

A POSITIVE WORK-LIFE FOR THE TERMINALLY ILL

This guidance focuses on how branch and trade union reps as well as employers need to consider the specific needs of workers diagnosed with terminal illness in their negotiations over sickness absence policies, disability leave, time off for

medical appointments and ill health retirements.

It briefly explains the protection available to workers and highlights the TUC initiative – the Dying to Work charter – that all employers should be encouraged to sign.

It is sadly inevitable that some of our members will be diagnosed with a serious illness during their working life. For some the illness may be terminal, particularly as more and more of us have to work to a much older age.

All staff suffering with a long-term illness deserve sensitive treatment in the workplace, in line with the requirements of employment, health and safety and equality law.



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supporting UNISON members when life gets tough

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If you are struggling through an unexpected crisis there for you is here to help.

It's your charity, so contact us now.

Speak to your branch welfare officer or call us on 020 7121 5620.

For immediate debt advice call 0800 389 3302.

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UNISON Welfare is an independent charity supported by UNISON. Registered charity number 1023552 Scotland SCO38305



Yet employers rarely consider the specific needs of employees with terminal illnesses.

For many people, a diagnosis of terminal illness does not mean immediately having to give up on normal activities.

Work is an important part of all our lives and an individual's opportunity to continue contributing within the workplace and socialising with work colleagues, may be a positive part of coming to terms with the diagnosis, and enjoying their remaining life to its full. It also crucially helps provide financial security for themselves and their loved ones.

UNISON recognises that all our members and their dependants may need advice and support when life gets tough. We aim to help provide it through our welfare charity, There for You.

Employers too should be encouraged to treat the terminally ill within their workforce with compassion.

Protection under the Equality Act

Three potentially progressive and life-threatening conditions - Cancer, HIV and Multiple Sclerosis - are regarded as disabilities from the point of diagnosis. However it is likely that other long-term and terminal illnesses will also qualify as disabilities under the Equality Act. Under the Act a disabled employee has a physical or mental impairment that has an adverse effect on their daily activities, and the effect is substantial and long term.

Disabled employees have the right not to be treated less favourably in the workplace based on their condition. Importantly employers also have a duty to consider reasonable adjustments to help disabled employees stay at work.

A health and wellbeing approach

Employers have a duty of care to all their staff. As part of this there should ideally be a proactive health and wellbeing approach to work and the working environment. Staff members should be able to be open about their health issues and encouraged to take proper care of themselves.

Line managers in particular should be appropriately trained to sensitively and empathetically handle communications about health and wellbeing. Then employees may be more willing to be open about a diagnosis of a serious illness. This can lead to discussions on workload and work adjustments well in advance of any problems. Good communications are important in order to get the appropriate support and protection at work for our members.

However it should always be up to the individual whether they want to share their diagnosis with other staff at their workplace, and confidentiality should be respected by managers if requested. If it is to be shared, the impact on other staff will need to be considered carefully. These workplace conversations should not only be sensitively handled but presented in a non-dramatic, positive and straightforward manner as agreed as appropriate with the affected employee.

It may be helpful to have an alternative, appropriately trained person within the workplace such as an identified HR officer that an employee can turn to when initially diagnosed should they find talking to their line manager difficult.

Trade union and branch reps may also be the first point of contact for members with a concern about the impact of such a diagnosis on work and their future and their family's future. It is key that they ensure members are fully aware of their employment rights, including sick pay, time off and any access to occupational health services.

Sickness absence policies and fit notes

When an employee is off sick for seven calendar days or more, their GP will provide them with a 'fit note' if they consider their fitness for work is impaired. As Government guidance for employers explains, there is a recognition that employers may have to make changes in order to help the employee back to work. It points out that "often, a few simple and / or low-cost changes can help someone with a health condition come back to work earlier. Access to Work can help employees with a disability or health condition. This includes paying towards equipment or support."

The Government also recommends that discussions take place with the employee, involving trade union reps, HR and occupational health as appropriate, on what changes are required in the workplace or to the work role. These changes may be:

- "A phased return to work: a gradual increase in work duties or hours
- Altered hours: changing their work times or total hours
- Amended duties: changing their work duties
- Workplace adaptations: changing aspects of the workplace."

As well as the necessary changes that should be made, negotiations with employers are also likely to focus on the sickness absence policy itself, in particular the need for flexibility in its operation, as well as showing a clear differentiation between sickness and disability related absence. It is also important as part of any sensitive treatment of employees with terminal illness that managers are responsive where they can to the particular needs of the employee, and not just stick to arbitrary trigger points or a time-limited availability of contractual sick pay.

