

Supporting employees with terminal illness

A guide to workplace policies and practice

What does this guide cover?

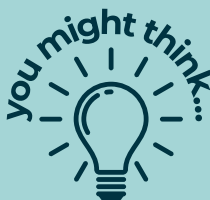
This guide is an introduction to the topic of work and terminal illness, rather than a comprehensive set of instructions. This is because there is currently very little evidence of 'what works' to most effectively support employees with a terminal illness.

This guide is designed to provide insights and information that you can use to develop policy and recommendations that are aligned to your particular organisation and employees.

This guide sets out the most important things you should think about, including:

- What people working with a terminal illness tell us about their experience and needs at work;
- What managers need to know, and how to support them in their role;
- How to build a positive and compassionate working culture around terminal illness;
- How to make the case for a dedicated policy to directors or trustees.

When we talk about terminal illness, we mean an illness or condition which cannot be cured, and which is likely to lead to someone's death within months or sometimes years.



Sometimes our instincts about what terminally ill people might need aren't borne out by their experience or the evidence. This is partly because terminal illness is often a taboo subject, and open conversations are difficult for many. Look out for this symbol for common pitfalls and how to avoid them.

The Resources section at the end of this guide has links to information and further reading from a range of organisations all seeking to improve the lives of those working with terminal illness.



Is this guide for me?

If you've found this guide, and our [Work and Terminal Illness](#) research, you're probably looking for advice on how to enhance your organisation's capability in supporting employees with a terminal diagnosis.

You may be:

- Responsible for HR policies and procedures in your workplace, whether or not you are an HR professional;
- Responding to the sudden diagnosis of a colleague, or to the experience of family, friends or peers who are dealing with this;
- Tasked with writing a policy or guidance on this topic, or with making recommendations to directors or trustees;
- Working in an organisation that has signed the TUC's [Dying to Work Charter](#), or the [Working with Cancer Pledge](#), and exploring how to put this commitment into practice.

Whatever your reasons, this guide is designed to help you think through this important area in a way that's practical and supports you to develop plans and policies. If you're creating a terminal illness workplace policy, you should involve a qualified HR, legal or employment professional. A terminal illness is likely to fall under the definition of a disability, and the Equality Act is likely to apply. You'll need to check your policy is legally compliant for your specific organisation or workforce.

We'd like you to take the guide and test it out, check it against your own experience and that of your employees, and let us know what you think. You can send us your feedback by filling out this [form](#).

Who contributed to this guide?

This guide has been developed in collaboration with HR leads and occupational health professionals from across different sectors and workplaces, including local authorities, universities, hospitals, charities, retail chains, broadcasting companies and others. Like you, they have all been developing policies and approaches to support their terminally-ill colleagues.

The guide also draws on contributions of those with a terminal illness, who have shared their experiences - positive and negative - of work after a diagnosis. They provide an essential perspective on how managers, colleagues and HR professionals can support someone's wellbeing at such a difficult time.



Why it matters

...that we support those who want to, to continue working with terminal illness and when it's time, allow people to leave with dignity.

Workplaces

Are where people spend a large proportion of their time and are an important part of the 'community' of employees.

Can provide stability and social networks at a time that is deeply uncertain and often isolating.

Are well-placed to provide support through the emotional and practical challenges of a terminal illness diagnosis.

At the same time:

- People with a terminal illness face stigma and insecurity in the workplace;
- Inadequate workplace support leads to poorer outcomes in all areas of a person's life, including mental health and economic prospects.

Showing your workforce they will be supported if they're affected by terminal illness underlines your organisation's culture and values.

Key legal points

Employers will want to support affected people sensitively and each situation will be unique. Nevertheless, the key legal matters which employers should consider include:

- Contractual and statutory sick **pay entitlements**;
- Any private and or permanent **health insurance benefits**, or other benefits your organisation might provide;
- **Equality Act 2010 rights**, including for those with a disability under the Act, the duty to make reasonable adjustments. Under the Act, cancer, HIV and multiple sclerosis are deemed disabilities;
- Any **risk, health and safety** issues that may arise;
- **Pension benefits**, including appropriate and timely action in relation to ill health retirement, and any other death in service benefits;
- Ensuring a **fair process** is followed in any case of dismissal;
- Providing **appropriate notice pay** (including the right to full pay in some circumstances), where applicable.

