





Turner Syndrome & **Employment**

‘Supporting people with Turner Syndrome (TS) to thrive at work while enabling employers to benefit from their strong work ethic and commitment.’

A guide for those with TS, their employers and colleagues

TURNER SYNDROME
TSSS
SUPPORT SOCIETY [UK]

This booklet, published by the Turner Syndrome Support Society (UK), provides guidance for employees with Turner Syndrome (TS), as well as their employers and colleagues. Although not definitive, it draws on the shared experiences of people with TS and their employers. The guidance aims to support effective partnerships between employees with TS and their employers.

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Abbreviations: The abbreviations below are used throughout this leaflet and have the following meanings:

TS = Turner syndrome; TSSS = Turner Syndrome Support Society (UK).

Welcome

Many women with Turner Syndrome have successful and fulfilling careers across a wide range of professions. Like anyone else, they may have individual strengths, challenges and support needs.

Their resilience, attention to detail, and empathy make them valuable team members, and their ability to adapt can be an asset in any role.

This booklet has been created to help women with Turner Syndrome feel confident about their rights at work, understand the support available to them and recognise when an adjustment could make a positive difference.

It is also designed to help employers, managers and colleagues understand Turner Syndrome without making assumptions about what an individual can or cannot do.

Employers who are aware of the challenges women with TS may face and who take proactive steps to accommodate their needs can create an inclusive and supportive workplace that benefits all employees. The Equality Act 2010 ensures that women with TS have the right to fair treatment, and reasonable adjustments should be made to support them in their professional roles.

Some women with Turner Syndrome may experience hearing difficulties, fatigue, physical accessibility issues, differences in attention or working memory, or challenges with social communication. Others may experience few or none of these difficulties in their working lives.

With appropriate support, accessible working practices and an inclusive workplace, women with Turner Syndrome can develop their skills, progress in their careers and make a valuable contribution to their organisations.

"Kerry does not allow her Turner's Syndrome to hold her back. She is a very loyal, hardworking and proud member of our team and the service we provide. She is usually the first to volunteer for most tasks that arise."

Kerry's Line Manager

Women with Turner Syndrome can, in turn, take charge of their health, communicate openly, and leverage their skills to thrive in their careers. Together, these efforts create a workplace that is not only more inclusive but also more innovative and productive.

For further advice, guidance, or resources, please refer to the **Turner Syndrome Support Society UK** or contact them directly.

What is Turner Syndrome? (TS)

Turner Syndrome (TS) is a genetic condition that affects females, occurring when one of the X chromosomes is missing or incomplete. While the syndrome affects each individual differently, it can lead to a variety of physical and medical challenges, as well as potential developmental and psychological impacts.

The condition affects approximately 1 in 2,000 live female births. In the UK, there are thought to be some 15,000 girls and women who have TS, and the estimated global figure is 1.5 million; however, TS often goes undiagnosed.

Turner Syndrome does not determine a person's intelligence, personality, career potential or ability to succeed.

Common signs and symptoms of Turner Syndrome

Medical and Physical Challenges

Women with Turner Syndrome may face a range of medical issues, including:

Short Stature: Many women with TS are shorter than average. Depending on the workplace and role, this may mean that equipment, shelving, desks or other physical features need to be adapted.

Hearing Impairment: Hearing difficulties are common in Turner Syndrome and can vary from mild to significant. Hearing loss may affect conversations, meetings, telephone calls or communication in noisy environments, this may require adaptations.

Heart and Kidney Problems: Congenital heart defects and kidney issues are more common in women with TS. They may need regular medical monitoring. They carry a cardiac alert card with instructions regarding sudden onset of chest pain. It is rare but important to be aware of the risk.

High Blood Pressure (Hypertension): Elevated blood pressure is common in TS and may require regular medical monitoring or treatment.

Thyroid Problems: Thyroid conditions, particularly hypothyroidism, are more common in TS. If symptoms such as fatigue or difficulty concentrating affect work, an individual may benefit from appropriate workplace support.

Bone Health Issues: Some women with TS have reduced bone density and may need to consider this when carrying out physically demanding work or working in environments where falls are a risk.

Hormonal Imbalances: TS can affect ovarian function, leading to low levels of estrogen. Most women with TS will need hormone replacement therapy (HRT), like any menopausal woman. Treatment needs vary from person to person and are managed with their healthcare team.

