



Tuberous Sclerosis Complex (TSC) and Employment

To whom it may concern,

This letter provides information to employers about people with Tuberous Sclerosis Complex (TSC). TSC is a rare and genetic condition that causes non-cancerous tumours to grow in various organs in the body, such as the brain, heart, kidneys and skin. Issues caused by TSC are due to the location and size of these tumours. A person is born with TSC, but diagnosis can happen at different life stages.

TSC affects everyone differently. Two people live with TSC could have very different symptoms. However, common challenges with TSC include: Epilepsy, autism, depression/anxiety and kidney problems. TSC symptoms can be visible and also invisible. People with TSC might also be more susceptible to infections or viruses. Someone with TSC might consider themselves to be disabled, depending on how the condition impacts on their health and their life. You can find out more about TSC at www.tuberous-sclerosis.org.

As an employer, you can support an employee who has TSC by talking to them about the condition and how you can help. Your employee can ask for reasonable adjustments to be made under the Equality Act (England, Wales, Scotland) or Disability Discrimination Act (Northern Ireland). Reasonable adjustments might include:

- Flexible working arrangements and hours
- Providing information in alternative formats
- Additional training and/or mentoring
- Time off for medical appointments, and/or allowance to take medicine at set times

Whether TSC influences an employee's ability to do their job depends on how TSC affects them, as well as the type of job that they have. Some people might have very minor issues or no issues at all, whereas others might need more specific arrangements to help them flourish. It is common for people living with TSC to have regular medical appointments to monitor or treat their TSC. Occasionally, someone with TSC might need to have surgery or a procedure. If an employee with TSC does need to take time off work, keeping in touch can help to ensure that they feel supported when they return to work.

Creating an open and supportive working environment can help to overcome barriers. If an employee with TSC is adequately supported in the workplace, it can benefit everyone.

You can find best practice information on supporting employees with TSC in the TSA's Guide for Employers (available on our website) and through other organisations such as ACAS. You can contact the TSA's Support Line for information about TSC (freephone 0808 801 0700 or email support@tuberous-sclerosis.org).

Thank you for taking the time to find out more about TSC in order to support the health and wellbeing of your employee.

Yours faithfully,

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