



Turner Syndrome Support Society (TSSS) **Employment**



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This leaflet is intended as a guide for women who have Turner Syndrome (TS) with employment issues they may face. It has been produced by Dr Paul Chadwick, a Clinical Psychologist with expertise in TS, and members of the Turner Syndrome Support Society (TSSS). It was funded by a grant from Jeans for Genes. The leaflet is provided as a guide only and is by no means definitive. More comprehensive medical information can be obtained by reading "Turner Syndrome Lifelong Guidance & Support" available from the TSSS office. For additional reading refer to the Bibliography.

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Abbreviations The following abbreviations are used throughout the text and the meanings below relate solely to their use in this leaflet: TS = Turner syndrome TSSS = Turner Syndrome Support Society (UK)

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What is Turner Syndrome (TS)?

Turner Syndrome (TS) is a relatively common chromosomal disorder affecting only females. It exists where all or part of the X chromosome is either missing or damaged in some cells of the body. The condition affects around one in two thousand live female births. In Britain, there are thought to be some 10,000 girls and women who have TS, and the estimated global figure is 1.5 million, however, TS often goes undiagnosed.

Common signs and symptoms of TS

- Short stature
- Thyroid problems
- High blood pressure
- Hearing difficulties
- Infertility
- Heart problems
- Difficulties with vision (myopia and astigmatism).

However, as the name suggests TS is a syndrome which means that those with it can show none of these signs, all of them or anywhere in between.

KEY TIP

Don't assume that all women with TS will be impacted in the same way.

It is also worth noting that TS does **not** affect intellectual capacity, Women with TS have an intellectual capability range which mirrors the rest of the population.

KEY TIP

Although often shorter than their peers care needs to be taken that this does not lead to judgements being made about ability. Women with TS need to be treated according to their age and ability, not their height.

How does TS impact employment?

Most women with TS are able to work, and, with the right support, contribute effectively in many different roles. Many choose careers in the caring professions; however, they are successful in a very wide range of roles.

Colleagues may work alongside a woman with TS for months, or years without ever realising she has TS.

This leaflet aims to outline some aspects of TS that are helpful for you to be aware of. Although there are a range of potential impacts of TS listed below, many women only exhibit some of these. For the vast majority this does not impact on their ability to be a really effective and valued member of your organisation.

Hearing Impairment

Many women with TS have hearing difficulties. It is important to ensure that colleagues know this so that they can speak clearly and repeat things where necessary. Reasonable adjustments may need to be made by the employer, for example, the provision of specially adapted phones and or headphones.

Women with TS also need to take personal responsibility for making sure a hearing aid is worn and to explain to their colleagues how they can help.

KEY TIP

Contact the Royal National Institute for the Deaf. The RNID can help with issues specifically related to hearing and are able to provide hearing specific equipment. (www.rnid.org.uk)

“My bosses have got me hearing aid compatible headphones to make things easier.” Hayley

Lack of stamina

Women with TS are often able to make a great effort and get through a particular task, but energy levels can be a problem and there are times when this needs to be understood and allowed for. It is not necessarily laziness. Any symptoms that a woman has will be magnified when they are very tired. They don't always know how to pace themselves and may well go on until they drop.

Clumsiness

These difficulties can be very apparent with practical tasks due to a lack of spatial awareness; some women may appear to be rather clumsy at times.

Concentration Difficulties

Hormone imbalances can result in poor concentration in women who have TS. Like anyone they can be affected by being over tired or stressed. Allowing a short break to re-focus and breaking tasks down in to manageable sizes, will minimise any impacts this may have.

KEY TIP

A little patience and understanding can help enormously.

Anxiety

Women with TS have a tendency to be over-anxious, to dwell on things, taking the blame even when it is not their fault. Many have low self-esteem, and can be oversensitive to criticism. They frequently experience an intense need for security, and constant reassurance.

KEY TIP

Regularly let a woman with TS know when she has done a good job, once may not always be enough.

“My current employer and HR manager have been positive in trying to help me settle in to where I am at the moment, I still sometimes feel overwhelmed, but I am hoping my employer and I can work together to combat my anxiety and worry.” **Olivia**

Being literal

Many women with TS tend to take things very literally when told what to do. Although excellent at following instructions, instructions need to be extremely clear. Sometimes they will give the impression that they have understood when they are still unclear, or will struggle with concepts that are overwhelmingly simple to others. Alternatively they can quickly grasp an essential feature of a situation which others have failed to perceive.