It is important to remember that not all women with Turner Syndrome are impacted in the same way.

"My bosses in the past have provided me with hearing aid compatible headphones to make things easier"
Hayley

Learning and cognitive considerations

TS does **not** affect intellectual capacity. Overall intellectual ability is generally within the average range, although some women with TS have specific differences in particular areas of thinking or learning.

Spatial Awareness: Some women may find certain tasks involving spatial awareness, visual information, directions or judging position and distance more difficult.



Mathematics and Problem Solving: Some individuals with TS may experience specific difficulties with maths, abstract reasoning, and complex problem-solving tasks. This does not mean that they cannot work in roles involving numbers.

Attention and Memory: Some women with TS may have difficulties with attention span or working memory, which can affect their ability to multitask or retain large amounts of information. However, their long-term memory is exceptional. In time learned skills move to the long-term memory.

Emotional and Psychological Factors

Mental Health, confidence and wellbeing: Some women with TS experience anxiety, low self-esteem, social anxiety or periods of low mood. These experiences can be influenced by many factors including health, hearing, social experiences, self-image and the pressures of managing a lifelong condition.

Fatigue and stress can also affect concentration, confidence and emotional wellbeing. A supportive workplace can help this. Clear communication, reasonable adjustments and supportive management can all reduce unnecessary barriers.

Low energy levels/stamina: Women with TS don't always know how to pace themselves and may well go on until they drop. They are hardworking and diligent; they will often make a great effort and get through a particular task but may need time to recover. This needs to be understood and allowed for. Any symptoms that a woman has can be magnified when they are very tired.

Neurodiversity: Many women with TS may experience differences in areas such as spatial awareness, executive functioning, attention, or social cognition. These are unique to each individual.

Why should you employ a woman with Turner Syndrome and what can they bring to the workplace?

Despite the challenges they may face, women with TS work in a wide range of occupations and industries. They bring many unique strengths and qualities to the workplace:

Strong work ethic and determination

Many women with TS develop a high degree of resilience in overcoming challenges, often leading them to be highly committed, diligent, and motivated employees. They tend to approach tasks with thoroughness and dedication.

Attention to detail

Women with TS, particularly those who have specific cognitive challenges, often develop excellent attention to detail. They may excel in roles that require precision and careful work, such as data entry, quality control, or research.

Empathy and compassion

Experiencing the challenges of Turner Syndrome can foster empathy and a strong sense of compassion. Women with TS are often sensitive to others' needs, making them valuable team players and leaders in roles that require emotional intelligence, such as caring professions or customer service.

"Anna brings warmth, kindness, and positivity to the workplace, and she is genuinely valued by everyone she works with. She is well-liked, respected, and trusted by colleagues at all levels. We are extremely fortunate to have Anna as part of our team, and she is a wonderful example of how, with the right environment, people can truly flourish at work."

Anna's Line Manager

Adaptability

Having to navigate the complexities of medical treatment, personal development, and social challenges, women with Turner Syndrome often demonstrate high levels of adaptability. This can make them particularly effective in environments that require flexibility and creative problem-solving.

Loyalty and longevity

Many women with Turner Syndrome highly value stability and are grateful for supportive employers. As a result, they tend to prefer to remain loyal to an employer over the long term, contributing to low turnover rates and high retention.

Supporting women with TS in the workplace

Reasonable Adjustments

Providing reasonable adjustments in the workplace can help ensure women with TS thrive professionally. Some examples are:

Flexible Working Hours: Due to medical appointments or fatigue, flexible working hours or remote work options can help maintain work-life balance.

Ergonomic Workspaces: Women with TS who are shorter may benefit from desk adjustments, special seating, or tools designed for easier access.

Assistive Technology: Tools that aid with organisation, time management, and communication can be helpful for women with TS who experience difficulties with hearing, attention or memory.



There is no standard list of adjustments for Turner Syndrome. The most effective approach is to talk to the individual about what they find difficult at work and what would help remove or reduce the disadvantage.

Health and Wellbeing Support



Fatigue and energy levels can vary. Some women may push themselves through fatigue because they are committed to completing their work, and may then need additional recovery time. Employers can support the health of employees with Turner Syndrome by:

Encouraging regular medical check-ups, particularly for heart, kidney, and hearing issues.

Creating a supportive environment for mental health, including providing access to counselling or stress-management resources.

