



hospice<sup>UK</sup>  
**Compassionate**  
Employers



# Human Resources guide

Compassionate Employers Programme

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# Introduction

This guide is part of the Hospice UK Compassionate Employers Programme and is designed for the human resources (HR) team. As well as being a practical guide, inside there are a series of links to places where you can find more detailed information or support if you want it. You can find all the links on the Compassionate Employers section of the Hospice UK website. There are companion guides for line managers and employees. These guides are intended to help organisations be prepared to support their people through personally challenging circumstances.

Over time, whatever its size, your organisation is likely to include people who are:

- living with a life-limiting or terminal illness
- caring for someone else with a life-limiting or terminal illness
- living with bereavement.

These are all personal matters which can be difficult to talk about for staff and managers alike. Each person's circumstances are unique to them. It is up to them how much confidential information they choose to share.

A compassionate employer is a company that will help people feel confident and comfortable approaching managers and HR, knowing that they will help. As part of that, HR can help by making the relevant information easy to find, and by being ready to talk through the practical implications of the options available.

There is a lot employers can do to support people in these circumstances, such as having policies about flexible working and compassionate leave. Some employers are able to go further, with income protection schemes.

The HR team is where everyone turns for advice on the organisation's legal responsibilities towards people dealing with life-limiting or terminal illness, or bereavement, and for details of the organisation's own policies in these areas.

There is help available from other organisations outside of the Compassionate Employers Programme including:

- carers and disability benefits
- carer's allowance
- carer's assessments by local council or trust.

Various organisations offer support to people living with and dealing with particular conditions and bereavement, including confidential helplines (see the useful resources section at the back of this guide).

There is also a wealth of information available on specific issues such as 'What to do when someone dies' on the **GOV.UK** website.

In HR, you aren't responsible for making employees use these services but you can help by knowing where to find this information and signposting individuals as they need it.

## Training

All of the issues discussed throughout this programme are personal and sensitive. Getting it right for staff and managers relies on good communication. It can be difficult for anyone to raise these subjects and as a manager it is not easy to give the right response if you are taken by surprise. HR staff themselves need to know what their organisation's policies are, and they also need the right training to help them guide colleagues. This is a key area that the Compassionate Employers Programme can help with.

Training for managers is invaluable so that they are not caught unprepared when they need to talk to someone who has received a life-limiting or terminal diagnosis, who suddenly finds that they have caring responsibilities, or to someone who has been bereaved.

When you book training sessions through the programme, you may want to include union representatives too. Union members may turn to the union for advice and they will be best placed to provide it if they are part of the organisation's efforts to be a compassionate employer.

## Exit interviews

Your organisation will want to do everything reasonable to help your people to carry on working for as long as possible. Inevitably though, there will come a time for some when they have to leave. For example, it may be that their illness has reached a stage when they need to stop working.

When anyone leaves the organisation, you can carry out an exit interview with them. This is a chance to ask staff how well you are doing supporting people at work while they cope with challenging personal issues. What they tell you is an essential part of helping your organisation to keep learning and improving.



# Someone living with a life-limiting or terminal illness

A life-limiting illness is one which cannot be cured, though it can be treated, and which will shorten a person's life. A terminal illness is one that is incurable; however, the effects of the illness can be managed so that a person can live with it for days, weeks, months or even years.

There are a wide range of life-limiting and terminal illnesses including heart failure, lung disease, Duchenne Muscular Dystrophy and cancer that are no longer responding to treatment.

How the individual is affected will depend on a range of different factors and will change over time. There is the diagnosis itself, the stage the condition has reached and the likely prognosis, as well as questions such as the treatment options. They may only have a short time to live or they may have years of active life ahead of them.

It is up to the employee how much they want to share with their colleagues, managers and HR but the more they feel able to confide the better the organisation will be able to support them.

People are likely to want to carry on working for as long as possible, which is good for both them and the organisation, but the time will come when they need to stop. HR needs to be able to advise on the financial aspects of giving up work.

## Disability

As they progress, life-limiting and terminal illnesses can become disabling. The Equality Act 2010 sets out employers' duties towards disabled staff. Some conditions are automatically treated as a disability, including:

- cancer – including skin growths that need removing before they become cancerous

- multiple sclerosis
- an HIV infection – even if the person doesn't have any symptoms.

If someone is disabled by their condition, they are entitled to reasonable adjustments to help them in the workplace.

