

Debate Pack

16 December 2024

Number CDP-0175 (2024)

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Employment rights of people with a terminal illness

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Background

A Westminster Hall debate on the employment rights of people with a terminal illness is scheduled for Wednesday 18 December 2024, from 9:30 to 11:00am. The debate will be led by Lee Baron MP (Labour).

There is little specific reference in employment law to terminal illness – however in most cases the usual legal protections against disability discrimination and duties to make reasonable adjustments will apply.

1.1 Protections against discrimination

Definition of disability

Under the Equality Act 2010 people with disabilities are protected against discrimination at work. Disability is defined in the act as any impairment that has a “long-term” and “substantial” adverse effect on the person’s ability to “carry out normal day-to-day activities”.¹

“Long-term” is further defined as a condition likely to last at least 12 months or “for the rest of the life of the person affected”.² Because of this wording, terminal illnesses will usually be classed as disabilities at least from the point they begin to have an impact on people’s ability to carry out day-to-day activities.

Furthermore, people with cancer, HIV infection or multiple sclerosis are always automatically considered to have a disability, regardless of symptoms.³

Discrimination at work

Direct and indirect discrimination

Both direct and indirect discrimination at work on the grounds of disability is prohibited under the Equality Act 2010. As explained by [guidance from the Advisory, Conciliation and Arbitration Service \(Acas\)](#), direct discrimination means treating someone less favourably “because of” their protected characteristic.⁴ [Indirect discrimination](#) means having a “working practice, policy or rule” that is “the same for everyone but has a worse effect

¹ [Equality Act 2010, section 6](#)

² [Equality Act 2010, Schedule 1, paragraph 2](#)

³ [Equality Act 2010, Schedule 1, paragraph 6](#)

⁴ Acas, [Direct discrimination](#), 15 November 2024

on someone because of a 'protected characteristic', unless the employer can justify this rule as a "proportionate" means of achieving a "legitimate aim".⁵

Discrimination by association and discrimination arising from disability

Two other kinds of disability discrimination are also prohibited; discrimination by association – discriminating against someone because they have a connection with a disabled person; and discrimination arising from disability – discriminating against someone because of needs or behaviours that arise because of their disability, such as having an assistance dog or absence from work to attend hospital appointments.⁶

Application of discrimination protections

These protections against discrimination apply to all areas of someone's treatment at work, including recruitment, pay, promotion, training and dismissal. While dismissals of people with terminal illness on the grounds of capability may still be lawful in some circumstances, employers would need to be mindful of a range of factors, including whether other more suitable roles may be available or whether adjustments could be made to allow the person to continue working.

Acas has specific guidance on managing disabilities that get worse over time. This notes that all legal obligations continue to apply and that "The employer should not assume what someone can or cannot do, or what someone wants to do." The guidance notes that in some circumstances, people may no longer be able to do their work but would like to continue working. In those circumstances they employer should explore reasonable adjustments (see below) and other sources of support. However, in some situations the guidance recognises this may not be enough:

If there are no adjustments or support that would allow the person to continue in their job, the employer should consider whether there's a suitable alternative job. This might include retraining or considering other adjustments.

The employer should do everything they can to keep the person in work. But in some circumstances an employer might need to consider ending someone's employment or taking other action.⁷

Reasonable adjustments

As part of their duties to avoid disability discrimination, employers are also under an obligation to make reasonable adjustments at work for any workers with disabilities.

⁵ Acas, [Indirect discrimination](#), 15 November 2024

⁶ Acas, [Types of disability discrimination](#), 11 September 2024

⁷ Acas, [Disabilities that get worse](#), 10 September 2024

Broadly, an employer is under a statutory duty to take such steps as are reasonable in the circumstances to:

- avoid putting disabled persons at a substantial disadvantage where a provision, criterion or practice would put them at that disadvantage compared with non-disabled persons;
- remove, alter or provide means of avoiding physical features (e.g. stairs) where that feature puts a disabled person at a substantial disadvantage compared with non-disabled persons; or
- provide an auxiliary aid where a disabled person would, but for the provision of that aid, be put at a substantial disadvantage in comparison with persons who are not disabled.⁸

A “substantial” disadvantage is one that is “more than minor or trivial”.⁹

What is considered a ‘reasonable’ adjustment will depend on all the facts and circumstances of any particular case. However, this is an objective test, not merely what an employer considers to be reasonable in their opinion.