Prepared by: Employment Relations Unit, Workforce Team, Local Government Association



... that a terminally ill person would want to leave work and fulfil some sort of bucket list, but working can actually be part of the bucket list.

Barry was a soil scientist, husband and father. He was diagnosed with advanced cancer in his early forties. He worked throughout most of his two year illness, and died very shortly after medical retirement.

“When Barry was diagnosed with cancer, he really wanted to keep working – it provided a really effective distraction from the emotional and the physical suffering he was experiencing. Being a typical scientist, he had plenty of data that he had collected, but not done as much with as he wanted to. So he worked away analysing that data and publishing the results during a good deal of the two years of his illness. To be honest, I found it hard sometimes, because he kind of vanished behind his laptop screen when I wanted to savour all the time I could with him. However, I know it really worked for him. Barry worked with the British Geological Survey, Keyworth and his line manager and HR lead were very flexible. He stopped doing some of the more physical aspects of his work, but continued the brain and computer based scientific work, and he continued to supervise students.”

Professor Ruth Parry, talking about her late husband Dr Barry Rawlins' experience

Facts and figures

Working age people at the end of life are twice as likely to be in poverty than those of working age¹.

Working age people with children are more likely to fall below the poverty line at end of life than any other group¹.

Only 44% of organisations and workplaces have policies in place for terminal illness².

When organisations don't have written policies in place, there is more chance that employees have unjust and inequitable experiences².

The employer lottery

“We will review pay on an ad hoc basis”

“It would be at the discretion of the Senior Management Team”

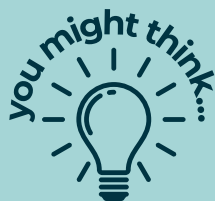
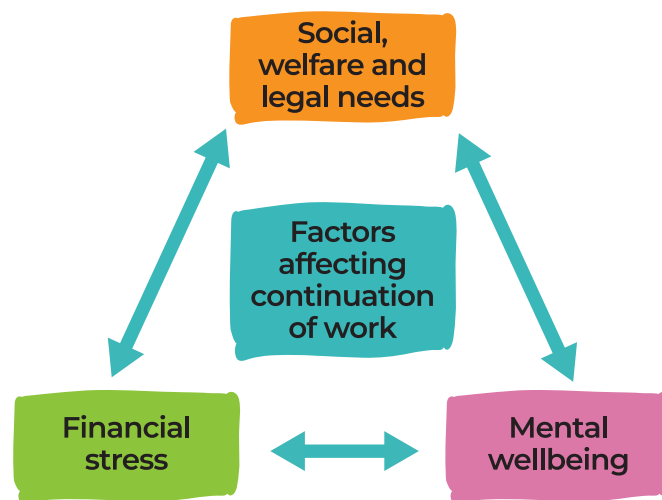
“Depends on situation and employee level”

“In reality it varies in ways that reflect their status”

“Depends on who or what but probably can't support greatly”

“It hasn't got a formal process. It's ad hoc”

Research suggests that when people of working age are diagnosed with a terminal illness, they often have unmet social, welfare and legal needs. This can have an impact on their mental wellbeing and cause financial stress. These unmet needs have important impacts on whether a person continues to work².



... that people who are diagnosed with a terminal illness automatically want to stop working, but this is often not the case. This is why it's so important to be led by the individual.

Evidence tells us that work can be very important for people with a terminal illness. Research by Marie Curie estimates that the financial impact of a diagnosis of terminal illness is £16,000³. Work provides **essential income and financial stability** for people after their diagnosis.

Additionally, work can provide **a sense of normality** in the midst of intense change and uncertainty. **Social contact** with colleagues, and a **sense of purpose** provided by work can buffer someone's wellbeing when their health and future are a source of distress. Understanding someone's motivations for wanting to continue working is key to finding the right way to support them.

"Managers and co-workers should be clear on the employee's motivations for continuing to work. Their priority could be, for example financial, purpose, structure or routine, social connectivity, feeling 'normal', psychological support, or a combination of any number of these. Ensure that communication, work adjustments and day-to-day management both reflect and respect these as far as possible."

