by employee	Yes Date
Resolution to seek legal advice as to the complexity of the case and to seek clarity around employee and employer rights and responsibilities	Yes Date
Financial adviser engaged or encouraged	Yes Date
Up-to-date superannuation insurance information provided	Yes Date
Counselling offered to other employees	Yes Date
Review: Employee Date: Coping with work load: Changes to privacy requests / communication plan Other	
Review: Affected colleagues Date: Coping with work load: Other	
Review: Employee Date: Coping with work load: Changes to privacy requests / communication plan Other	
Review: Affected colleagues Date: Coping with work load: Other	
Review: Employee Date: Coping with work load: Changes to privacy requests / communication plan Other	
Review: Affected colleagues Date: Coping with work load: Other	
Risk management: Intellectual property / Contacts / Contracts / Passwords / PINs / etc. Notes:	
Contact family re work property in employee's possession and/or personal property at work:	



APPENDIX 3

USEFUL TIPS FOR STAFF

It is often difficult for staff when a colleague announces their life-limiting illness.

Below are some tips to share and discuss with staff after the announcement of a colleague's diagnosis with a life-limiting illness. Let your team know:

- it's alright to ask the person if they want to talk about it
- it's helpful to just listen
- they should check how often a person wants to be asked how they are or if it would be better just to 'be there' when they raise it
- they are not required to do anything
- they can send cards, telephone or visit if it is appropriate
- they should find out what help would most be

appreciated; this could include: running errands / helping with difficult tasks / cooking meals / providing transport / taking children to school / walking the dog / washing / ironing

- it's usually welcome to talk about things other than illness
- they should avoid 'smothering' the person by doing / offering too much
- it's okay to encourage helpful coping strategies such as exercise and good nutrition to overcome treatment side effects, but be sure not to overdo the helpful advice
- they can use appropriate forms of humour (follow the lead of the affected person)
- to continue to include the person in social events
- they can encourage the person to access counselling, psychology services and support groups.

These tips can also apply when a colleague is a carer of someone with a life-limiting illness.

APPENDIX 4

RETURN TO WORK CHECKLIST

Return date	
Research illness / condition if known, to better understand what the affected employee is experiencing. Notes:	
Arrange meeting prior to return date to discuss: <ul style="list-style-type: none"> • work duties, any changes required, updates on workplace progress (for example, clients, contracts, job tasks, etc.) • communication with colleagues prior to return in accordance with their privacy wishes • any possible workplace health and safety issues arising from illness or treatment • workplace changes during the employee's absence • whether they would like to access to EAP services. 	
Check access to internal systems, if it has been a long absence.	
Prepare internal staff communication—format and content —to advise of their return.	
Arrange to be there on date of return. If unable, organise a substitute and diarise to phone and check in.	
Follow up: diarise to check in after a few days and beyond to discuss progress / concerns, etc.	



Last Aid

We all know about First Aid, but what about Last Aid?

What is Last Aid?

Last Aid is a 4-hour international standardised introductory level community education program.

Who can attend?

This course is for all members of the community. You need no training or experience in the space.

Why attend?

The way we care for our dying is a significant indicator of the kind of society we are.

Serious illness, dying, death and grief are a part of life.

This education program is for members of the community, community groups, businesses, retirees, who want to improve their confidence and skills in supporting carers, family members, colleagues or people experiencing a serious illness, dying, death or grief.

This education program is not designed for health professional or professional carers.

What topics are covered?

- Dying as a normal part of life
- Planning ahead
- Relieving suffering
- Final goodbyes

palliativecareqld.org.au/lastaid



An initiative of

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QUEENSLAND
PALLIATIVECAREQLD.ORG.AU

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