This can apply to workplace banter and comments too. Women with TS can think that what is being said is actually meant. This can result in humour being misinterpreted, affecting relationships, self-esteem, confidence and how she is judged by her colleagues.

KEY TIP

Be explicit at all times e.g. when you need something done, ask a direct question rather than expecting her to do it without being told.

Need for routine

Some women with TS have a definite dislike of sudden disruptions to routine or unexpected changes of plan. Clearly this cannot always be avoided, but when faced with distress at a change, knowing this will enable you to adjust your approach.

There are occasional problems with planning time and prioritising a heavy workload. Some women can work independently without any problems at all - others may need clear guidance as to which tasks should be completed first.

KEY TIP

Ask questions to check, don't assume.

Medical appointments

Women with TS will need time off occasionally to attend hospital appointments. The time needed will vary from woman to woman - it can be as little as one hour a year to a few hours a month. Most women are conscientious and will only take time off work where it is genuinely needed.

KEY TIP

Be as understanding and as flexible as possible.

Relationships with colleagues

Like many non-TS employees, when tired or stressed, relations with colleagues can become strained. Extreme behaviour is unlikely, however, if it does occur, you should, as with any other employee, make clear that it is inappropriate. When this is done in a positive way you are likely to receive a correspondingly positive reaction.

• Lack of intuition

Women with TS can sometimes display a strong reluctance to accept another person's point of view in a given situation, with an occasional tendency towards obstinacy. This is due to women with TS finding it hard to pick up on body language or facial expressions to judge the other person's response. This can result in a woman with TS not being able to realise if someone is becoming irritated with them.

• Low self esteem

Self-confidence can be a challenge for many women with TS and can have a significant impact on their working life as they may be less inclined to identify issues or adjustments that would make them far more productive in the workplace.

“A positive, energetic approach can generate confidence and start to heal a bruised self-esteem; it can also influence others' view of us and our actual performance. Many women with TS have a natural talent for the performing arts; this talent is not only for the stage.”

Robina

- **Team dynamics**

Some women may find it hard to fully participate in a team, and remain isolated, at least initially. This can extend, in particular, to social gatherings outside work, where women with TS may find it hard to play a full part in the conversation and feel awkward (often exacerbated by hearing difficulties and low self-esteem).

KEY TIP

Openness is the best policy. Women with TS will respond well if issues are raised with them in an appropriate manner and will readily modify their behaviour.

Bullying in the workplace

Women with TS are more at risk of becoming the victim of workplace bullying than other colleagues in the workplace. They are easy targets and their tendency not to make a fuss and complain at the early stages can mean that the situation becomes serious before you, as their employer, are aware of it and able to do something about it.

“I thought initially that I must be in the wrong even though my friends said that she was picking on me. I didn't want to tell anyone about it as I thought it must be something I was doing that was causing the problem. When I did eventually tell someone it was sorted out really quickly, and I wished I had done it sooner.” **Kylie**



KEY TIP

Be more aware of potential bullying behaviour towards a woman with TS and take action sooner rather than later.

Please note that the difficulties outlined above cover a broad range of problems. Not all women with TS are going to display all these types of behaviour, and certainly not all of the time!

Why employ a woman with TS?

Women with TS can bring many qualities to the workplace, which make them really good employees to have on board. Although each woman is different there are general personality traits that are quite common, these include:

- Honesty, sincerity and loyalty – many stay with the same organisation for many years
- A good sense of humour
- Ability to inspire tremendous affection among colleagues
- A fresh and innovative approach to problem solving, and a fresh perspective on any given situation
- A conscientious and hard-working attitude, with a real determination to please
- A strong desire to succeed and put in the hours needed to do a good job.

With the right support, Women with TS can amaze themselves and others with the sheer scale of their achievements.



“My current manager has a condition herself which has enabled her to understand my needs making me more effective at work. I have also found it is helpful to have a few allies around at work to support me when needed.” **Clare**

What is the Equality Act 2010, how does it affect me and those around me?

The Equality Act 2010 has brought together all of the legislation covering discrimination on the grounds of age, disability, sex, gender reassignment, sexual orientation, race, religion or belief into one act.

Although this Act is now law it will be implemented over the next few years. It incorporates the aspects previously covered by the Disability Discrimination Acts (DDA) 1995 & 2005. The DDA originally introduced new measures aimed at ending the discrimination which many disabled people faced in their everyday lives.