Stephen Bevan, Head of HR research development at the Institute for Employment Studies (IES)⁴

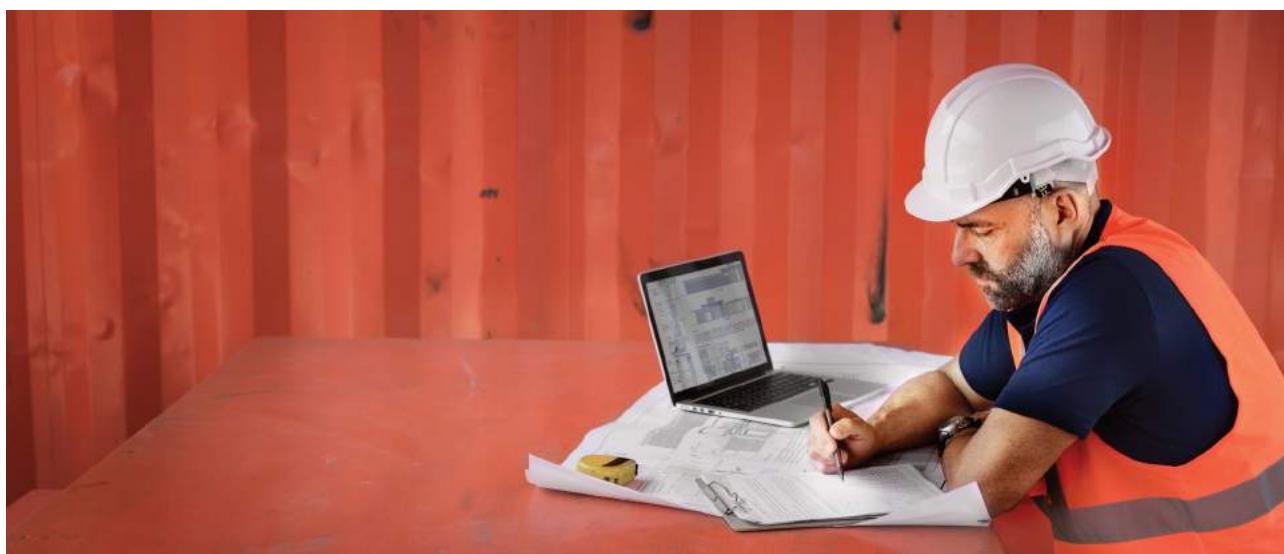
What to include in a terminal illness policy

Developing and adopting written guidance on how cases of terminal illness are managed within your organisation supports trust, fairness, consistency and inclusion. Managers, colleagues, HR leads and Occupational Health professionals all have key roles to play. Think about the different contributions each can make in your organisation's approach.

Remember, a terminal illness policy should be flexible so that adjustments can be tailored to an employee's individual circumstances.

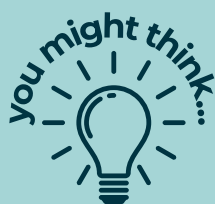
In this guide, we cover six areas:

1. Attendance flexibility
2. Adjustments to work arrangements
3. Managing absence
4. Sources of support
5. Financial wellbeing
6. Stopping and leaving work



1. Attendance flexibility

An employee's fitness to work may fluctuate depending on physical and psychological symptoms, including fatigue, pain, memory and concentration. These can be due to their illness itself and/or to side-effects of treatments. A person's difficulties may be unpredictable, which can make it hard to plan attendance at work. Offer as much flexibility as is manageable and reasonable, bearing in mind that different adjustments may be needed at different times.



... that once people are diagnosed, their illness will then steadily deteriorate over time.

Actually, it's very hard to predict the progression of many illnesses, and every case is different. The same diagnosis may result in different treatment options, outcomes and impairments for different people.

Treatment may come in waves over months or even years, which can affect people's ability to work over time. You might also think that once people stop treatment they will need to stop work. For some people, the ability to work may be affected more by treatment which can have debilitating side effects like pain, nausea and brain fog, and they may feel more able to work once they start palliative care.

"When I was diagnosed with terminal cancer my employer was incredibly supportive. They gave me all the time off I needed following discharge from hospital, regularly keeping in touch with my progress. They supported a phased return to work over the next 12 months on a part time basis with the option to step away from certain parts of my role to suit me. During this time I was given time off for medical appointments and when I returned full time this was offered on a flexible basis, allowing me to take time off during the day if I felt fatigued. This approach made me feel supported and appreciated and gave me a bit of 'normal' during a difficult period."