Ensuring workplace safety and awareness of potential medical emergencies related to Turner Syndrome.

Open Communication

Open, honest communication between the employer and employee is key. This, of course, applies to any employee-employer relationship. Employers should:

Encourage a supportive, non-judgmental environment where employees feel comfortable discussing their needs.

Promote mental health and wellness by providing resources, such as employee assistance programs or access to therapy.

Training and Awareness for Managers and Colleagues

Educating managers and colleagues about Turner Syndrome can create a more inclusive and understanding workplace. This may include:

Awareness Training: Provide training on the specific challenges women with Turner Syndrome may face, including how to communicate effectively and supportively.

Team Support: Encourage team members to be patient and understanding when working with colleagues who may need adjustment for difficulties.

"It is just me working alongside my boss, who is very supportive, understanding, and kind. I feel it is has grown my confidence, being supported to learn skills without the physical demand and the right adjustments made for me by my own support company and honestly, they have changed my life."

Eleni

How might Turner Syndrome affect someone at work?

Most women with TS can work and, with the right support, contribute effectively in many different roles. Colleagues may work alongside a woman with TS for months or years without ever realising they have TS.

This leaflet aims to outline some aspects of TS that you should be aware of. Although the potential impacts of TS listed below range widely, many women exhibit only some of them. For the vast majority, this does not impact their ability to be an effective and valued member of your organisation.

Hearing

Many women with TS have hearing difficulties. It is important to ensure that colleagues know so that they can speak clearly and repeat things where necessary. Reasonable adjustments that may need to be provided might include 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



Lack of stamina

Women with TS don't always know how to pace themselves and may well go on until they drop. They are hard-working and diligent, they will often make a great effort and get through a particular task but may need time to recover. This needs to be understood and allowed for. Any symptoms that a woman has will be magnified when they are very tired.

Visual-spatial and motor skills

Some women with TS experience differences in visual-spatial or motor skills. This can sometimes make activities involving judging distances, navigating unfamiliar spaces, reaching, coordination or handling objects more difficult. This may even just be put down to clumsiness. Where relevant, practical adjustments, clear instructions and a well organised workspace can help.

Anxiety

Some women with TS may experience increased anxiety, worry or sensitivity to criticism. This can be particularly noticeable when someone is tired, stressed or uncertain about expectations. They may overthink, dwell on things or take the blame when it is not their fault.

Clear communication, constructive feedback and a supportive working environment can help with this.

"Like many people, Anna can feel overwhelmed at times, but she has shown remarkable self-awareness and growth. She has learned to communicate openly when she needs support or adjustments, which has made a significant difference and speaks volumes about her professionalism and resilience."

Anna's Line Manager

Clear Communication

Many women with TS tend to take things very literally when told what to do. Although excellent at following instructions, instructions need to be clear and concise. Sometimes they give the impression that they have understood when they are still unclear, or struggle with concepts that are straight forward 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 meant. This can result in humour being misinterpreted, affecting relationships, self-esteem, confidence and how she is judged by her colleagues.

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 knowing this will enable you to adjust your approach when faced with distress at a change.

Occasionally, women with TS may need support 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:
Be explicit at all times e.g. when you need something done, ask a direct question rather than expecting her to do it. Ask questions to check, don't assume without being told.

"If employers understand and can make necessary adjustments to help, such as:

- *making things easier for me to reach*
- *explaining any unwritten rules that I may not have picked up on*
- *understanding that I can take things very literally when I shouldn't."*

Vicki

Medical appointments

Some women with TS have regular medical appointments or treatment related to their condition. The time needed will vary from woman to woman - it can be as little as one hour a year to a few times a year. **The time needed also depends on how much travel is required.** Most women are conscientious and will only take time off work where it is genuinely needed.



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.

Understanding social cues

Some women with TS may find it harder to interpret facial expressions, body language or subtle social cues. This can sometimes lead to misunderstandings, particularly in unfamiliar situations or where expectations are not stated clearly. Clear, respectful communication can reduce misunderstandings.

Confidence and self-advocacy

Asking for support can feel difficult, particularly if someone has had previous negative experiences. 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, particularly if hearing and social communication difficulties are present.

This can extend to social gatherings outside work, where women with TS may find it hard to play a full part in the conversation and feel awkward. Inclusive practices can help everyone participate.

