



DYING
TO WORK

**Negotiating guidelines:
Supporting members with a
terminal illness**

Terminally ill employees

Many workers get a serious illness at some time in their working lives. They may require time off, often many months, to get treatment or recover. There is good guidance that has been produced by the TUC and others to deal with cases of long-term illness, or return to work for those who are disabled as a result of an illness or injury.

However, sometimes there is no effective treatment. In these cases the worker may face a time of huge emotional stress, fear and uncertainty. Trade unions can try to ensure that when that happens, they try to remove any additional stress and worry.

A terminal illness is a disease that cannot be cured or adequately treated and there is a reasonable expectation that the patient will die within a relatively short period of time. Usually, but not always, they are progressive diseases such as cancer or advanced heart disease.

UK Social Security legislation defines a terminal illness as: “a progressive disease where death as a consequence of that disease can reasonably be expected within 6 months”, however many patients can have a terminal illness and survive much longer than 6 months.

Implications of a terminal diagnosis.

Being told that you are to die as a result of a disease for which there is no cure or effective treatment and that you only have months, or at best a year or so to live is a traumatic event and everyone will react differently.

Sometimes the nature of the illness is such that the person is unlikely to be able to work again. In other cases, a person may decide that they do not want to work anymore and would rather spend their remaining time with their family and friends, getting their affairs in order, or simply doing what they want. However, a lot of workers with a terminal diagnosis decide that they want to continue working as long as they can, either because they need the financial security or because they find that their work can be a helpful distraction from their illness. Whichever choice a person makes, they should be able to expect help and support from their employer. Unfortunately the experience of many workers is that their employer is either unsympathetic or puts up barriers to them continuing in work.

If a worker with a terminal illness loses their job they lose their income. They can also lose any death in service payments they have earned through a life-time of work but are only payable to those that die while still in employment.



Case Study – Jacci's story

The following is a real-life account of GMB member Jacci Woodcock who has been diagnosed with terminal breast cancer and her on-going case.

“Back in June 2012, I knew something was wrong. I went to the doctors and I got diagnosed with terminal breast cancer. I didn't even take any days off until nearly a year later when I hit a wall of complete exhaustion.”

“People think the protection is there but I'm categorically saying it isn't!”

“I visited my GP, he gave me a sick note for a couple of weeks and I sent this into work. At this point, it had never occurred to me that they wouldn't support me.”

“When I returned to work, I asked to meet with HR. Over the course of the meeting she questioned my capability to do important aspects of my job, incorrectly claimed they had made adjustments for me and told me that the company had already been kind enough to pay my salary whilst I attended my hospital appointments. Finally, she told me that she had done a lot of research into the benefits I would be entitled to if I wasn't in work.”

“For the first time, I began to feel anxious because I now understood that they were trying to get rid of me. I was upset but giving up was not an option. I thought this is not right, not fair and incredibly wrong! I feel strong and determined to use the time I have left to do my upmost to get the law changed to protect terminally ill people. People think the protection is there but I'm categorically saying it isn't!”

Role of Unions

Unions should not wait until someone becomes ill before raising the issue with their employer. Instead they should seek to reach an agreement with their employer that they will provide their workers with the security of employment that will allow them to make the decisions they want to help get them through the challenges that they will face after a diagnosis of a terminal illness. This may involve changing existing sickness agreements, or asking for a formal commitment from the employer (see what employers can do).

Unions can also ensure that they support any members who do have a terminal diagnosis. The TUC have teamed up with Macmillan Cancer Support to provide training, both in formal courses and online, on supporting workers with cancer. Much of what is covered on the course applies to all terminal illnesses.

Unions should also make sure that they keep in touch with any members who have a terminal condition, so that they know they can come to the union if they have any problems relating to their work, even once they have left the workplace.

What employers should do?

Unions should be clear about what they want from their employer. Just getting a vague commitment is not enough. 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 (see box).

Model Charter



This charter sets out an agreed way in which 'Sample Company' employees will be supported, protected and guided throughout their employment, following a terminal diagnosis.

- We recognise that terminal illness requires support and understanding and not additional and avoidable stress and worry.
- Terminally ill workers will be secure in the knowledge that we will support them following their diagnosis and we recognise that, safe and reasonable work can help maintain dignity, offer a valuable distraction and can be therapeutic in itself.
- We will provide our employees with the security of work, peace of mind and the right to choose the best course of action for themselves and their families which helps them through this challenging period with dignity and without undue financial loss.
- 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.

Chief Executive of Sample Company

Further information

Dying to work campaign

<http://www.dyingtowork.co.uk>

Sickness absence and disability discrimination: A TUC negotiators guide

https://www.tuc.org.uk/sites/default/files/tucfiles/sickness_absence_and_disability_discrimination_feb2013.pdf

Working through Cancer, An employers Guide (Macmillan)

<http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/WorkingThroughCancer/WorkingThroughCancer2010/Workingthroughcancer2010.pdf>

UnionLearn courses

<https://www.unionlearn.org.uk/>