These might be:

- changes to policies
- changes to working practices
- changes to physical layouts
- providing extra equipment or support.

All kinds of policies, procedures and ways of working are included as reasonable adjustments – written or unwritten, formal or informal. They can include:

- dress codes
- working hours
- working practices
- recruitment policies
- absence policies
- promotion criteria
- redundancy selection criteria
- work allocation.

An employer only has to make reasonable adjustments if they know or could reasonably be expected to know someone is disabled, and that they are disadvantaged because of it. The first step is a discussion to work out what the employee wants; these conversations could involve HR, their line manager, or occupational health. It is a good idea, following the meeting, to ensure everything agreed is documented. You could ask the employee to write to you so you and occupational health have something concrete to work through.



There is no limit on the kind of changes employers can make, but they could include:

- changing hours of work, permanently or for a short while, if someone is coming back to work after being off sick
- changing someone's work duties – like reducing their workload if they have work-related stress
- allowing someone with back pain more breaks to allow them to stand and move away from their desk
- providing a chair with the right support.

### **Mental health**

It can be stressful dealing with a life-limiting or terminal illness. Carrying on working can help someone's mental health, but it can also bring its own stresses. A compassionate employer will want to be as supportive as possible, helping staff to manage their work as well as their illness. Managers may ask for guidance on policies that can make things easier. For example, if travelling to work has become difficult, it might be possible for a member of staff to do some work from home.

Your workplace may offer a counselling service that could help:

- If your organisation is signed up to an Employee Assistance Programme (EAP), staff will have free access to a 24-hour confidential helpline, offering information and advice.
- Depending on which provider you work with, they may be able to ask for face-to-face counselling sessions.
- An EAP can provide support to line managers as well as to employees directly affected.

Alternatively, many charitable organisations provide confidential, usually free, helplines for people coping with particular conditions such as cancer, or help such as online communities for anyone dealing with life-limiting or terminal illness, or bereavement. Find links to these in the useful resources section at the back of this guide.

## Long-term sick leave

If someone is off sick for more than four weeks, this counts as long-term sick. They may still be able to return to work, maybe by working flexibly or part-time, or doing different or less stressful work.

Managers may ask HR for advice on the organisation's policies and on what options might be available, such as whether it is possible to move someone to a different role in the organisation.

## Stopping work

A life-limiting or terminal illness may eventually mean that an employee has to give up work. This is likely to be a tough decision. HR needs to be able to advise on any schemes the organisation offers such as income protection, ill health retirement, or whether the employee can take their pension early.

## Difficult conversations

Employees don't have to tell the organisation about a diagnosis even if it is life-limiting or terminal, but a sign of a compassionate employer is that they feel confident to do so. This can involve difficult conversations about uncomfortable topics. The Hospice UK **Dying Matters** campaign produces helpful guidance about how to go about this, which HR can signpost line managers to.

These conversations will lead to practical outcomes and plans for how employees will manage their work alongside their illness. One aspect of planning which line managers can helpfully signpost to is planning for future care. This prompts individuals to think well ahead of time about issues such as treatments they would or would not like to have, where they would like to be cared for, and what sort of funeral they want. These may only be tangential to their life at work but they allow people to take charge at a time when they may feel control is slipping away from them. The peace of mind this can bring will help them at work as well as elsewhere in their life.

**For an employee with a life-limiting or terminal illness, HR can help in particular with:**

- workplace adjustment, including working from home
- long-term sick leave and disability rights
- taking pension early
- insurance schemes.



# Someone caring for a person with a life-limiting or terminal illness

Carers are employees with significant caring responsibilities that have a substantial impact on their working lives. These employees are responsible for the care and support of a child with a life-limiting condition, or a relative or friend who is older, disabled or seriously ill and unable to care for themselves.

Caring support can go on for years but can start suddenly when someone's relative or partner becomes ill. Caring can be difficult to manage alongside a job, especially where its demands are unpredictable or may grow over time.

You are very likely to have carers in your organisation. The **Carers Trust** reports that in the UK nearly one in eight workers is a carer and that one in five carers give up employment to care. This can be a big loss of talent, expertise and experience. Helping staff who are carers to cope with both roles makes good business sense, as well as being good employment practice.

Carers have legal rights which can be different in different parts of the UK. The law sets out basic entitlements but many employers go further.