Suzie Taylor, PA to the CEO and Executive Group working for a large national charity

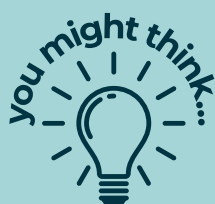
Think about:

- Changes to start and finish times
- Introducing more breaks during the day
- Condensed and flexible working hours, and working from home
- How much time off someone can have
- Allowing greater flexibility in taking annual leave



2. Adjustments to work arrangements

Providing adjustments may allow an employee to continue working, to work more productively, or to return to work after a period of treatment. Employees may be able to suggest possible adjustments, but bear in mind, they may still be learning about their diagnosis, and they also may not be able to identify what adaptations may be reasonable and/or practicable. Occupational Health professionals can help line managers consider adjustments. Line managers will need to assess, and keep under review, an employee's fitness for work. If they are in a safety critical role, this is absolutely essential.



... that work adjustments only relate to how people do their job, rather than the type of job they do.

But it's often the case that people's abilities and capacity changes so that they are no longer able to do the job they were doing before their diagnosis, but are still able to contribute to the workplace and their colleagues in different ways. Having conversations that take a broad view about someone's contribution may help navigate changing levels of energy or capacity, and can support people to feel they are valued as part of the team.

Here's what Stephen Bevan, whose research has focused on the health of the workforce and who has also been working with a terminal cancer diagnosis, said:

"There were some practical things I just wasn't able to do when I was having my treatment. But one of the things I was really keen to capture was my knowledge, and my know-how, and my connections and so my employer basically said 'Look, we'll get somebody else to do some of these other things you now can't do. We'll bear the expense of that, but what we will do is we'll use you to help coach some of our younger colleagues to make sure we're transferring knowledge from you before you get to the point where you can't make a contribution any more.'"

Think about:

- Adjustments to the role itself - could approaches like job crafting⁵ that support employees to redesign their own jobs helpful?
- How health and/or adjustment passports might be used
- Workload and adjustment or removal of particular duties
- How performance management arrangements can be adapted
- Redeployment opportunities
- Adjustments to the work premises or environment, for example providing a quieter space, or working from home
- Adjusting workstations and providing new equipment
- Providing support for travel to and from work
- Providing a closer parking space
- Updating risk assessments
- How adjustments made for one team member might affect colleagues and co-workers

The role of Occupational Health

Occupational Health professionals can provide expert advice on employees who are working with a terminal illness. They are able to add insights on how symptoms the employee may be experiencing (or might experience in the future) could affect their ability to perform their role. They can help develop solutions and suggest adaptations that will enable staff to continue to work safely.

Occupational health professionals can:

- assess and advise on your employees' fitness for work
- provide health assessments for your employees working with a terminal illness
- provide recommendations to line managers on workplace adjustments
- manage and monitor cases over time
- support your employees to manage their health and wellbeing
- advise on eligibility for ill health retirement (dependent on your organisation's policy)

Occupational health nurses and doctors have a professional duty to protect patient confidentiality. They will not disclose any information without the employee's consent, unless someone may be at risk of serious harm, and in line with the law.



... that palliative care is the same as end of life care.

Although palliative care can include end of life care, palliative care is much broader and typically lasts for longer. Having palliative care doesn't necessarily mean that you're likely to die soon - some people have palliative care for years.

Palliative care can include:

- Managing symptoms
- Offering emotional and psychological support
- Providing practical support, including planning for the future
- Supporting your wellbeing and giving you a good quality of life

3. Managing absence

One of the most revealing findings from our 2022 survey on HR practices for terminal illness, was that almost 6 in 10 employers continue to manage and record absence associated with terminal illness within their standard sickness reporting procedures². This means line managers are mandated to follow standard procedures and respond to 'triggers' of poor attendance. The practices involved in standard sickness reporting procedures, can place additional stresses and strains on both the employee and line manager. A much better approach is to ensure line managers have the capability and confidence to adopt a fair, consistent yet flexible and compassionate approach to managing sickness absence. This includes providing guidance for managers on how to maintain contact in a sensitive and appropriate way.

Think about:

- Removing employees with terminal illness from standard sickness reporting procedures - this could be a reasonable adjustment
- If the organisation's established financial arrangements for sick pay could be enhanced for employees with a terminal diagnosis
- Allowing paid time off work for employees to attend medical appointments
- Supporting line managers to develop and maintain a trusted, supportive dialogue with employees to help prevent them feeling isolated, especially if they are off sick
- Who and how employees should notify if they are unable to attend work - might adjustments to your standard procedures work better?