The key aspect of the Equality Act 2010, that affects Women with TS, is to make it unlawful for an employer to discriminate because of a 'protected characteristic', (which under previous legislation was described as a disability):

- In the terms of employment offered
- In the opportunities for promotion, transfer, training or receiving any other benefit
- By refusing, or deliberately not offering you any such opportunity, or
- By dismissing, or subjecting you to any other negative treatment.

Together, the legislation provides all people with a protected characteristic certain rights, and places duties on those who provide services, education and employment. It also encourages employers and employees to work together to break away from rigid employment practices, identify what adjustments and support might be needed and find flexible ways of working that may benefit the whole workforce.

The Equality Act will introduce additional protection for carers of those protected under the Act e.g.: the mother of a girl with TS. Further information will be available once the Act is fully implemented.

Under the new legislation there is a slightly different test of what 'disability' means compared to the previous legislation which will make it easier to include TS as a disability. Under the Equality Act, where a woman with TS has difficulty carrying out her day to day activities, she will now come under the definition of 'disabled person' and will be protected by the Act.

The law is there to offer you a level of protection both within the working environment and many other areas of life.

Types of discrimination

The Equality Act defines discrimination in a number of ways and outlines specific types of discrimination:

- **Direct discrimination** – when a disabled person is treated less favourably than someone else who has similar circumstances and abilities, or when the treatment is for a reason relating to the person's disability
- **Indirect discrimination** – when the new law comes in, it will be easier for a disabled person to make a claim for discrimination that happens because of something connected with their disability. It will count as 'unlawful discrimination' if someone who knows the person is disabled, treats them unfavourably because of something that results from their disability, provided that treatment can't be justified. This is called 'discrimination arising from a disability'.

EXAMPLE

Your employer brings in a new shift pattern which means that everyone has to work fewer days, but longer days. Because of your TS you're exhausted after two long days of working. So the new shift pattern puts you at a disadvantage. Your employer will have indirectly discriminated against you if they can't justify the new shift pattern.

- **Failure to make reasonable adjustments** – an employer has a duty to make reasonable adjustments where working practices or the physical working environment place a disabled person at a substantial disadvantage compared with people who are not disabled. They must take reasonable steps to prevent that disadvantage.
- **Victimisation** – where a person is treated less favourably because they have or are likely to:
 - Bring an action under the Equality Act
 - Do something else relating to such an action e.g. supporting the person taking action
 - Allege that someone has breached the Equality Act.

What are reasonable adjustments?

The Equality Act does not define 'reasonable' or even give a complete list of what reasonable adjustments may be. Ultimately it is up to the courts to decide. This is because an adjustment is related to a particular individual, their experience of their impairment and the situation they are in. However, it does set out four tests of reasonableness:

- **The effectiveness in preventing the disadvantage** – How much will the adjustment made, reduce the disadvantage? The more effective an adjustment is in reducing disadvantage, the more reasonable it is likely to be
- **The practicality of the step** – It is more likely that an employer will be expected to take a step that is easy than to take a step that is hard
- **The financial and other costs and the extent of any disruption caused** – When trying to decide whether an adjustment is reasonable, the cost of the adjustment and any disruption it might cause should also be considered
- **The extent of an organisation's financial and other resources** – larger, more successful organisations are more likely to have to make a reasonable adjustment than smaller ones.



“One thing my bosses have done is to move bolts on doors and cupboards to a lower position to enable me to reach them. Apart from that I generally manage by asking someone to help, which has been fine.”

Hayley

How else might the Equality Act help me?

Asking questions about health and disability at interview

Employers will generally no longer be allowed to ask questions about health or disability before they offer a job, or before they include candidates in a pool of people to be offered a job when a vacancy arises. However, they can ask such questions if they have good reason.

Protection for carers

If someone looks after a disabled person, they're already protected from being discriminated against at work because of their association with the person they care for. The new law will make this protection clearer.

In addition, direct discrimination and harassment because they care for a disabled person will be banned when:

- They're shopping for goods and services
- They use facilities like public libraries or cafes and
- They use service like public transport.

Although for the vast majority of women and girls with TS this will be of little consequence, it is worth noting.

EXAMPLE

You care for your sister with TS and you try to go to a nightclub with her. They refuse to let you in because they say disabled people aren't good for their image. Your sister may have a claim of disability discrimination and, when the new law is in full force, you may also have a claim of direct discrimination because of your direct association with her as her carer.

Should I disclose my TS to my employer?

Disclosure of TS at any point within your life is fraught with potential pitfalls, and is never going to be easy, either for the woman with TS or even the person being told the information. The workplace is no exception, and all sorts of things will be going through your mind as you put in for a new job.