There may be things which the organisation can help with directly, such as flexible working. HR can also help by signposting to other possible sources of financial and practical help, such as a carer's assessment or carer's allowance. You can find further links in the useful resources section at the back of this guide.

## Difficult conversations

Carers don't have to tell the organisation about their caring role but a sign of a compassionate employer is that they feel confident to do so. This can involve difficult conversations about uncomfortable topics. There is helpful guidance on the Hospice UK **Dying Matters** website about how to go about this, which HR can signpost line managers to.

## Pre-bereavement

If someone has been suffering from an incurable illness, such as dementia, their family may begin the grieving process long before the person actually dies. They will need the same sort of consideration and support as they go through this pre-bereavement period as they will later on when the person has died.

## Flexible working

The law gives employees the right to ask for flexible working once they have been employed for 26 weeks. The legal right is to make such a request once a year but as a carer's responsibilities can change, sometimes unexpectedly, your organisation may want to allow more frequent requests. The member of staff and their manager may want to:

- try out a plan and see how well it works
- review it and agree any changes needed
- keep this conversation going.

A carer may need occasional leave for emergencies, for example if care arrangements break down unexpectedly which means they may not be able to give notice. Your organisation can treat this as part of their annual leave or it may have a more flexible approach, such as a policy of offering paid emergency leave for a given number of days per year.

There may be occasions when a carer needs to spend several days at a time away from work. Some employers offer unpaid leave to allow for this. If this might affect the person's eventual pension, you could allow for them to carry on making pension contributions for the time they are unpaid.

If the person being cared for gets worse, or is about to die, they may need to spend time in hospital or in a hospice. This may change the carer's practical role if they have been looking after someone at home, but they will still need time to play their part. For example, they may need to join in meetings with the professional staff looking after a dying person, and they may want to spend as much time as they can with that person. When someone has only a short time to live, every day can be precious. As a compassionate employer, you may want to have a policy allowing paid leave for carers so that they can be with their loved ones in their last months.

### Flexible working options

Depending on how big your organisation is, how it is structured and what the carer's job is, there are all sorts of variations on flexible working that you may be able to offer:

- **flexi-time** – employees may be required to work within set times but outside of these 'core hours' have some flexibility in how they work their hours
- **home working or teleworking** – teleworking is where employees spend part or all of their working week away from the workplace and homeworking is just one of the types of teleworking
- **job sharing** – usually two employees share the work normally done by one person
- **part-time working** – employees might work shorter days or fewer days in a week
- **term-time working** – employees don't work during school holidays and either take paid or unpaid leave or their salary is calculated pro-rata over the whole year
- **shift-swapping or self-rostering** – employees agree shifts among themselves and negotiate with colleagues when they need time off, with the process being overseen by managers
- **staggered hours** – employees have various starting and finishing times meaning that goods and services are available outside traditional working hours





- **compressed hours** – employees work their total hours over fewer working days, for example a 10 day fortnight is compressed into a nine day fortnight
- **annualised hours** – employees' hours are calculated over a whole year and then split into 'fixed shifts' and 'reserve shifts' which can be agreed on a more flexible basis.

## Carer's assessment

A person caring for someone who is disabled, ill or elderly is entitled to a carer's assessment by their local council or trust. If the council decides that the carer has eligible needs, the council have a legal obligation to meet these needs if the carer wants them to. Some councils and trusts in England, Wales and Northern Ireland charge for carers' support. If they do, then they carry out a financial assessment to decide what, if any, contribution they charge. Carers in Scotland are not charged for support provided by the council. Guidance on the criteria is available from the **Social Care Institute for Excellence** and can help an individual decide whether or not to apply.

Services can be provided directly to the carer, or to the person they are looking after, or a combination of both.

## Help available to carers

Help available directly to a carer might be:

- help with transport costs, such as taxi fares or driving lessons
- costs for a car where transport is crucial, such as repairs and insurance
- technology, such as a mobile phone, computer where it is not possible to access computer services elsewhere
- help with housework or gardening
- help to relieve stress, improve health and promote wellbeing such as a gym membership.

Help available through a carer's assessment to the person being looked after might be:

- changes to their home to make it more suitable

- equipment such as a hoist or grab-rail
- a care worker to help provide personal care at home
- a temporary stay in residential care/respite care
- meals delivered to their home
- a place at a day centre
- assistance with travel, for example to get to a day centre
- laundry service
- replacement care so the carer can have a break.

