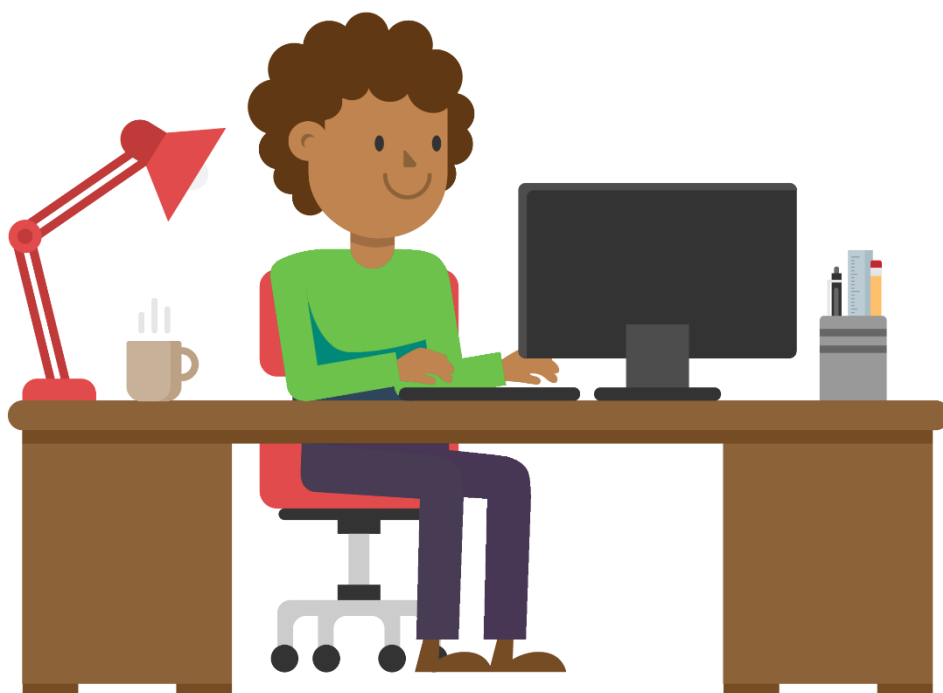


TSC and Employment: A Guide for Employers



If you are reading this, then it is likely that you have an employee who has told you that they have Tuberosus Sclerosis Complex (TSC). You may have questions about TSC, how it may affect your employee and what you can do to support them at work. This guide will help you to understand what it means to have TSC, as well as the legislation and support available for managing employees with TSC.

What is Tuberosus Sclerosis Complex (TSC)?

TSC is a rare, genetic condition that affects around 1 million people worldwide. TSC causes non-cancerous tumours to grow in various organs in the body, such as the brain, heart, kidneys and skin. The issues caused by TSC are as a result of the location and size of these tumours. A person is born with TSC, but diagnosis can happen at different life stages, depending on how the condition affects individuals.

TSC affects everyone with the condition very differently

What are the common symptoms of TSC?

TSC affects everyone differently – just because two people live with TSC does not mean that they will experience the condition in similar ways. However, common symptoms of TSC include epilepsy, autism, depression/anxiety and kidney problems. Other issues can include problems with the skin, lungs, eyes and heart. Some symptoms of TSC are visible and some are invisible.

Is someone who lives with TSC considered disabled?

Having a disability can mean different things to different people. Whether someone who lives with TSC considers themselves disabled as a result of the condition depends on how TSC affects them, with the condition impacting everyone differently.

Some people living with TSC may not consider themselves to have a disability, but they might still qualify for protection against discrimination if they have a long-term health condition as a result of TSC. This protection would come under the Equality Act 2010 (England, Wales, Scotland) or the Disability Discrimination Act (Northern Ireland).

A person can still be protected by the Equality Act even if their symptoms are controlled by medication, as treatment is rarely considered when determining whether somebody has a disability.

How is TSC treated and managed?

There is currently no cure for TSC, but it can often be managed with an increasing number of treatments and therapies. As TSC affects everyone differently, the treatments they receive will also depend on how the condition affects them. Treatments **may** include:

- Immunosuppressant medication to reduce the size of tumours in the body
- Anti-epileptic medication to reduce the number and severity of seizures
- Medication and therapies to reduce the impact of TSC-associated neuropsychiatric disorders (TAND) such as anxiety and depression
- Topical creams and/or laser treatments to reduce the size and severity of skin growths

The impact of ongoing treatment and management of TSC could mean that a person with the condition **might**:

There are no cures for TSC, but in many cases it can be well managed

- Be more susceptible to colds and viruses
- Need to schedule and take time to attend appointments and check-ups
- Need to have greater focus on maintaining their mental health

Does TSC affect an employee's ability to do their job?

As TSC affects individuals differently, whether TSC affects an employee's ability to do their job depends on how their TSC affects them, as well as the type of job that they have. Some people may have only very minor issues or no issues at all, whereas others may need more specific arrangements to help them flourish.