Example clause for your sickness absence policy:

[Name of employer] is committed to supporting terminally ill employees with dignity, respect and compassion. Where a worker has been diagnosed with a terminal illness, managers will need to be particularly sensitive.

An employee with a terminal diagnosis will not be dismissed because of their condition. Each case must be assessed and progressed on an individual basis ensuring that the employee's personal wishes (wherever possible), and relevant financial implications are considered including any death in service benefits, ill health retirement or termination of employment with a lump sum payment. . HR Advice should be sought as a number of options are available for the employee and must be fully researched before a decision is made.

It is recognised that some employees may wish to remain in work as long as possible and if appropriate, reasonable adjustments will be considered to support the employee in this decision.

The roles of the safety rep and the equality rep

Trade union safety reps have an important role to play in supporting individuals through sickness absence management processes and helping to improve and develop agreements that focus on employee rehabilitation and healthy workplaces.

Safety reps have the legal right to be consulted on health and safety issues in the workplace, and this includes sickness absence. The Health and Safety Executive (HSE) suggests that union safety reps work with the employer by:

- Helping to identify measures to improve worker health and prevent it being made worse by work.
- Suggesting that their employer develops workplace plans and policies on sickness absence management.
- Helping to keep workers who are on sick leave in touch with work.
- Helping their employer to plan adjustments that will enable workers to return to work.
- Supporting workers to help them to return to work.
- Helping to promote understanding of impairments, health conditions and disability in the workplace.

All these workplace issues are of course of great importance to all workers including those diagnosed with a terminal illness.

Workplace equality reps and branch equality co-ordinators can also play a key role as they can provide support on equality and discrimination issues that may affect disabled workers who may include those diagnosed with a terminal illness. This support should involve talking to members to ensure that they are being treated fairly, as well as to managers to ensure they are implementing the organisation's equality policies, and that these policies comply with equality law (see page 3 above).

Carers' policies

At the same time, branch and workplace reps may also want to negotiate a carers' policy for their workplace including the provision of paid carers' leave. This would then lead to recognising the important role individuals play in caring for loved ones including those with terminal illnesses.

Further details on bargaining on the rights for carers, focusing on workers with a responsibility for caring for adults, along with a model carer's policy, can be found in the bargaining support guide, 'Bargaining on Carers' Policies' www.unison.org.uk/content/uploads/2018/06/Carers-policies-guide.pdf

Putting the case to employers

Not only are there strong legal and moral cases for employers to treat employees with a terminal illness sensitively, there is a business case as well:

- Costs of dealing with long-term sickness absence and recruitment can be minimised by encouraging and supporting staff to stay in work with a terminal diagnosis and to plan for when they are ready to leave work
- Potential legal costs and discrimination awards are avoided
- Managers are able to support their teams more effectively, and help create trust and loyalty in the employees
- The employer will benefit from being seen as a caring employer, improving its reputation not only for potential recruitment but also with clients and the general public.

When it's time to stop working

Branch and workplace reps need to check that the employer is also suitably prepared for when the employee needs to stop working.

Ideally managers should be able to signpost affected employees to advisers on benefits and financial options available, as well as support and advice from an employee assistance programme and occupational health service.

It may also be appropriate to discuss early ill-health retirement and any pension provision with the employee so that they can plan appropriately. There may be other benefits available that should be highlighted such as critical illness cover and death-in-service benefit.

A good employer will also signpost the employee to agencies that will provide advice on personal affairs such as writing a will and making a lasting power of attorney.

Ultimately when the employee does die, conveying the sad news to work colleagues and friends will need to be handled delicately, recognising the need for staff to grieve.

Additionally, there may be other practical issues to consider such as sending condolences to family members and commemorating the person who has passed away.