Someone caring for a child with a life-limiting or terminal illness, provided they have been employed for more than a year, can take up to 18 weeks unpaid parental leave, up to a maximum of four weeks in a single year. Organisations can be more generous if they choose.

## Financial support

If someone is spending 35 hours or more a week on caring they may be eligible to claim carers' allowance. There is a cap on how much they can earn and still qualify. If an employee is having to reduce their hours, HR could signpost them to explore this option.

### For an employee with caring responsibilities, HR can help in particular with:

Helping carers carry on working effectively by supporting flexible working. HR can also signpost carers to other forms of support, including financial help. If your organisation is signed up to an EAP, that provider may be able to advise employees confidentially on issues such as the care of older people, and financial matters. Other forms of help could include:

- local networking groups where carers can offer mutual support and exchange experiences
- carer events and training such as falls prevention, stroke awareness, understanding dementia, understanding finance and benefits.

# Someone living with bereavement

Death is a single event but bereavement does not end.

People react differently to being bereaved and over different timescales. Different cultures and religions have their own rituals, requirements and attitudes to death. From the point of view of a compassionate employer:

- there is the immediate issue of allowing time for someone to arrange and attend a funeral
- the bereaved person may need different help in the weeks and months following the death, especially if it means that they have a changed role and new caring responsibilities within the family
- if the person who died was the primary wage earner, they may need to reevaluate their own job and working patterns
- in the short and medium term, they may be responsible for executing a will or dealing with an estate, which could take a year or more to complete.

## Experiencing bereavement

How someone experiences bereavement will be affected by the circumstances of the death. A suicide will be quite a different matter from death at the end of a long illness. Losing a baby during pregnancy is quite another thing again.

It is not possible to fully understand and appreciate what someone is going through. But knowing the sort of death the bereaved person is coping with will help a compassionate employer respond as helpfully as possible. In the same way, if you know that the bereaved person comes from a particular culture or religion, that will help steer you to make the best response, but it is best to allow them to lead. For example, there are many different Christian denominations and many different Muslim sects so it would be a mistake to assume that all

Christians or all Muslims treat death in the same way. There are some helpful summaries of different faiths by **Public Health England** that can provide a useful guide.

Most people are able to cope with bereavement without professional help. Grief is not an illness, though it can be exhausting and unpredictable. It does not have a set, or even a usual, length. People who were managing well can be caught unexpectedly by triggers such as:

- birthdays or significant anniversaries
- the due date of a baby who died in pregnancy
- the date of the funeral
- less obvious dates such as the date of diagnosis.

Christmas can be difficult, especially the first one after the death, and if it is an option the bereaved person may choose to work through the holiday as a distraction. Some people choose to become very busy after a bereavement, whether with the legalities of managing the estate or by campaigning for a relevant charity or making a complaint against a hospital they feel was at fault. This sort of activity can have the effect of postponing grief.

## Respecting diversity

Organisations work hard to respect diversity in their staff and the Equality Act 2010 sets out their obligations to do so. People do not have to share information about their religious background if they prefer not to. However, if they do, this can help colleagues to say the right thing and provide the right support when they need to deal with sensitive issues such as bereavement. Questions which might be directly relevant to providing support to an employee who has been bereaved include:

- do they need leave to travel to allow them to fulfil religious obligations?
- is there a cultural expectation that they return the dead person to the country where they were born?

- are there any cultural practices, such as fasting, which colleagues need to know about?
- would it be appropriate for colleagues to attend the funeral? If so, is there anything those colleagues need to know? For example, often only men attend Muslim burials
- if you plan to arrange a collection, what would be a suitable tribute? For example, flowers might be appropriate for one religion but not for another.

This summary of different faiths written by **Public Health England** provides some helpful insight.

### Traumatic death

Any death, even an expected one, is likely to come as a shock when it happens. When a death is completely unexpected, the shock and surprise make it even harder to know how to respond to the bereaved person. Sudden deaths can be natural, such as those caused by illness, like a heart attack or stroke. Others might be:

- accident
- suicide
- murder or manslaughter.

Sudden or unexpected death automatically involves the coroner and an inquest. This is normal and does not imply that anyone is to blame.