Do you put TS on your application form, so they know from the start? - This should no longer be included on the application form, any questions related to a disability will normally only be put after an offer has been made.

Should you mention it at interview? – Again the interview should be assessing your skill and competence to do the job so it would be very unusual for your disability to be discussed at interview.

Will it put an employer off? - Who knows? But how you perform in the job is far more important to an employer than whether or not you have TS.

The Equality Act does not force you to tell anyone. But if you don't tell your employer:

- They won't be able to make any reasonable adjustments that could help you to be successful in your job

FOR WOMEN WITH TS

- They will not be able to take it into consideration when considering changes that might result in indirect discrimination
- They won't be able to realise that employing a woman with TS will have enormous benefits for their organisation.

“I have always disclosed my TS, not at interview, I confess, but very soon afterwards. The response has always been positive from my bosses. They've always been supportive of any time off I've needed for hospital appointments and made any adjustments I might have needed to enable me to do my job.” **Hayley**

Declaring any disability can be difficult for many different reasons:

- You may feel that you will not get a job if you say you have a disability
- No one can see the condition that affects you and you feel embarrassed about bringing it up
- You may be worried how an employer will respond, particularly if they have been unsympathetic to someone else in a similar situation
- You may not like asking for help because you feel you can manage or because you don't want to make a fuss and draw attention to yourself
- You think that your manager will dismiss your concerns and just tell you to get on with it
- You are afraid that you might be labelled as not able to do the job.

Some or all of these may be real fears, but remember almost one in four people has either a disability or a health condition, or is close to someone who does.

At the end of the day it is up to you whether or not to declare your disability or health condition. If you do, you can choose when to speak, it could be at the interview stage or at any point up to and including when you have been there for a while. Generally it is best to be honest in work about your health or disability and what you need. This way you can work together with your employer to ensure that you are as successful as you can be.

“I didn’t disclose my TS as I didn’t feel the need at the time, now I feel it would have been beneficial to have done so.” **Olivia**

In truth there is never a right or easy stage in the application process to discuss the condition, and every woman must do what feels right for her at the time.

Once you are in employment there is help available from human resources, trade unions, ACAS and occupational health departments.

If you are unsure it is worth contacting one of these to talk things through to help you work out for yourself what will be the best thing for you to do.

How do I know if my employer is likely to be sympathetic to my TS?

The Two Ticks symbol is granted to employers who demonstrate their commitment to the employment of disabled people. This commitment involves:

- The promise of an interview to all disabled applicants meeting the minimum requirements for the job
- Making necessary adjustments, and
- Supporting people with a disability once appointed ensuring that they are working together to ensure that any requirements are met.



If you see the two tick symbol displayed on an advertisement it can be seen as an indication that this employer is more positive towards disabled people generally.

It is not a guarantee, but the more open you feel you can be, coupled with the protection you receive from the Equality Act – you might be just surprised by the response you get!

“Our natural talents of persistence and tenacity can form the basis of an assertive and direct approach to tasks in the workplace.” **Robina**

Other tips for being successful at work?

Be aware of some of the tendencies outlined above and the impact that they may have on you and your work colleagues. In particular remember

- You do not always need to explain out loud how you plan to approach a task unless asked, this can normally be a dialogue that takes place in your head
- Set your expectations according to how you are impacted by your TS.

For example:

- If you are particularly affected by being able to work as part of a team, look for a role that involves more individual work
- If you are affected by being very literal, look for a role that is very bound by rules and procedures
- If you are prone to be anxious look for a role that does not include a high level of stress

There are lots of different occupations out there that require a whole range of skills and capabilities, there will be a role that will suit you.

You only need to look around at the range of successful women within the TSSS to see that, although TS may be a disability, it does not have to hold you back at work.

ACAS

Helpline 08457 474747
www.acas.org

Citizens Advice Bureau

www.adviceguide.org.uk

Access to work

[www.Direct.gov.uk/Disabled People/Employment](http://www.Direct.gov.uk/Disabled%20People/Employment)

Department for Work and Pensions

www.dwp.gov.uk

Equality and Human Rights Commission

Helpline numbers

- England 0845 604 6610
- Scotland 0845 604 5510
- Wales 0845 604 8810

www.equalityhumanrights.com

Employers Forum on Disability

www.employer-forum.co.uk

Trades Union Congress

www.tuc.org.uk

Remploy

www.remploy.co.uk



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