4. Sources of support

Line managers, HR leads and colleagues can all provide support when an employee is working with terminal illness. It's also important that those providing support have information, advice and guidance to draw on themselves. Support can come from a range of providers including national charities for example Marie Curie and Macmillan Cancer Support or social enterprises like Working with Cancer. The Resources section at the back of this guide lists some of the most developed online resources.

If your organisation has an external employee assistance programme, and depending on your contract, the provider might be able to provide tailored support for the employee, their family, line managers and colleagues. GPs, hospices, Maggie's Centres and other local voluntary and community organisations may also be good sources of support. Many local services, for example charities providing counselling, financial support and legal help, have pressures on resourcing so it is not uncommon for people to be experiencing long wait times for appointments.



Think about:

- If you don't currently provide an Employee Assistance Programme, could you buy this service for a terminally ill employee? Or pay for counselling services?
- Opening up Employee Assistance Programmes to family members of employees working with terminal illness
- Allowing an employee access to your Employee Assistance Programme for a period after they leave work; or allowing family members access for a period after an employee has died
- Investigating what support workplace Trade Unions can provide
- Developing sector or workplace employee networks for example bereavement cafes and working with cancer networks

5. Financial wellbeing

In this guide we have taken a broad definition of terminal illness, as a health condition that cannot be cured and one that a person will very likely die from. We deliberately didn't include a specific time frame in our definition, as our research and practice insights suggest that in a workplace context, an inclusive definition is most helpful.

However, in relation to financial wellbeing, if a doctor or a medical professional has told someone that they are likely to have 12 months or less to live, the person might be able to access benefits to help with living costs, for example Employment and Support Allowance, Universal Credit and Personal Independence Payment. For benefits like these, there are what are called 'special rules for end of life'. If the person is in receipt of such benefits, this might enable them to access social tariffs for energy, water and broadband costs. It might also be possible for an individual to access their pension before age 55 on the grounds of serious ill-health, provided they have obtained medical evidence that their life expectancy is less than one year. If an employee does access their pension early, this could affect any means-tested benefits they are receiving.

Financial wellbeing at the end of life is incredibly complicated. One of the most important things that an employer can do is to make it as easy as possible for an employee and their family to access independent financial advice, so they can choose the best option for them and for people who are financially dependent on them.

Think about:

- Supporting employees to access independent financial advice for end of life. If you have an existing EAP provider, do they have expertise to advise employees in this very unusual financial context? Are there local organisations who could help?
- Removing costs and limitations on providing pension projections for employees with terminal illness
- How your employee hardship or staff welfare fund could help people working with a terminal illness. If you don't have one, could you set one up?
- Encouraging all staff to complete a nomination or expression of wish detailing where they would like death in service benefits, pension savings and entitlements to go to in the event of their death; and to review this regularly

6. Stopping and leaving work

At some point, an employee with a terminal illness may decide that it is the right time for them to stop working. In exceptional circumstances, an employer may consider redundancy or dismissal. In section 5 above, we've discussed the challenges of navigating the complex range of financial options surrounding retirement, pensions and benefits. Here we focus on ensuring employees are treated with kindness and compassion, and can leave their job with dignity.

Think about:

- If/how the employee would like to share news of their leaving with colleagues, and the wider organisation
- Maintaining contact with your employee after they leave your organisation, if that is something they'd like. Is there a way for them to continue to receive newsletters and updates from the organisation?
- Supporting individuals to maintain workplace friendships
- Would they like to share contact details of a close family member or friend?
- Marking their contribution to your organisation, for example with an article in a staff newsletter, or a special recognition award
- Recruiting to the vacancy with sensitivity
- If they would like news of their death to be shared with you
- How will colleagues be told of their death, and funeral arrangements shared with those who may want to attend
- Allowing compassionate leave to staff asking to attend a former colleague's funeral
- Supporting employees to remember their colleague for example through tree planting, commissioning a bench, or doing an activity in their memory
- Intervening in automatic processes that normally occur when a member of staff leaves. These might include correspondence about office/desk/locker reallocation and retrieval of work equipment for example laptops, phones or a company car. Standard wording and processes might be ill fitted to the circumstances where someone is leaving due to a terminal illness.



Three principles for effective action

Writing down and adopting workplace policies to support employees working with a terminal illness is important, however, we know that the way in which you put a policy into practice influences its effectiveness.