Social media means that news and rumours spread very quickly and easily. The media may not have the full facts so don't assume that they are giving a true picture. It may be that the authorities have asked for some details to be kept confidential. If the death is of a staff member and generates publicity, HR may need to take charge of internal and external communications to avoid any speculation.

If the bereaved person wants to talk about the death and their feelings they will do so, and they may themselves have many questions they want answers to, especially in the early days when the death is being investigated. You can help by letting them know who they can talk to in the organisation, including any counselling services available to them.

If the death was the result of murder or manslaughter, the investigation may go on for months or even years. Depending on how the bereaved person was involved, they may need to attend an inquest or be a witness at a trial. If they suffer from post-traumatic stress disorder (PTSD), they may need specialist help to overcome it before they are able to grieve.

### Bereavement when a baby or child dies

A parent who has lost a child will need the same support in their bereavement as anyone else. Their grief will be coloured by their role as a parent and their instinct to protect a child. Here are some pointers for if line managers need help in responding:

- If a colleague has lost a baby in early pregnancy colleagues may not even have known that they or their partner were pregnant. The baby – not to be described as a foetus or an embryo – will have been important to the parents and they will grieve for the death.



- Bereaved parents are usually offered a photograph of their dead baby. Line managers may wish to know about this in case the bereaved parent wants to show this to colleagues. Being forewarned will allow them to respond sympathetically even if they find the image upsetting.
- Colleagues should not be alarmed if the police have been involved. This is standard practice with all unexpected child deaths even if they are caused by illness.
- This is not just about small children and babies. A parent who loses an adult child experiences the same feelings of loss and wrongness as any other bereaved parent.

## Occupational health

Carers and people who have been bereaved may find that their own health, both physical and mental, is affected. If an organisation has an occupational health service, it can offer health checks for these staff.

## Counselling and chaplaincy

If your organisation offers either of these services, they could be helpful not only to carers and bereaved people but also to those managing and working with them. They may be available through an EAP, with access to either a 24-hour confidential helpline or face-to-face counselling or both, depending on your provider.

There are a variety of organisations who offer free, confidential helplines (see the useful resources at the back of this guide). For more information and signposting, visit the Compassionate Employers section of the **Hospice UK** website. There are specific services for different types of grief, for instance the loss of a child.

If someone is not comfortable talking but would like to be able to interact with others, they could try an online community. They are free to use and can offer a safe and confidential environment for anyone to discuss what they are going through in bereavement.

## Returning to work after bereavement

Coming back to work after a bereavement can be daunting for the person who has been bereaved and uncomfortable for their colleagues. Line managers may ask for help about how best to manage the process to avoid awkwardness as much as possible. Here are some tips to make it easier for everyone:

- The bereaved person might return towards the end of the week or on a part-time basis for the first few days to help them to adjust back into work.
- Most people want their loss to be acknowledged and to be treated as normally as possible when they return to work.
- The first reference to the bereavement should be private and as natural as possible. Line managers may not need to set up a special meeting if their workplace layout allows them to have a short private conversation.
- Line managers should let colleagues know that the bereaved person will be coming back and share with them any information they can about what has happened, how the bereaved person would like to be treated and where colleagues can find support if they need it.

As part of treating the bereaved person normally, the line manager will want to make sure that they are brought up to date with what has been happening in the workplace, including staff changes, and planning their work schedule. People can be over optimistic about how easily they will get back into their work routine so it is good practice for line managers to:

- make a point of checking regularly how well the bereaved person is managing and adjust workload if necessary
- reassure them of the organisation's support
- remind them about what the organisation can do for them in terms of flexible working and compassionate leave.



**For an employee who is bereaved, HR can help in particular with:**

- Policies on compassionate leave and flexible working for bereaved people.

Organisations can offer a set period of paid compassionate leave, maybe five days, for funeral arrangements. If someone needs longer, for example if they have to travel abroad, there might be additional unpaid leave available.

Someone who is struggling to cope with grief may need flexible working arrangements to help them. They may also need to be advised to see their doctor and get advice from an occupational health service.

Practical tasks which may need time away from work include:

- registration of the death
- arranging the funeral
- attending the funeral
- interment or scattering of ashes
- dealing with the estate
- organising and attending a memorial event
- attending an inquest
- attending a trial.

## When a work colleague has died

If the death was related to the person's work, you will need to refer to the **Health and Safety Executive's** website and your own organisation's legal adviser.