The duty to make reasonable adjustments is proactive as well as reactive – employers should make such adjustments even if they are not asked for by the employee, so long as the employer knows or could reasonably have been expected to know the employee has a disability.

Terminal Illness (Support and Rights) Bill 2022-23

On 15 June 2022 Labour MP Alex Cunningham introduced the [Terminal Illness \(Support and Rights\) Bill 2022-23](#) as a ballot bill, after he came 12th in the private members’ bill ballot for that session.¹⁰

The bill would have extended the Warm Home Discount scheme and Energy Company Obligation Scheme to terminally ill people. In addition, clause 3 of the bill would have required the Secretary of State to make regulations requiring employers to take terminal illness into account before either dismissing or reducing salary for an employee due to a period of sickness absence, as an extension of their existing duties to make reasonable adjustments.

The second reading debate began on 18 November 2022 but was adjourned when the moment of interruption was reached at 2.30pm.¹¹ The debate was not resumed before the end of the 2022-23 session and therefore the bill fell at the end of the session without completing its second reading.

⁸ [Equality Act 2010, sections 20-21](#) & Schedule 8

⁹ [Equality Act 2010, section 212](#)

¹⁰ [Private members’ bill ballot](#), 19 May 2022

¹¹ [HC Deb 18 November 2022, c1014](#)

During the adjourned second reading debate, Alex Cunningham MP set out what he hoped clause 3 of his bill would achieve:

The third and final clause of my Bill aims to put the demands of the TUC's Dying to Work campaign on a statutory footing, ensuring that terminal illness is recognised as a protected characteristic, so that an employee with a terminal illness would enjoy a protected period during which they could not be dismissed as a result of their condition. This protection will provide those who have received a terminal diagnosis and are still of working age with the choice of how to spend their final months, and the peace of mind of knowing their job is protected and the future financial security of their family is supported.¹²

1.2 TUC Dying to Work Charter

The TUC run a [Dying to Work campaign](#) encouraging employers to sign up to a voluntary Dying to Work Charter, to support workers with a terminal illness. The TUC asks employers to agree to several steps including to:

- 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.¹³

According to the TUC, as of March 2024 there were over 1.5 million workers in the UK whose employers had committed to the Dying to Work charter.¹⁴

1.3 Access to work and Disability Confident

Access to Work and Disability Confident both look to support employers to take on disabled people, and to provide support to disabled people in the workplace. Information on these, and the other programmes that are in place to support disabled people to find and stay in work, are provided in the Library briefing [Disabled people in employment](#).¹⁵

¹² [HC Deb 18 November 2022, c1006](#)

¹³ TUC: Dying to Work, [5 Steps to the Charter](#) [accessed 16 December 2024]

¹⁴ St Helena, [St Helena commit to TUC's Dying to Work Charter](#), 1 March 2024

¹⁵ Commons Library research briefing CBP-7540, [Disabled people in employment](#)

Access to Work

The Access to Work scheme was introduced in 1994 and provides support to disabled people in the workplace. Access to Work grants are available to employees and to the self-employed and aim to provide practical and financial support to help disabled people find or stay in work.¹⁶

Access to Work provision was approved for 67,720 people in 2023/24, which was the highest level of approvals in any financial year since 2007/08.¹⁷ Of the individuals it was approved for, 3,100 reported that their primary medical condition was difficulty in seeing. There are usually around 3,000 approvals with this primary medical condition every year.