“ Employers must navigate some choppy waters to make sure that those who want to stay at work for as long as possible can do so with dignity and purpose. The key here is authenticity and dialogue. For some, staying at work represents a way of connecting with what passes for a ‘normal life’ for as long as that lasts. At the same time, the terminally ill don’t want pity or to feel that they are getting a free pass. A mature conversation with employers about how we can help ‘ramp down’ our working lives is all that is needed. ”

Stephen Bevan, article for Working with Cancer⁶

Much of the focus for this section is on line managers as they are often the first person an employee who has received a terminal diagnosis talks to, and they are pivotal to considering and implementing work adjustments.

Unfortunately, there is no quality published research on factors that make terminal illness policies effective. Therefore in this section we extrapolate from broader research on successful workplace health and wellbeing practices ^{7,8}.

Here we describe three principles for effective action:

1. Compassion

2. Communication

3. Consistency



Principle one: Compassion

Compassionate leadership, and a compassionate workplace culture can help employees with a terminal illness feel understood and supported by colleagues and managers.

In a compassionate workplace:

- People show empathy; noticing, feeling and responding to their colleague's terminal diagnosis.
- People recognise that their colleague is having an incredibly difficult time, that they are probably managing symptoms of their illness including pain and fatigue, and that they may be feeling angry, miserable and uncertain about their future.
- People aren't judgemental about the choices a person with a terminal illness has made, and might make in the future about their work.
- It is acknowledged that people may become upset or distressed when sharing feelings and challenges.
- Coping strategies to reduce stresses experienced by employees, and manage the emotions experienced, are explored and enacted.

You can read more about creating a compassionate culture at work on CIPD and Marie Curie websites (see Resources section).

Principle two: Communication

It is normal to worry about how to talk to someone with a terminal diagnosis. Many people find it hard to know what to say and lack confidence. They might worry that they will say the wrong thing and that it will make them feel worse.

“ All I would say is that it's usually better to connect than not. Some of the most touching messages have been from people who say 'I had no idea what to put in a message, but just wanted to reach out to you'. They have nothing profound, lyrical or consoling to say but they realise the power of a fleeting and kind acknowledgement. ”

Stephen Bevan, article for Working with Cancer⁶

It's not just colleagues and co-workers who find this hard, we know that line managers and HR professionals can find it very difficult too. Having sensitive and supportive 'keeping in touch conversations' are a key element of managing employees working with a terminal illness. The next two pages provide a framework for having sensitive and supportive conversations.

Having sensitive and supportive conversations

By Prof. Ruth Parry, Emeritus Professor of Human Communication and Interaction, and Communications Consultant.

Prepare for the conversation

- Have relevant organisational policies to hand.
- Check you have the correct details of the person's role, team and preferred contact.
- Check you have the most up to date information on the person's health and personal situation.
- Arrange a private, undisturbed place to talk.
- If you can, block out a small amount of time in your diary for after the meeting. Prepare a debrief for yourself - acknowledge that this is a difficult conversation for you too.

At the very start

- Check it is (still) an OK time to talk.
- Tell them how long you have for this conversation - if you have limited time, assure them of a further conversation.
- Express sympathy.
- Convey reasons for this conversation - "to understand more about your situation", "to understand what are you hoping for".
- Contextualise, for example you might say "this is the first of many conversations".

As the conversation develops

Here, your aim is to get their perspective.

- How are they feeling?
- What seems to be their current emotional state and how is that affecting what they are able to talk about right now?
- Are they in a frame of mind where they have already thought about what they want at and from work? Or do you need to give them time, and ask them to put some thought into this and/or talk with others (their doctor, their loved ones, their close colleagues)?
- What words are they using and not using? For example, are they using the term cancer, or do they talk about "my diagnosis" or "my situation". Listen and notice, then try to match their way of talking about their situation.

Continuing the conversation

Narrow your questions if there are specific things you want to know, and if you judge they are likely to be able to engage with these now.



Dealing with distress

Two elements of how you communicate are important here. The first concerns working to avoid causing the employee to feel and express overwhelming distress. The second concerns how to deal with expressions of distress, for example crying, if it occurs.