People spend so much time at work that colleagues can develop close relationships. If a colleague dies there is likely to be an emotional reaction, rippling out from that person's immediate team and touching anyone they worked with. The actual nature of the reaction will depend on how well known, and well liked, the person was and the circumstances of the death. If it was an accident or suicide, people are more likely to feel shock than if someone had been known to be ill.

Many people will find out through word of mouth or through social media, but the organisation will want to provide accurate information and be compassionate and supportive. This includes letting the family know what is being said, especially if there is an internal website or any sort of media contact.

As soon as the news is known, the employer (probably a senior manager and preferably someone who knew the person) needs to take the lead to make sure that communication takes place quickly and sensitively across the organisation. If the person had regular contact with external stakeholders, they will need to be informed too.

### When a work colleague has died, HR can help in particular with:

- making sure that legal and payroll duties are handled quickly – there may be death-in-service payment to be processed, for example
- making sure that communication is handled sensitively.

## Additional practical guidelines for HR

- Have ready an outline letter of condolence to be completed quickly for a senior manager to send to the family.
- Someone from HR may be the best person to act as liaison with the family over any support to be provided, and to relay information about the funeral to colleagues who need to know.
- Help organise a book of condolence, to offer a chance for everyone who wishes to express their sympathy to the family. HR can play a part in making this happen, working with the person's closest colleagues and possibly the family too to make sure that this is the right thing under the circumstances and will be welcome.
- Help arrange for personal items in the workplace to be returned to the family, or workplace equipment such as a laptop or phone to be returned from home to the organisation.

HR can make sure that close colleagues of the person who has died have access to the information and support they may need, as they will be experiencing bereavement. It may not be as intense as for a family member but there can still be a profound sense of loss and shock.

## Funerals and remembrance

HR may want to have a policy about who should attend the funeral of a team member. It may be that everyone who wishes to go can be given the time, but there may need to be cover arrangements. If the funeral is at a distance, the organisation may wish to provide transport for those attending or for whoever is chosen to represent the workplace.

The organisation may wish to do something like planting a tree in memory of the person who has died. Such a gesture is likely to be welcomed but you will want to be careful about setting a precedent that might cause problems in the future.

## Delivering bad news

Delivering bad news can be stressful for the person doing it as well as distressing for those receiving it. HR can support managers in this task with guidance on how best to go about it. For example, it helps to think through beforehand where the best place might be. Whether you are talking to one person or to many, you want to do so in a quiet place where you won't be interrupted, including by phones. You will want to be sure that you are clear about the facts you are passing on and you will want to prepare your audience, checking what they already know.

If a manager has to deliver bad news to an individual:

- it is best if there can be another person there too to offer support
- they will want to allow enough time for this as it is hard to predict how someone will react to such news.

If the bad news affects the whole organisation, for example if a senior manager dies, HR will want to lead on the communication to all staff. They may be concerned about their own future as well as shocked by the death. It is important that the message is as reassuring as possible as well as factual and compassionate.

## Help for line managers

This guide aims to help you to support colleagues through some of the most difficult challenges of their lives and to support their line managers. By doing so you will be helping both them and your organisation. Line managers may find that providing this support is challenging – both as a line manager and as a person. There will be organisational demands to manage and there will be their own emotional response to their colleague's situation. This can be intense for them especially if they know their colleague well or if it brings back memories of their own experiences. Line managers might therefore also need support.

Their own line manager will be able to provide support, for example, confirming that the practical steps they have taken to help their colleague are the right thing to do. They may have experience and ideas of their own to contribute. The training you offer will provide a firm basis to help them to cope.

The confidential helplines and online forums can help line managers as well as people directly affected by terminal illness. If your organisation offers chaplaincy or counselling, that will be open to them if they need it, as will any confidential helpline or counselling available through your organisation's EAP.

# Glossary of terms

## Occupational health

The branch of medicine dealing with the prevention and treatment of job-related injuries and illnesses.

## Employee Assistance Programme (EAP)

An employer funded benefit intended to help employees deal with personal issues that might adversely impact their work performance, health and wellbeing. EAP include assessment, short-term counselling and referral services for employees and their immediate family.

## Dying Matters

Dying Matters is a coalition of individual and organisational members across England and Wales, which aims to help people talk more openly about dying, death and bereavement and to make plans for the end of life. The coalition is led by Hospice UK.