Bullying in the workplace

Everyone has a right to be treated with dignity and respect at work. Women with TS are more at risk of becoming the victim of workplace bullying than other colleagues in the workplace. 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.

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 will display all these types of behaviour, and certainly not all the time!

"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

Women with Turner Syndrome possess unique skills, determination, and strengths that can significantly benefit any workplace. By understanding the challenges, they face and providing appropriate support and adjustments, employers can help ensure these individuals thrive, fostering a diverse and inclusive work environment.

Employing women with Turner Syndrome is not only about meeting their needs but also recognising the valuable contributions they bring to the team. A supportive workplace environment fosters talent, loyalty, and a collaborative culture that benefits everyone.

Although each woman is different, there are general personality traits that are quite common, these include:

- 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.
- A fresh and innovative approach to problem-solving, and a fresh perspective on any given situation.
- Honesty, sincerity and loyalty – many stay with the same organisation for many years.
- A good sense of humour
- An ability to inspire tremendous affection among colleagues

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

For more information, support, or advice on Turner Syndrome, please visit the **Turner Syndrome Support Society UK** website or contact them directly.

Top Tips for Employers: Supporting Women with Turner Syndrome

Encourage open communication - Create a workplace culture where women with Turner Syndrome feel comfortable discussing their needs and challenges. Encourage regular check-ins and be proactive in seeking feedback on how they are managing tasks and any adjustments that might be helpful.

Make reasonable adjustments - Provide reasonable adjustments, as required by the Equality Act 2010. This might include adjusting workstations, offering flexible working hours, or providing assistive technology to support memory, concentration, or communication needs.

Be understanding about medical appointments and health needs - Women with TS may need time off for medical appointments or treatments. Create a flexible attendance policy that accommodates medical needs and doesn't penalise employees for health-related absences. Remember, regular check-ups or treatment schedules are an important part of managing TS.

Provide mental health support - Mental health is crucial, and women with TS may be more vulnerable to anxiety or depression. Ensure there are resources available, such as Employee Assistance Programmes (EAP), counselling services, or access to mental health support. Foster a workplace culture that prioritises mental well-being.

Be patient and provide clear instructions - Women with Turner Syndrome may struggle with attention, memory, or spatial awareness. Be patient and provide clear, step-by-step instructions when assigning tasks. Use visual aids or written instructions to complement verbal communication.

Promote inclusivity and awareness - Raise awareness about Turner Syndrome and the potential challenges it brings through training programs or workplace seminars. Educate colleagues and managers to be sensitive to the needs of women with TS and to create an inclusive, supportive environment.

Focus on strengths and talents - While understanding challenges is important, focus on the unique skills and strengths that women with TS bring to the workplace. Many employees with TS demonstrate incredible attention to detail, perseverance, and empathy — qualities that can enhance team dynamics and contribute to a positive workplace culture.

Be flexible with remote working arrangements - If remote working is an option, provide the flexibility for women with TS to work from home, where they may feel more comfortable and can tailor their workspace to their needs. Ensure remote employees have access to all the tools and resources they need to thrive.

A word from an Employer:

I have worked with Hayley for 9 months now and prior to meeting Hayley, I had never met anyone living with Turner's Syndrome.

So, in 9 months, I have been able to learn about Turner's Syndrome through Hayley, as she is very passionate and knowledgeable about this diagnosis, but I have also been able to experience the benefits of working alongside a woman with Turner's Syndrome. For example, Hayley is very determined, and she is committed to ensuring that all tasks are completed quickly and effectively.

However, when I first met Hayley, she informed me that due to her diagnosis of Turner's Syndrome, she was aware that her memory was not as sharp as she would like it to be. Yet rather than letting this affect her work, Hayley's determination and dedication to her role has allowed her to put systems and processes in place to ensure that she does not forget tasks, deadlines and alike – Hayley is now so organised and efficient that she is often the one who is reminding me to complete various task and ever-changing deadlines!

Hayley also has a strong sense of fairness – Hayley advocates for what is right, and she is very loyal to her colleagues. Hayley is very reliable and trustworthy, which is very important in the role that she is in and in the sector that we work in. Hayley also has the ability to work independently, as she is the only person in her role, whilst also being able to work as part of a team as her role often requires her to liaise with other departments within the home.