Access to Work provision includes elements such as:

- Communication support for interviews
- Special aids and equipment
- Adaptations to premises and vehicles
- Help with travel costs
- Support workers
- Mental health support¹⁸

The most common element that was approved was a support worker, which was approved for just under half of those who had any provision approved.

The maximum annual amount an individual can receive was set at £69,260 from 8 April 2024. This is updated annually every April.¹⁹

Employers may be expected to pay some of the cost of the elements that are implemented by Access to Work.

Adjustments to Access to Work

As part of the March 2023 [Transforming Support white paper](#), the Department for Work and Pensions (DWP) announced it will pilot a new Access to Work “enhanced package”, which will be aimed at disabled people who need more support than the existing scheme can provide.²⁰

¹⁶ GOV.UK, [Access to Work: get support if you have a disability or health condition](#)

¹⁷ Data for years prior to 2007 is not available due to unreliable data

¹⁸ DWP, [Access to Work Statistics](#), 31 October 2024, table 1

¹⁹ DWP, [Access to Work factsheet for customers](#), 10 April 2023

²⁰ DWP, [Transforming Support: The Health and Disability White Paper](#), 15 March 2023

Two new elements have been tested as part of this expanded “Access to Work Plus” support:

1. An enhanced package of personal support.
2. Support for employers “who are willing to make adjustments to the workplace and/or shape the job roles” to provide employment opportunities for disabled people who have high in-work support needs.²¹

The pilot of this new package was expected to last for up to 12 months.

Since summer 2021, the DWP has begun a series of adjustment passport trials. These passports provide information on a disabled person’s working requirements and the workplace support and adjustments that they require. The passport can then be shared with employers, with the aim of reducing the time it takes to obtain an Access to Work award.²²

The roll-out of a health adjustment passport, which is intended to support disabled jobseekers, was completed by May 2022.²³

Criticism of the Access to Work scheme

In the consultation before the Transforming Support white paper, respondents said the Access to Work scheme is helpful, but that not enough people know about it and that the application process can be complex.²⁴

Similar criticisms about a lack of awareness of the scheme and a difficult application process were provided in the evidence for the Work and Pensions Committee’s [Disability employment gap inquiry](#).²⁵ The committee called on the DWP to launch a marketing campaign targeted at employers and disabled people who are in, or applying for, work. It also said that the “digital transformation” of the application process was long overdue.²⁶

The DWP reported in May 2024 that Access to Work grants could now be applied for online.²⁷

Outstanding applications

There has been a large increase in the number of people waiting for Access to Work assessments in recent months.

²¹ PQ 168044 [on [Employment: Chronic Illnesses and Disability](#)] 17 March 2023

²² DWP, [Transforming Support: The Health and Disability White Paper](#), 15 March 2023

²³ DWP, [Health Adjustment Passport](#), 23 December 2022

²⁴ DWP, [Transforming Support: The Health and Disability White Paper](#), 15 March 2023

²⁵ Work and Pensions Committee, [Disability Employment Gap](#), 30 July 2021

²⁶ Work and Pensions Committee, [Disability Employment Gap](#), 30 July 2021

²⁷ DWP, [DWP’s Access to Work applications go digital](#), 8 May 2024

In October 2024 the government said that there are 55,500 applications outstanding nationally.²⁸

Mims Davies, the then Minister for Disabled People, Health and Work, reported there were 36,721 applications outstanding on 7 May 2024.²⁹ This was an increase from 26,924 applications reported as of February 2024 and 21,780 reported as of September 2023.^{30 31}

Mims Davies also said that the average timescale for an application in April 2024 was 43.9 days.³²

The government has said it will look to reduce waiting times for Access to Work applications by increasing the number of staff processing claims and by prioritising applications from customers who are about to start a job.³³

Disability Confident

The Disability Confident scheme aims to help employers “to think differently about disability and take action to improve how they recruit, retain and develop disabled people”, and to identify organisations “who are committed to inclusion and diversity in the workplace”.³⁴

Employers can sign up to the scheme, and may be given accreditation to one of three levels:

- Level 1: Disability confident committed
- Level 2: Disability confident employer
- Level 3: Disability confident leader

Employers will join the scheme at level 1 and can then work their way up to level 3.