## Palliative care

Palliative care includes support to those with an illness that can't be cured, by managing pain and other distressing symptoms. It also involves psychological, social and spiritual support for the patient, their family or carers.

## Hospice care

Hospice care is provided by multi-disciplinary teams of staff and volunteers who offer expert support which takes care of a person's physical, emotional, social and spiritual needs. This care and support extends to carers, friends and family before and after bereavement. Most hospices are independent charities, though some are run by the NHS.

## Life-limiting / terminal illness

A life-limiting illness is one which cannot be cured, though it can be treated, and which will shorten a person's life.

A terminal illness is one that is incurable; however, the effects of the illness can be managed so that a person can live with it for days, weeks, months or even years.

# Legal protection for UK employees

## What must companies do by law with regard to giving people time off when they are caring, ill or recently bereaved?

### Flexible working

- The right to request flexible working was extended on 30 June 2014 to all employees with 26 weeks' continuous employment by the Children and Families Act 2014.
- This includes reduced hours or job share, staggered hours, flexi-time and home working arrangements.

### Emergencies

- The Employment Rights Act 1996 stipulates that Employers must give someone 'reasonable' time off to deal with an emergency involving a dependent. For example, a breakdown in care arrangements.
- This time off is likely to be short-term, around one or two days, but there is no legal definition of how long a reasonable amount of time off should be. For further information see: [www.gov.uk](http://www.gov.uk)
- Employers do not have to pay their employees for emergency time off. For further information see: [www.gov.uk](http://www.gov.uk)

### Carers

- The Employment Act 2002 allowed certain carers the right to make a formal request for flexible working.
- The legislation initially gave the right to parents of children under six or disabled children under 18.
- It was some years later before the scope was expanded to include other carers.



## Bereavement

- Female employees who suffer a stillbirth after 24 weeks are entitled to up to 52 weeks statutory maternity leave and/or pay. Similarly the subsequent death of a child born alive would not affect the mother's entitlement to maternity leave. There is more information on the **GOV.UK** website: [www.gov.uk](http://www.gov.uk)

## Useful resources



There are organisations that can provide support and information. A selection of these resources are listed here.

### About Hospice UK's Compassionate Employers Programme

The **Compassionate Employers Programme** provides practical guidance to support employees and employers to deal with the challenges they face around terminal and life-limiting illness, caring responsibilities and bereavement. For further resources and signposting visit our website.

Website: [www.hospiceuk.org/compassionate-employers](http://www.hospiceuk.org/compassionate-employers)

### About hospice and palliative care

Visit **Hospice UK's** website for information about hospice and palliative care, where to find local services and a step-by-step guide to getting hospice care.

Website: [www.hospiceuk.org](http://www.hospiceuk.org)

**Together for Short Lives** is a charity for children living with life-limiting conditions, and their families. Visit their website for information about hospice and palliative care support for children and young people.

Website: [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)

### The workplace

**ACAS** and the **UK Government's** website are amongst the resources offering guidance on topics such as parental leave, reasonable adjustments in the workplace for workers who are disabled and benefits such as Personal Independence Payments:

- **ACAS:** [www.acas.org.uk](http://www.acas.org.uk)
- **GOV.UK:** [www.gov.uk](http://www.gov.uk)

## For carers

The charity **Carers UK** provides information and help for carers ([www.carersuk.org](http://www.carersuk.org)). Resources include:

- a factsheet on working carers' legal rights
- information about carer's assessments (for adult carers of people aged over 18 years)
- information about the carer's allowance.

The website **GOV.UK** also has information about the carer's allowance and guidance on topics such as flexible working: [www.gov.uk](http://www.gov.uk)

## Coping with terminal illness and looking to the future

The **NHS website** has advice on coping with a terminal illness. Website: [www.nhs.uk](http://www.nhs.uk)

See Hospice UK's booklet, '**Planning for your future care: a guide**', for information about advance care planning. Download the booklet at: [www.hospiceuk.org](http://www.hospiceuk.org)

For advice on making a will, see the **UK Government** website: [www.gov.uk](http://www.gov.uk)

## Spiritual care

Produced by Public Health England, '**Faith at the end of life: a resource for professionals, providers and commissioners working in communities**' (2016) outlines the importance of faith at the end of life. It includes an overview of the main end of life beliefs, practices and rituals relating to the six major faiths in England.