Overall, I would say that Hayley's diagnosis of Turner's Syndrome actually elevates her professional capabilities and as she has consciously put processes in place to aid her in the areas that may be challenging for her, Hayley is now a very competent and hard-working individual, who we are all very lucky to work with every day.

"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



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

In England, Scotland and Wale, the Equality Act 2010 protects individuals from unfair treatment based on disability among other characteristics.

Whether Turner Syndrome meets the legal definition of disability depends on how it affects the individual. Under the Equality Act, a person is generally considered disabled if they have a physical or mental impairment that has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

You do not have to describe yourself as "disabled" to talk to your employer about support.

If you live or work in Northern Ireland:

The Equality Act 2010 does not apply in Northern Ireland. Different disability discrimination legislation applies, including the Disability Discrimination Act 1995 and related legislation.

For advice specific to Northern Ireland, contact the Equality Commission for Northern Ireland. https://equalityni.org/equality-laws-ni

Key rights under the Equality Act 2010

Protection Against Discrimination: Employees with TS have the right not to be discriminated against because of their condition. This includes protection against discrimination in recruitment, pay, promotion, training, and day-to-day workplace interactions.

Types of discrimination

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

Direct discrimination – Treating someone less favourably because of their disability.

Indirect discrimination – Applying a rule, policy or practice to everyone which as a result puts disabled people at a particular disadvantage, unless the employer can objectively justify it.

Discrimination arising from disability – Treating someone unfavourably because of something that results from, or is connected with, their disability, unless the treatment can be justified in law.

Failure to make reasonable adjustments – Employers have a legal duty to make reasonable adjustments where required. Failing to do so can amount to disability discrimination.

Harassment – Unwanted behaviour related to disability that violates someone's dignity or creates an intimidating, hostile, degrading, humiliating or offensive environment.

Victimisation – Treating someone badly because they have complained about discrimination or supported someone else's discrimination complaint.

Discrimination by perception – Treating someone poorly because you incorrectly believe they have a protected characteristic.

Discrimination by association – Treating someone poorly because they are connected to someone who has a protected characteristic.

Examples:

Direct discrimination

Sarah has Turner Syndrome and applies for a promotion. Her manager knows about her condition and says, ***"I don't think this role would be suitable for you because of your health."*** A colleague with similar skills and experience, who does not have a disability, is given the promotion instead.

If Sarah was treated less favourably because she has Turner Syndrome, this could amount to direct disability discrimination.

Indirect discrimination

An employer introduces a new working pattern requiring everyone to work three 12-hour shifts each week instead of five shorter shifts.

The same rule applies to everyone. However, some employees with Turner Syndrome may experience significant fatigue after very long shifts and may be particularly disadvantaged by this working pattern.

If the employer cannot objectively justify the working pattern, this could be indirect discrimination.

Discrimination arising from disability

Emma has Turner Syndrome and experiences fatigue related to her condition. Her employer knows about her condition and has previously discussed her fatigue with her.

Emma is occasionally late to work because she has experienced severe fatigue in the morning. Rather than discussing whether a reasonable adjustment to her start time could help, her employer gives her a formal warning specifically because of these disability-related episodes.

Failure to make reasonable adjustments

Lucy has hearing loss associated with Turner syndrome. She tells her employer that she finds it difficult to follow large meetings when several people speak at once and asks for captions and written follow-up notes.

Her employer refuses to consider any changes and says, ***"Everyone has to attend meetings in the same way."***

Depending on the circumstances, failing to make a reasonable adjustment could amount to disability discrimination.

Reasonable Adjustments: Employers are required to make reasonable adjustments to support employees with disabilities. Depending on the individuals circumstances these adjustments might include:



- Flexible working hours
- Changes to working patterns
- Adapted equipment or furniture
- Accessible communication
- Additional breaks
- Written instructions
- Changes to the physical workplace
- Working from home or hybrid working where appropriate
- Time off for medical treatment or appointments where appropriate
- A phased return after illness
- Additional support or training

Protection Against Harassment: Women with TS are protected from harassment related to their condition. Harassment can include unwanted behaviour that creates a hostile or intimidating work environment.

Access to Employment: Employers must ensure that recruitment and selection processes do not disadvantage applicants with disabilities. Reasonable adjustments during interviews, such as providing materials in accessible formats or offering extra time, may be necessary.

By understanding and implementing these rights, employers can create a more inclusive and supportive environment for women with Turner Syndrome, ensuring they can contribute to their fullest potential.