19,321 employers were signed up to the scheme in November 2024.³⁵ Of these: 75% were disability confident committed, 22% were disability confident employers and 3% were disability confident leaders.

The DWP has said it is not possible to accurately estimate how many disabled people these employers have working for them.³⁶

²⁸ [PQ 6749](#), 14 October 2024

²⁹ [HC Deb 13 May 2024](#)

³⁰ [PQ 12720](#), 8 February 2024

³¹ [PQ 197834](#), 11 September 2023

³² [HC Deb 13 May 2024](#)

³³ [PQ 9705](#), 23 October 2024

³⁴ DWP, [Disability Confident employer scheme](#), 15 June 2021; GOV.UK, [Disability Confident](#)

³⁵ DWP, [Disability Confident: employers that have signed up](#), 7 November 2024

³⁶ [PQ HL167](#), 14 January 2020

Review of the Disability Confident scheme

In its [July 2021 inquiry report on the disability employment gap](#), the Work and Pensions Committee called on the DWP to explore ways to measure the success of the scheme.³⁷

It also called on the DWP to “urgently announce” plans to evaluate the scheme, to establish an independent body to carry out external assessments of disability confident employers and to consider whether the existing disability confident commitment is “sufficiently challenging and encourages meaningful change from employers”. The committee also recommended that any new commitments should include a requirement for disability confident employers to recruit disabled people before being awarded a higher level.

In September 2023, the DWP published a report on the findings of a survey of employers who were disability confident members.³⁸ Two thirds of surveyed employers agreed joining the scheme had a positive impact on their organisation, and just under two thirds reported they had recruited a disabled employee, or an employee with a long-term health condition, since joining the scheme. Employers also reported that they were [more likely to take a range of disability recruitment activities](#) after signing up for the scheme.³⁹

³⁷ Work and Pensions Committee, [Disability Employment Gap](#), 30 July 2021

³⁸ DWP, [Disability Confident: survey of participating employers, May 2022](#), 18 September 2023

³⁹ DWP, [Disability Confident: survey of participating employers, May 2022](#), 18 September 2023

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Press and media articles

The following is a selection of press and media articles relevant to this debate.

Please note: the Library is not responsible for either the views or accuracy of external content.

[How to Compassionately Manage an Employee with a Terminal Illness](#)

Harvard Business Review

Chidiebere Ogbonnaya, Vijay Pereira, Benjamin Laker, Mayowa Babalola, and William Degbey

2 October 2024

[How HR can help inform guidance to support employees who have cancer](#)

HR Magazine

Zofia Bajorek

3 April 2024

[Employers must improve support for terminally ill workers](#)

Personnel Today

Rachel Stuff

26 January 2024

[Terminal illness: Guidance for people professionals](#)

Chartered Institute of Personnel and Development (CIPD)

23 January 2024

[DWP is 'penalising' terminally ill people for 'not dying fast enough', campaigner warns](#)

Big Issue

Hannah Westwater

15 December 2023

[Four action areas for supporting employees with terminal illness](#)

Personnel Today

Stephen Bevan and Barbara Wilson

31 May 2023

[“No-one should die in poverty”: Alex Cunningham, MP proposes new bill](#)

North East Bylines

16 November 2022 (updated 14 February 2023)

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Parliamentary questions

Employment: Disability

07 May 2024 | 24484

Asked by: Neil Coyle

To ask the Secretary of State for Work and Pensions, how much his Department has spent on its Disability Confident employer scheme.

Answering member: Mims Davies | Department for Work and Pensions

The Disability Confident scheme is delivered by a small policy team within the department, and by colleagues across the Jobcentre Plus network, who engage with employers and partner organisations as part of their day-to-day business. Total scheme expenditure is not separately recorded within departmental budgets.