Website: [www.gov.uk](http://www.gov.uk)

## Talking about end of life issues

**Hospice UK** has a range of leaflets which are designed to help everyone, whatever their situation, begin conversations about end of life issues. They present useful information in a clear and easy to read manner on subjects including making plans, writing wills, bereavement, talking to children about death and avoiding misconceptions about dying.

Browse the range of leaflets at: [www.dyingmatters.org](http://www.dyingmatters.org)

## Information, advice and support after someone has died

### What to do when someone dies

Covering how to register the death, notifying government departments and managing financial issues, the **UK Government** website features a step-by-step guide on what to do after a death.

Website: [www.gov.uk](http://www.gov.uk)

Local branches of **Citizens Advice** may also be able to offer information and advice – find out about local services at: [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

### Bereavement, grief and loss

The **NHS website** includes information about dealing with grief and loss.

Website: [www.nhs.uk](http://www.nhs.uk)

### Hospice bereavement support

Hospices offer support and information to the family and friends of people who were cared for by the hospice – both before and after a death.

Some hospices provide bereavement support services to the wider community, meaning that someone does not need to have already been under the care of the hospice in order to access this support.

The directory on **Hospice UK's** website can help you find out about local hospices in the UK (and also the Channel Islands and Isle of Man): [www.hospiceuk.org](http://www.hospiceuk.org)

### Other sources of bereavement support

**Cruse Bereavement Care** is a national charity which provides support, advice and information to children, young people and adults when someone dies. This includes coping with traumatic loss.

Website: [www.cruse.org.uk](http://www.cruse.org.uk)

The national charity **Sue Ryder** provides an online bereavement counselling service which offers free short-term support for anyone grieving for a loved one.

Website: [www.sueryder.org](http://www.sueryder.org)

The **Childhood Bereavement Network** offers information and advice on supporting bereaved children and young people.

Website: <http://www.childhoodbereavementnetwork.org.uk>

**Child Bereavement UK** provides information and support (including a helpline) when a baby or child of any age dies or is dying, and when a child is facing bereavement.

Website: [www.childbereavementuk.org](http://www.childbereavementuk.org)

### Other helplines and online forums

Hospice UK's **Dying Matters online community** is for people dealing with terminal illness or bereavement: [www.dyingmatters.org/overview/community](http://www.dyingmatters.org/overview/community)

There are opportunities to talk to people who may be going through similar experiences. Charities and other organisations which support people living with particular illnesses or conditions often have online chat forums or advice and support services. For example:

- the **Alzheimer's Society** offers an online community called Dementia Talking Point: [www.alzheimers.org.uk/](http://www.alzheimers.org.uk/)
- **Macmillan Cancer Support** has an online community: <https://community.macmillan.org.uk>
- **Marie Curie** has an online community for anyone aged 16+ affected by a terminal illness: <https://community.mariecurie.org.uk>
- **Together for Short Lives** provides a helpline and has a Family Support Hub which offers emotional support and practical advice: [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)
- **Carers UK** has an online forum: [www.carersuk.org](http://www.carersuk.org)

To find organisations for specific illnesses and conditions that can offer advice and support, try the Health A-Z on **NHS Choices**.

Website: [www.nhs.uk](http://www.nhs.uk)

### Additional sources for Legal protection for UK employees

- **GOV.UK**. Time off for family and dependents: [www.gov.uk](http://www.gov.uk)
- **Carers UK**. Support in work: [www.carersuk.org](http://www.carersuk.org)
- **ACAS**. Parents and carers: [www.acas.org.uk](http://www.acas.org.uk)
- **ACAS**. Time off for dependants: [www.acas.org.uk](http://www.acas.org.uk)

If you would like further information about the programme or any sources referenced, please contact us at: [compassionateemployers@hospiceuk.org](mailto:compassionateemployers@hospiceuk.org)





 hospice<sup>UK</sup>  
**Compassionate**  
Employers

## Get in touch

Speak to us today about how you can become a compassionate employer.

[compassionateemployers@hospiceuk.org](mailto:compassionateemployers@hospiceuk.org)

[www.hospiceuk.org/compassionate-employers](http://www.hospiceuk.org/compassionate-employers)

You can also follow us on LinkedIn:

[www.linkedin.com/company/hospice-uk](http://www.linkedin.com/company/hospice-uk)

[www.hospiceuk.org](http://www.hospiceuk.org) 020 7520 8200

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