Should I disclose my TS to my employer?

Deciding whether to disclose Turner Syndrome at work is a personal choice.

Some women find that telling their employer makes it easier to request adjustments and helps colleagues understand their needs. Others may prefer to keep their diagnosis private unless a specific need arises.

There is no single right answer. The decision may depend on your health, your workplace, the support you need, your relationship with your employer and how comfortable you feel sharing personal information.

"Employment can often be tricky for women with TS as people don't have a lot of knowledge about it and women with TS can feel nervous about disclosing it. I have always found that disclosing does make it easier for employers to understand and to make necessary adjustments to help." Vicki

Advantages of disclosing Turner Syndrome

Sharing information about your condition may make it easier to explain why an adjustment is needed and to discuss what support would help.

Access to reasonable adjustments

Sharing information about your condition may make it easier to explain why an adjustment is needed and to discuss what support would help.

Protection under equality legislation

You do not have to disclose your diagnosis in order to have rights under disability discrimination law. However, telling your employer about a disability can be important when you need reasonable adjustments, because employers need sufficient knowledge of a disability and the disadvantage it causes to understand what support may be required.

Improved understanding and communication

Being open helps colleagues and managers understand:

- Why medical leave or regular check ups are necessary
- Why certain tasks may be more challenging (e.g., heavy multitasking, noisy environments)
- Any emotional or mental health impacts that may arise

This can create a more supportive and trusting working environment.

Reduced stress from hiding symptoms

Choosing not to disclose can create pressure to “mask” or hide difficulties.

Disclosure can:

- Reduce anxiety
- Increase authenticity
- Make seeking help easier

Access to Reasonable Adjustments

Many women find this improves confidence and engagement at work.

"My 2nd interview for one admin job I previously had required candidates to do a 5-minute powerpoint presentation on any subject of their choice. I decided to do mine on TS.

My decision was questioned by the people around me. However, I decided that it was a risk worth taking and to bite the bullet. If my employers didn't know about my condition, they couldn't make allowances for me and give me the understanding I need.

I do have hospital appointments that I need to attend and I need for my bosses and work colleagues to understand that. If this wasn't appreciated and understood, then this wasn't a company I wanted to work for.

I ended up working for this company for six and a half years, so it proved to be the right decision in the end.

Whilst this worked for me, I appreciate that it is a risk and may not work for everyone." Hayley

Disadvantages of disclosing Turner Syndrome

Fear of stigma or misunderstanding

Even with equality laws, there is a worry that:

- Employers may not understand the condition
- Managers might wrongly assume someone is less capable
- Physical differences could be over noticed or talked about

This emotional risk can feel significant.

Concern about career impact

Some women fear disclosure could:

- Affect future promotions
- Influence how colleagues perceive their abilities
- Lead to subtle bias in task assignment

Even if this bias is unconscious, it can feel like a potential threat.

Loss of Privacy

Turner Syndrome involves personal medical, hormonal, and fertility-related information.

Once personal health information has been shared, you may understandably want reassurance about who will have access to it and how it will be used.

You can ask your employer:

"Who will need to know this information, and how will it be kept confidential?"

Uncertainty about employer response

Not all managers are trained or experienced in supporting long-term health conditions.

A woman with TS may worry that:

- The employer won't know what adjustments are appropriate
- They might over-accommodate or under-accommodate
- Her condition will become a focal point, even when not needed

Disclosing Turner Syndrome can create opportunities for support, protection, and understanding – but it also involves risks around privacy, stigma, and how others may perceive or treat her. Every woman with TS must weigh her comfort, workplace culture, and personal needs before deciding.



You do not have to wait until you are struggling before asking for support.

Reasonable adjustments are about removing or reducing barriers, not proving that you cannot cope.

If you know that a particular change would help you work effectively, it is reasonable to discuss it with your employer.

"I have always disclosed my TS, not at interview, I confess, but very soon afterwards. My bosses have always responded positively. 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

"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

Example script for disclosing Turner Syndrome at work

If you choose to disclose your TS at work, here is an example of a confident, clear, and psychologically safe script.

Opening the conversation

"Thanks for meeting with me. I'd like to share some information about a medical condition I have because it has some relevance to my wellbeing and the reasonable adjustments that might support me in my role."