Social Security Benefits: Terminal Illnesses

20 Jun 2023 | 189327

Asked by: Ian Lavery

To ask the Secretary of State for Work and Pensions, whether he has made an assessment of the potential merits of providing additional financial support to people who have been diagnosed with a terminal illness and are unable to work.

Answering member: Tom Pursglove | Department for Work and Pensions

The department is committed to supporting people nearing the end of life. The main way the department does this is through special benefit rules, called the Special Rules for End of Life. These enable people who are nearing the end of their lives to get faster, easier access to certain benefits, and in most cases receive the highest rate of benefit, without needing to attend a medical assessment or serve waiting periods.

From 3rd April 2023, individuals with 12-months or less to live, where they meet the relevant eligibility criteria, are able to claim Universal Credit, Employment and Support Allowance, Personal Independence Payment, Disability Living Allowance, and Attendance Allowance, under the Special Rules for End of Life. These changes mean that thousands of people nearing the end of life are able to claim fast track financial support from the benefits system.

Employment: Disability

24 May 2023 | 185262

Asked by: Seema Malhotra

To ask the Secretary of State for Work and Pensions, what recent assessment his Department has made of the quality of outcomes from the Disability Confident employment scheme.

Answering member: Tom Pursglove | Department for Work and Pensions

In 2021, we began a review of the Disability Confident scheme which was announced in the National Disability Strategy (NDS). The review was exploring ways the scheme could be strengthened, including the quality of outcomes for disabled people.

In January 2022, the High Court declared the NDS was unlawful because the UK Disability Survey, which informed it, was held to be a voluntary consultation that failed to comply with the legal requirements on public consultations. The Secretary of State wanted to minimise the risk of acting inconsistently with the Court's declaration therefore, we paused a limited number of policies referred to in the strategy, including work directly related to the Disability Confident review. The Secretary of State has successfully obtained permission to appeal this decision. The Court of Appeal hearing is due to take place on 28 and 29 June 2023.

I am exploring what additional steps we can take, whilst respecting the Court's decision and awaiting the outcome of the appeal.

Employment: Disability

03 May 2023 | 182395

Asked by: Rosie Duffield

To ask the Minister for Women and Equalities, what recent assessment she has made of the adequacy of legal protection for disabled people when (a) applying for work and (b) having their employment terminated.

Answering member: Stuart Andrew | Women and Equalities

There is long-standing legal protection for disabled people under the Equality Act 2010 (the Act). The Act makes it unlawful for an employer to discriminate against a disabled job applicant or employee because of their disability, provided the Act's definition of disability is met.

Specifically, the Act requires employers to make reasonable adjustments in relation to the disabled job applicant's assessment and interview process and, once employed, the disabled employee's job and decisions made in relation to it. These adjustments ensure that disabled applicants or employees are not placed at a substantial disadvantage compared to their

non-disabled colleagues. The failure of an employer to make reasonable adjustments for a disabled employee or job seeker, or discounting a job application simply because the applicant is disabled could amount to direct disability discrimination under the Act. Similarly, where an employer is looking to reduce their staff, choosing someone for redundancy simply because they are disabled, may amount to unlawful discrimination.

However, the Act also recognises the need to strike a balance between the needs of disabled employees and the circumstances of their employers. What is 'reasonable' will therefore vary from one employer to another because of factors such as the practicality of making the adjustment, the cost of the adjustment to the employer and the resources available to different employers. In the event of a claim of alleged disability discrimination, it will ultimately be for the courts to decide on a case-by-case basis, what reasonable adjustments should be made for a particular disabled service-user, taking into account all relevant circumstances of the case.

In terms of employment law, should a person be unfairly dismissed because they have a disability, they can seek redress under the Act for being discriminated against by their employer. Where an employer treats a worker with a disability or life-limiting illness so badly that the worker is forced to resign from their job, the constructive dismissal provisions in employment law may apply.