- Take a cautious step-by-step approach towards the most difficult parts of the conversation. Don't bluntly raise sensitive topics, instead go there gradually.
- Don't use direct terms, for example "death" or "cancer", unless the person you are talking with uses these words first. Research from healthcare communication on end of life conversations shows that indirect but unambiguous terms and phrases can be more gentle^a. These include "coming to the end of your life", "passing away", "your disease", "your condition"..
- Show empathy and understanding without claiming you fully understand their situation - the fact is, you cannot possibly fully understand. Tentative wordings can be helpful, for instance "I guess this must be very hard...".

During the conversation, the person you are speaking to may become upset and start to show distress. You might hear or see this in different ways: more pauses, changes in voice quality, quietly speaking, a creaky or shaking voice all the way to full-on sobbing.

- Modify your own delivery to be softer and more lilting.
- Allow silence.
- Offer brief further sympathy: "I'm so sorry".
- Give the person you are speaking with time – repeated phrases such as "it's ok" and "take your time" can work well. Wait to move the conversation on until the person is calmer.
- The person crying may apologise – reassure them it is fine: "it's perfectly understandable to be upset".

Bringing the conversation towards an end

Try to avoid the phrase "anything else" because in some circumstances, we know this can be heard as conveying you're not expecting there to be anything else.

- Are there other things you would like to cover/say/ask/me to find out about?

If you want to check their understanding of what has been said, wording such as "Are there things I have not covered or explained enough?" removes the implication that the person has not understood things and lessens the burden on them.

- Future arrangements – what are the next steps, what will the next conversation be and when? Lessen the burden and tell them about these rather than waiting for them to ask, or leaving them in the dark.

After the conversation

Make a clear note of any actions and key discussion points, while they are still fresh in your mind. Take time for a break. Is there someone in your organisation that could be designated to listen if you wish to talk? If available, consider contacting your Employee Assistance Programme for support.

^a realtalktraining.co.uk/

Principle three: Consistency

It is important to ensure workplace health and wellbeing support for working employees with a terminal illness is consistent. This means that there is a coherent narrative on its importance and that this is evident to all employees, line and middle managers, and senior managers. Coherence comes from having elements of support that are self-reinforcing and integrated.

For example, if a line manager provides assurance to an employee that they can follow a revised process for attendance / sickness absence, but then the employee receives an automated email informing them that they have hit a 'trigger' for absence, and will be required to attend a formal meeting to discuss their absence levels, this can undo all your good work.

Importantly, coherence does not mean a lack of diversity in the elements of support for an employee with a terminal illness, or that managers and employees are prevented from developing new approaches for themselves. The emphasis is more that the elements are managed as a whole, and don't contradict one another.

It can also be helpful to think about consistency when you look across your organisation at existing processes, systems, and ways of working. What can you bring to this situation from existing people management practices and organisational capabilities?

Finally, as you develop your organisation's approach, think about sharing information and consulting with employees. Staff forums may be able to provide general feedback, but you might also have colleagues currently working with a terminal illness who could share their experience too. Trade Union representatives may also be able to share examples from national research and good practice.



Resources

Despite an increasing number of people working with terminal illness, there are very few specific resources on this topic. Many of the links below lead to information on associated topics for example talking about terminal illness and bereavement, that are not workplace specific.

Working with terminal illness

Marie Curie

Work and terminal illness

mariecurie.org.uk/help/support/diagnosed/practical-emotional-support/about-work

Macmillan

Work and Cancer

macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/work-and-cancer

Stopping work

macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/work-and-cancer/stopping-work

Working with Cancer

Reflections on a terminal diagnosis

workingwithcancer.co.uk/2023/04/03/a-last-hurrah-reflections-on-a-terminal-diagnosis/

Cancer survival - why staying positive is never enough

workingwithcancer.co.uk/2023/10/24/cancer-survival-why-staying-positive-is-never-enough/

Open University

Open Learn Article

open.edu/openlearn/health-sports-psychology/terminal-illness-and-wellbeing-supporting-people-the-workplace

Resources for Managers

Working with Cancer

Best Practice Guides workingwithcancer.co.uk/best-practice-guides/

CIPD

Terminal illness: Guidance for people professionals

cipd.org.uk/knowledge/guides/terminal-illness/

Managing and supporting employees with long-term health conditions

cipd.org.uk/knowledge/guides/support-long-term-health-conditions/ and

cipd.org.uk/knowledge/guides/manager-guide-long-term-health-conditions/

Managing a return to work after long-term sickness absence

cipd.org.uk/knowledge/guides/managing-return-to-work-after-long-term-absence/

Practical guidance to help employers support grieving employees

cipd.org.uk/knowledge/guides/bereavement-support/

Tackling in-work poverty

cipd.org.uk/knowledge/guides/in-work-poverty/

Health & Safety Executive

Principles to support disabled workers and workers with long-term health conditions in work