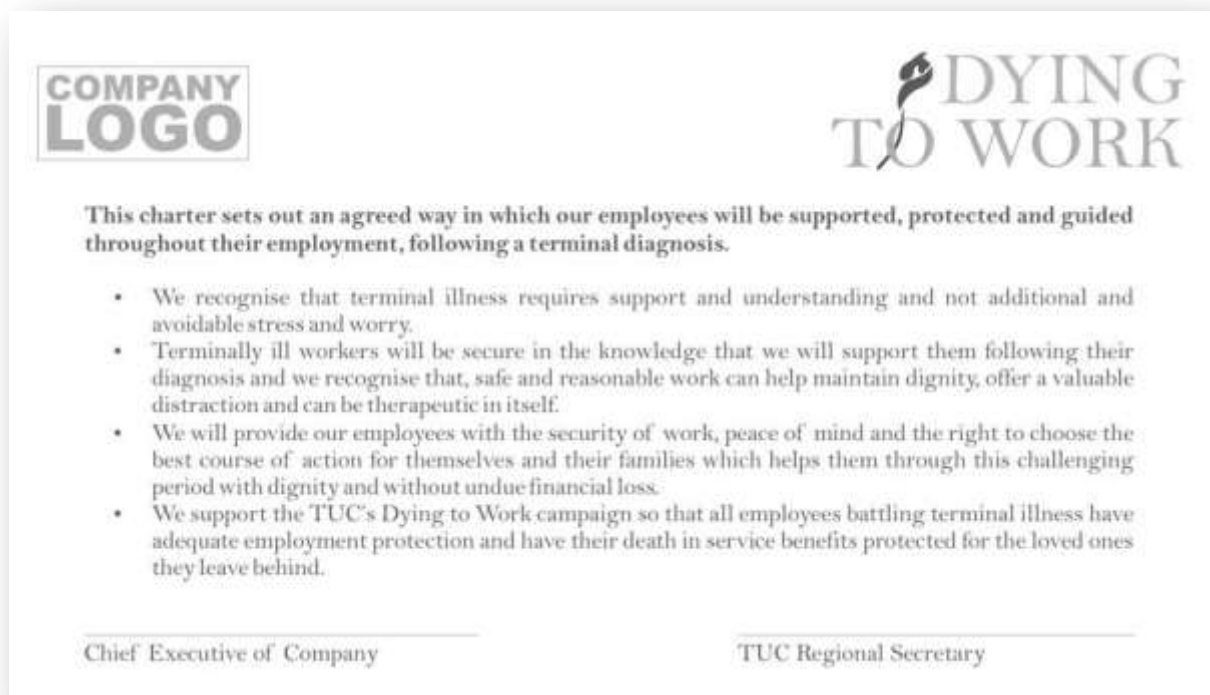
These issues cannot be ignored and the trade union has a responsibility to ensure that the employer seriously considers them.

Dying to Work charter

One way to tackle this sensitive issue would be to introduce the employer to the [Dying to Work \(www.dyingtowork.co.uk\)](http://www.dyingtowork.co.uk) charter.

The campaign says that: “union negotiators should seek agreement that their employer will:

- Review sick pay and sickness absence procedures and include a specific statement that they will not dismiss any person with a terminal diagnosis because of their condition.
- Ensure that that they have an Employee Assistance Programme that has the capacity and competency to provide support to any person with a terminal illness, including access to counselling and financial advice.
- Provide training to line managers and all HR staff on dealing with terminal illness, including how to discuss future plans with any worker who has a diagnosis of a terminal illness, and on what adaptations to work arrangements that may be necessary.
- Adopt the Dying to Work Charter and notify all employees that they have made the commitments contained in it.”



Signing up to the charter commits employers to provide security of work, peace of mind and the right to choose the best course of action in employment for workers with terminal illnesses.

The campaign presses for **“additional employment protection for terminally ill workers who need greater protection from heartless employers who utilise a loophole in the law to dismiss the dying due to their illness. Every person battling terminal conditions deserves the choice of how to spend their final months.”**

Their website highlights Jacqui Woodcock’s story: “Union member Jacqui’s job had only been saved when her union threatened to publicly expose the firm. She said ‘I was actually astounded about what HR asked. It was all about capability, capability, capability - no concern for me as their employee and no apparent care that I was dying’.”

Signing up to the voluntary charter could be recognised as part of an organisation’s equality and diversity policy, whereby it treats everyone with dignity and respect.

Full details of the employers who have already signed up to the charter can be found at www.dyingtowork.co.uk/whos-signed/

It includes the *Black Country Partnership NHS Foundation Trust*, the *Mid and West Wales Fire and Rescue Service*, *Stockton-on-Tees Borough Council*, *Leicestershire Police Service*, *South Lanarkshire Council*, *University of Kent*, *Severn Trent Water* and many more workplaces where UNISON is recognised and branches have been active in encouraging employers to sign the Dying to Work charter.

“We support the TUC’s Dying to Work campaign so that all employees battling terminal illness have adequate employment protection and have their death-in-service benefits protected for the loved ones they leave behind.”