Employment: Terminal Illnesses

23 Sep 2022 | 49560

Asked by: Dr Julian Lewis

To ask the Secretary of State for Work and Pensions, what recent assessment her Department has made of the financial (a) impact upon and (b) assistance available to people of working age forced to leave their jobs following a diagnosis of terminal illness; and if she will make it her policy to enable such people to have early access to their state pension.

Answering member: Victoria Prentis | Department for Work and Pensions

The Government wants to do all it can to alleviate the pressures on those nearing the end of their lives, and on their families.

The main way that the Department for Work and Pensions (DWP) does this is through special benefit rules, sometimes referred to as "the Special Rules". These enable people who are nearing the end of their lives to get faster, easier access to certain benefits, without needing to attend a medical assessment, serve waiting periods and in most cases, receive the highest rate of benefit. For many years, the Special Rules have applied to people who have 6 months or less to live and now they are being changed so they apply to people who have 12 months or less to live.

Once the change has been fully rolled out across all benefits, each year, between 30,000 and 60,000 people may benefit from these changes to the Special Rules. This will mean that the Government is spending approximately £115 million a year more on people who are nearing the end of their lives.

There are no plans to allow early access to State Pension.

This Government is committed to providing a financial safety net for those who need it, including when they near or reach retirement. Support is available through the welfare system to those who are unable to work or are on a low income but are not eligible to pensioner benefits because of their age.

Government Departments: Terminal illnesses

28 Jan 2020 | 6604

Asked by: Jon Trickett

To ask the Minister for Women and Equalities, whether the Government has plans to sign up for the Trades Union Congress's charter entitled, Dying to Work; and if he will make a statement.

Answering member: Victoria Atkins | Women and Equalities

The Government supports the aim of enabling employees with terminal illnesses or life-threatening conditions to continue working for as long as possible. The Equality Act 2010 already provides protection for the workplace rights of people with terminal illnesses or life-threatening conditions. Cancer, HIV and multiple sclerosis are specified disabilities in the Act. This means anyone with any of the above-listed chronic and/or life-limiting conditions is considered disabled and is protected from discriminatory treatment as a result of having that condition. The Act also provides that people with progressive conditions that have effects that increase in severity over time should be regarded as meeting the criteria for having a disability before it actually has that effect.

The Act places obligations on employers regarding disabled workers to ensure that workers who have chronic diseases or conditions (whether terminal or not), or debilitating illnesses, are fully protected from any unlawful behaviour by their employers. The Government also supports the Disability Confident employer scheme. More information can be found at: <https://www.gov.uk/government/collections/disability-confident-campaign>

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Other Parliamentary material

EMPLOYMENT PROTECTION FOR THE TERMINALLY ILL

EDM: 8 (session 2014-15)

Mr Graham Allen

4 June 2014

That this House expresses concern about employment protection for the terminally ill; notes that terminal conditions are currently covered by current disability legislation, therefore terminally ill employees can be dismissed if they are no longer able to conduct their role with reasonable adjustments; understands that this can mean that terminally ill people can be subjected to stressful assessments, subsequent dismissal and the loss of death in-service benefits - all following the diagnosis of a terminal illness; and calls for additional Government protection for employees from the point of diagnosis.

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Further reading

[The Terminally Ill Adults \(End of Life\) Bill 2024-25](#), Commons Library research briefing, CBP-10123, 22 November 2024

[Supporting employees with terminal illness: A guide to work place policies and practice](#)

What Works Centre for Wellbeing and Marie Curie, Joanne Smithson, Ingrid Abreu Scherer, Izzie Baverstock Poppy, Stephen Bevan and Prof Ruth Parry, 2023

[Accessing benefits with terminal illness](#), Commons Library research briefing, CBP-8995, 1 March 2022

[Dying to Work](#) (website)
Trades Union Congress

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