[hse.gov.uk/disability/best-practice/overview.htm](https://www.hse.gov.uk/disability/best-practice/overview.htm)

UK Government

Supporting with employee health and disability

support-with-employee-health-and-disability.dwp.gov.uk/support-with-employee-health-and-disability

Occupational Health Services

UK Government Department for Work and Pensions

Get expert workplace health support

support-with-employee-health-and-disability.dwp.gov.uk/get-expert-workplace-health-support

CIPD

Factsheet on Occupational Health

[cipd.org/uk/knowledge/factsheets/occupational-health-factsheet/](https://www.cipd.org/uk/knowledge/factsheets/occupational-health-factsheet/)

Acas

Using occupational health services

[acas.org.uk/using-occupational-health-at-work](https://www.acas.org.uk/using-occupational-health-at-work)

The Society of Occupational Medicine

Tool to find a local occupational health provider

[som.org.uk/find-an-oh-professional](https://www.som.org.uk/find-an-oh-professional)

Talking about death and dying

Hospice UK

Dying Matters resources

[hospiceuk.org/our-campaigns/dying-matters/dying-matters-resources](https://www.hospiceuk.org/our-campaigns/dying-matters/dying-matters-resources)

Marie Curie

Bereavement and grief at work

[mariecurie.org.uk/help/support/bereaved-family-friends/work](https://www.mariecurie.org.uk/help/support/bereaved-family-friends/work)

Workplace compassion

Marie Curie

Create compassionate culture

[mariecurie.org.uk/help/support/bereaved-family-friends/work/employer-resources/create-compassionate-culture](https://www.mariecurie.org.uk/help/support/bereaved-family-friends/work/employer-resources/create-compassionate-culture)

The role of compassion in the workplace

[cipd.org/uk/views-and-insights/thought-leadership/the-world-of-work/compassion-](https://www.cipd.org/uk/views-and-insights/thought-leadership/the-world-of-work/compassion-)

Financial Wellbeing information for employees

MoneyHelper

A free service provided by the Money and Pensions Service

moneyhelper.org.uk/en

How to sort out your money if you become ill or disabled

moneyhelper.org.uk/en/family-and-care/illness-and-disability/how-to-sort-out-your-money-if-you-become-ill-or-disabled

Death and bereavement

moneyhelper.org.uk/en/family-and-care/death-and-bereavement

References

1. Marie Curie, 2022. Dying in poverty: Exploring poverty at the end of life in the UK. mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/h420-dying-in-poverty-5th-pp.pdf
2. Smithson, J., Kaushal, A., Baverstock-Poppy, I., Fantoni, R., Royston, S., Rahman, R. and Bignall-Donnelly, R., 2022. Working with terminal illness: what's known and what's needed. What Works Centre for Wellbeing. <https://whatworkswellbeing.org/resources/working-with-terminal-illness-scoping-review-and-hr-survey-findings/>
3. Marie Curie, 2019. The cost of dying: The financial impact of terminal illness. mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2019/00962-cost-of-dying_financial-impact-report.pdf
4. Bevan, S., and Wilson, B., 2023. Four action areas for supporting employees with terminal illness. Personnel Today. personneltoday.com/hr/supporting-employees-with-terminal-illness/
5. Bevan, S., 2019. Job Crafting: An employee-led approach to job redesign? Institute for Employment Studies. employment-studies.co.uk/news/job-crafting-employee-led-approach-job-redesign
6. Bevan, S., 2023. A Last Hurrah? Reflections on a Terminal Diagnosis. Working with Cancer. workingwithcancer.co.uk/2023/04/03/a-last-hurrah-reflections-on-a-terminal-diagnosis/
7. What Works Centre for Wellbeing, 2020. Five principles for effective action on workplace wellbeing. whatworkswellbeing.org/resources/five-principles-to-improve-workplace-wellbeing
8. Daniels, K., Watson, D., Nayani, R., Tregaskis, O., Hogg, M., Etuknwa, A. And Semkina, A., 2021. Implementing practices focused on workplace health and psychological wellbeing: A systematic review. *Social Science & Medicine*, 277, p.113888.

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