UNISON Hartlepool Local Government Branch Secretary, Edwin Jeffries

“Learning you have a terminal illness is devastating enough but it’s even worse for a worker and their loved ones if they get a P45 along with their doctor’s note. We’re glad Colchester Council has taken this step to treat their staff with dignity and respect as they go through the trauma of terminal illness.”

UNISON Colchester Borough Council Branch Secretary, Georgia Norton

Further information

UNISON

'Making sickness absence policies work better for us'

<https://www.unison.org.uk/content/uploads/2014/11/On-line-Catalogue226602.pdf>

Available from the online catalogue, stock number 2594

'Disability and health and safety'

<https://www.unison.org.uk/content/uploads/2016/12/24124-1.pdf>

Available from the online catalogue, stock number 3068

'Proving disability and reasonable adjustments'

www.unison.org.uk/content/uploads/2019/02/25362.pdf

'Disability leave bargaining guide and model policy'

www.unison.org.uk/content/uploads/2018/10/Disability-Leave-Bargaining-Guide-and-Model-Policy.docx

There for You

Members experiencing financial and emotional difficulties can contact UNISON's welfare charity, There for You, which provides a confidential advice and support service for members and their dependants.

www.unison.org.uk/get-help/services-support/there-for-you

The Dying to Work campaign

www.dyingtowork.co.uk

including Nottinghamshire County Council's '**Guidance for Line Managers on Supporting Employees Diagnosed with a Terminal Illness**'

www.dyingtowork.co.uk/wp-content/uploads/2018/10/Guidance-for-Line-Managers-on-Supporting-Employees-Diagnosed-with-a-Terminal-Illness.pdf

Acas

Conditions automatically treated as a disability - The Equality Act and Cancer, MS and HIV www.acas.org.uk/index.aspx?articleid=5847

Managing staff absence – long-term illness

www.acas.org.uk/index.aspx?articleid=4203

Managing bereavement in the workplace

www.acas.org.uk/index.aspx?articleid=4977

Government guidance for GPs, employers, hospital doctors and occupational health practitioners on using fit notes (statements of fitness for work).

www.gov.uk/government/collections/fit-note

Macmillan cancer support

Work and cancer – information for employers and employees

www.macmillan.org.uk/about-us/what-we-do/how-we-work/work-and-cancer

Supporting employees at the end of life

www.macmillan.org.uk/information-and-support/organising/work-and-cancer/if-youre-an-employer/bereavement.html#160603

‘A guide for employers: supporting employees affected by cancer’

www.macmillan.org.uk/documents/getinvolved/campaigns/workingthroughcancer/workingthroughcancer2010/workingthroughcancer2010.pdf

Contact your **regional education teams and / or LAOS** to find out what training and resources are available to assist you with negotiating with your employer or promoting the issues in this guide with your members <https://learning.unison.org.uk/>

Further model agreements and guides are available from the bargaining support unit www.unison.org.uk/bargaining-guides.

Bargaining checklist

- Does all training or induction for managers, staff and trade union representatives on sickness absence include a consideration of sensitively and compassionately treating employees diagnosed with a terminal illness?
- Does the workplace sickness absence policy or agreement include reference to sensitively dealing with employees with a terminal illness?
- Is there a specific statement included saying that the employer will not dismiss any person with a terminal diagnosis because of their condition?
- Is there also a discretionary option for the period of time that contractual sick pay is paid to be extended, particularly for those with a terminal illness?
- Does the workplace sickness absence policy or agreement include guidance for both staff and managers? Or signpost to guidance elsewhere?
- Does this guidance include reference to:
 - Training for line managers
 - The role of occupational health, HR and the trade union representatives
 - Making reasonable adjustments / changes to workplace and duties
 - Flexible working
 - Paid time off during treatment
 - Flexibility and discretion over attendance management procedures
 - Disability and sickness leave and pay available
 - Ill health retirement
 - Death in service benefits if available
 - Support available for employees including financial assistance and advice?
- Is all long-term illness and time off for treatment handled flexibly and sensitively so that workers are able to continue to work, and not forced to go through distressing capability procedures?
- Is there a disability leave policy?
- Are reasonable adjustments fully considered?
- Is there a workplace culture where workers are able to be open about ill-health issues and supported when taking time off for treatment?
- Has your workplace signed up to the Dying to Work charter?
- Does your workplace also have a carer's policy in place, ideally providing paid carer's leave?