Introducing the condition

"I have a genetic condition called Turner Syndrome. It affects only women and can influence heart health, blood pressure, hearing, and hormone levels. It's a lifelong condition, and I manage it well."

Reassurance & capability

"I want to be clear that Turner Syndrome does not affect my commitment, my ability to do my job, or my performance. I'm sharing this so I can work in the most effective and healthy way possible."

Explaining only what's relevant (not personal details)

"The main things that may affect me at work are:

- *occasional medical appointments or monitoring*
- *hearing challenges in noisy spaces or meetings*
- *sometimes needing clearer written instructions or extra time for tasks that rely heavily on spatial or numerical processing*
- *fatigue at times, which can affect my concentration or stamina."*

Requesting reasonable adjustments (without sounding demanding, in a clear and confident way)

Most of the time, I work completely independently. What helps me most is:

- *quiet or accessible meeting environments*
- *the option for flexible scheduling around medical appointments*
- *clear written follow-up notes for complex discussions*
- *being positioned where I can hear well in meetings*
- *understanding if I need short health-related breaks occasionally"*

Reinforcing boundaries & confidentiality

"I'd like to keep this information private and for it to be shared only with people who genuinely need to know. I'd also appreciate if we could keep our focus on the practical adjustments rather than personal medical details."

Checking understanding and next steps

"Do you have any questions about the adjustments I've mentioned? And can we confirm the best way to put these in place?"

Closing confidently

"Thank you for taking the time to understand this. I really value being able to have this conversation openly and professionally."

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

What is disability confident?

Disability Confident is a UK government scheme designed to encourage employers to improve how they recruit, retain and develop disabled people.

The scheme is designed to support employers in hiring and retaining disabled individuals. It provides free guidance and resources to help organisations of all sizes think about how the can employ disabled people effectively. The scheme encourages fair hiring practices, such as offering interviews to disabled applicants who meet the minimum selection criteria. Additionally, it aims to ensure that disabled people are treated fairly and have access to the same opportunities as everyone else.

Seeing the Disability Confident logo can be a positive sign that an employer is thinking about disability inclusion. However, it does not guarantee that an employer will be the right fit for you or that every adjustment will automatically be available.



The scheme also does not mean that every disabled applicant is guaranteed an interview, however, be open as with the protection you receive from the Equality Act you may be surprised by the responses you get!

Challenges and benefits of working remotely for women with Turner Syndrome

The best arrangement depends on the individual, their role and their working environment.

Challenges of Remote Work

Social Isolation: Women with TS may already experience social anxiety or difficulties with face-to-face interactions. Remote work can exacerbate feelings of isolation, making it harder for employees to form connections with colleagues or access support.

Communication Barriers: Women with TS who have hearing impairments or difficulties in social communication may find it harder to engage in virtual meetings or collaborate via email, video conferencing, and other digital platforms. This may lead to misunderstandings or exclusion from team discussions.

Overworking or Burnout: The flexibility of remote work can sometimes lead to longer working hours or difficulty separating work from personal life. This is especially important for employees who may experience fatigue or other medical symptoms related to Turner Syndrome.

Lack of Accessibility: Working remotely requires appropriate technology, which can be a barrier if the necessary tools are not readily available or if the employee faces challenges setting up their home workspace (e.g., ergonomics for short stature or difficulties accessing tools and documents).



Benefits of Remote Work

Flexible Working Hours: Some people find that remote work provides flexibility, allowing women with TS to attend medical appointments or manage health-related issues without the pressure of rigid office hours. It can also accommodate symptoms like fatigue or hormonal fluctuations that may vary throughout the day.

Customised Work Environment: Working from home allows employees to set up their workspace to suit their specific needs, such as ergonomic adjustments or accessibility tools, which may not always be possible in an office setting.

Reduced Social Anxiety: Women with TS who experience social anxiety or communication difficulties may feel more comfortable in a remote work environment. The ability to communicate via email or instant messaging rather than face-to-face can reduce stress and allow for clearer communication.

Improved Work-Life Balance: Remote work can improve overall work-life balance by eliminating commuting and offering a more relaxed, self-paced working environment. This can help reduce stress and improve mental health among employees with TS.

Increased Productivity: Many individuals with Turner Syndrome, particularly those who benefit from a quieter or less distracting environment, may find that remote work allows them to focus better and perform at a higher level in tasks that require concentration.