For employees with TSC-related epilepsy, some jobs or tasks, such as working at heights, may present health and safety concerns. If your employee has epilepsy, you must carry out a risk assessment and you may wish to write a care plan together, for if your employee has a seizure at work.

One of the most important things that a person living with TSC can receive at work is an open and supportive working environment, with a focus on flexibility and understanding in agreeing on working arrangements.

How can you support an employee with TSC?

Supporting an employee who lives with TSC or any disability does not need to be expensive, complicated or time-consuming:

- **Talk to your employee.** The best way to find out how you can support your employee is by talking to them. Not only will they be able to help to guide you, it will also help to build a trusting relationship that benefits all parties.
- **Regular reviews or 'check ins'.** Regular 'check ins' can give employees a safe space to tell you how their TSC is affecting them and how they are getting on at work. The way that TSC impacts on an employee at work may also change over time, so these reviews can help monitor the situation
- **Reasonable adjustments.** Your employee has the right to ask for reasonable adjustments to be made under the Equality Act (England, Wales, Scotland) or Disability Discrimination Act (Northern Ireland). By approaching this positively, you can ensure that this benefits everyone

Contact the TSA Support Line for any questions as an employer or employee

What sort of reasonable adjustments might an employee who lives with TSC require?

Reasonable adjustments for someone who lives with TSC and is employed will be unique to different people, but they may include:

Supporting an employee living with TSC does not need to be expensive or complicated

- **Flexibility in working hours.** Starting earlier or later in the day may be helpful for people who live with TSC-related epilepsy and have seizures at regular times (such as night-time seizures). Flexibility may also be requested to give people the opportunity to take medication at set times
- **Allowing time off for medical appointments.** As TSC is a lifelong condition that needs monitoring, someone with the condition may need to take some time away from work to attend scans or treatments
- **Providing information in alternative formats.** Some employees with TSC may benefit from information in specific formats, such as large-print, video, or voice notes
- **Providing additional training or mentoring.** Providing additional training or mentoring can help an employee manage their condition, or move to a more suitable role in the organisation if their TSC symptoms makes their current role unsuitable
- **Training of other employees.** Providing that the individual with TSC gives their permission, educating colleagues about TSC and what reasonable adjustments can be made can be beneficial

The first and often most important step is open and considerate conversations

Will someone living with TSC need additional time off work?

The way that TSC can affect people might mean that they need to take additional time off from work. Your organisation may already have a policy regarding time off related to a disability or long-term health condition. If not, a reasonable adjustment could be made.

Any employee absence as a result of TSC should be recorded separately to other absences, so that they are not discriminated against if your organisation takes sickness absences into account for bonuses or promotions.

Occasionally, an employee with TSC may need to see their health practitioner for scans or treatment reviews. A longer period of time off work may also be needed in more extreme situations if surgery is ever required.

Keeping in touch with your employee about how TSC could lead to absences and involving them in proactive planning and return to work procedures, can help to address concerns or misconceptions on all sides.

What support is available to help employers?

- **The TSA Support Line.** We can help to answer any questions that employers and employees may have
Freephone: **0808 801 0700**
Email: support@tuberous-sclerosis.org.

Our Support Line Advisers could provide you and your team with a professional TSC-awareness education session, helping you better understand TSC and how to support employees.

- **Advisory, Conciliation and Arbitration Service (ACAS).**
A free, confidential and independent advice service, for both employers and employees to prevent or resolve workplace disputes in England, Scotland and Wales.
Helpline: **0300 123 1100**
Website: www.acas.org.uk
- **Business Disability Forum**
A national organisation for employers for developing best practice in the employment of disabled people.
Phone: **020 7403 3020**
Website: www.businessdisabilityforum.org.uk
- **Citizens Advice**
Advice services in over 2,900 community locations. You can find details of your nearest office in England and Wales and specific information for people living in Scotland or Northern Ireland on their website
Website: www.citizensadvice.org.uk
- **Equality Advisory Support Service (EASS)**
Information, advice and support services for discrimination in the workplace
Phone: **0808 800 0082**
Website: www.equalityadvisoryservice.com
- **Equality and Human Rights Commission (EHRC)**
Information about the Equality Act and how it applies to employment
Website: www.equalityhumanrights.com
- **Equality Commission for Northern Ireland**
Get help to meet your responsibilities as an employer under the DDA in Northern Ireland
Phone: **028 9050 0600**
Email: information@equalityni.org
Website: www.equalityni.org
- **Occupational Health**
Occupational health services can help to assess what reasonable adjustments your employee may require:
 - **Fit for work (England and Wales)**
Phone: **0800 032 6235**
Website: www.fitforwork.org
 - **Fit for work (Scotland)**
Phone: **0800 019 2211**
Website: www.fitforworkscotland.scot
 - **Disability employment service (NI)**
Phone: **028 9025 2237**
Email: des@delni.gov.uk
Website: www.delni.gov.uk

www.tuberous-sclerosis.org

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