"Whilst I enjoy the flexibility that remote working gives me, and the cost savings as I don't have to commute, working from home sometimes can be difficult as I find it difficult to switch off. This can mean that I get exhausted very quickly. Although I do like being able to communicate more by email than face to face as I have time to think about my responses."

Anna

Top tips for women with Turner Syndrome (TS): thriving in the workplace

Communicate your needs

Don't be afraid to talk openly with your employer about your specific needs. This may include asking for flexible working hours, reasonable adjustments, or extra time for certain tasks. Clear communication helps employers understand how to best support you.

Take advantage of reasonable adjustments

Under the Equality Act 2010, you are entitled to reasonable adjustments in the workplace. These might include adjustments to your work environment (e.g., ergonomic desk setup), work schedule (e.g., flexible hours), or tasks (e.g., written instructions). Don't hesitate to request these adjustments if they will help you perform better.

Prioritise your health

Make sure to manage your health needs by scheduling medical appointments, monitoring your treatment, and taking breaks when necessary. Speak to your employer about how best to manage your health-related time off without fear of repercussions. Remember, your health should always come first.

Develop a support system at work

Building strong relationships with colleagues can create a support network that can help you navigate any challenges at work. If you feel comfortable, consider speaking to a trusted colleague or HR about your condition, so they can offer support when needed.

Practice self-care and manage stress

Dealing with the emotional and psychological aspects of Turner Syndrome can be challenging. Make time for self-care and seek support if you feel overwhelmed. Practicing relaxation techniques, engaging in hobbies, and seeking professional mental health support when needed can help you manage stress.

Leverage your strengths

Focus on your unique strengths. Women with Turner Syndrome often excel in areas like attention to detail, resilience, and empathy. Embrace these qualities and use them to your advantage at work. Think about how these traits contribute to your role and how they can help you stand out as a valuable team member.

Don't be afraid to ask for feedback

Seek regular feedback from your manager or colleagues to understand how you're doing in your role. This will help you stay on track, and it will also demonstrate that you're committed to improving and succeeding at your job.

If you are unsure about expectations, ask. If something isn't working, raise it. If an adjustment would help, request it.

Consider whether remote or hybrid working could help

If you find that a remote work environment better suits your needs, consider discussing this option with your employer. Remote work can offer the flexibility to manage your health and mental wellbeing while still being productive and contributing to the team.

Stay organised

Using tools like calendars, reminders, and task management apps can help you stay organised and on top of your workload. If you struggle with attention or memory, these tools can help you break down tasks into manageable steps and stay focused

Build Confidence and ask for support when needed

It's important to advocate for yourself, but it's equally important to ask for help when needed. You don't have to face challenges alone. Whether it's asking for a mentor, joining a support group, or simply discussing strategies with your employer, don't be afraid to reach out.

Women with TS work in every kind of career

Some of our members with TS work as:

- Teachers
- Nurses
- Veterinary nurses
- Nursery Nurses
- Doctors
- Accountants
- Solicitors
- Administrators

You know yourself best

Turner Syndrome is one part of who you are, it does not define your ambitions, your abilities, or your future.

You deserve to be in a workplace where you are respected, supported, and given the opportunity to do your best.

With the right understanding, support and adjustments you will be able to thrive in any career.

If you need further information, advice or support about Turner Syndrome and employment, please contact the Turner Syndrome Support Societ



Useful contacts and further information

ACAS

Helpline 08457 474747

www.acas.org

Citizens Advice Bureau

www.adviceguide.org.uk

Access to work

www.Direct.gov.uk/Disabled People/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

Equality Commission for Northern Ireland

https://equalityni.org

Employers Forum on Disability

www.employer-forum.co.uk

Trades Union Congress

If you are a member of a trade union, your union may be able to advise and support you with reasonable adjustments, discrimination, workplace policies and employment disputes.

www.tuc.org.uk

Remploy

www.remploy.co.uk

RNID – National Hearing Loss Charity

https://rnid.org.uk

TURNER SYNDROME
TSSS
SUPPORT SOCIETY [UK]

Turner Syndrome Support Society (TSSS)

12 Simpson Court
11 South Ave
Clydebank Business Park
Clydebank G81 2NR

Tel: **0141 952 8006**
Email: **turner.syndrome@tss.org.uk**
Website: **www.tss.org.uk**

Charity registration no ENG 1080507 SCO 37932