

Turner Syndrome & Education



a guide for parents, carers and teachers



Turner Syndrome Support Society [UK]



TSSS This booklet is published by the Turner Syndrome Support Society (UK), as a guide for parents, carers and school staff working with and caring for girls with Turner Syndrome (TS). It is not definitive but is written as a result of many shared experiences from those with TS, their parents, carers and teachers or other school based staff. The guidance provided is intended to support the partnership between parents and carers of girls with TS, the girl herself and the staff at the school they attend.

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How to support girls with TS to thrive and succeed at school



a guide for parents, carers and teachers



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Introduction

The information provided in this booklet is designed to provide a framework to support parents or carers and school based staff to work in effective partnership towards the shared aim of ensuring that all girls with TS are enabled to: consistently enjoy their time at school, engage with all the opportunities offered to them and consequently reach their full academic and personal development potential.

It should be noted that each girl with TS is an individual with her own needs but being well informed about TS and how it may affect girls with the condition is an essential starting point for all concerned. The best source of information with regards to how TS affects each individual girl is often the parents or carers and the girl herself so the relationship between home and school will be the key to planning successful provision and maintaining an overview of her unique needs. If these needs are identified at the earliest opportunity and every effort is made to meet them it will make a tremendous difference to their confidence and achievement.

In short, the overarching message is that girls with TS should never be underestimated or defined by their condition. They all have special qualities, skills and talents that should be nurtured, developed and encouraged and, like all children, they will then flourish. They just need, and are entitled to, the support, care and guidance to do so.

The TSSS would like to thank all those who helped in compiling and writing this booklet. Parents, who willingly shared their experiences of guiding their daughters who have TS through their school years, teachers who have generously given the benefit of their knowledge of teaching girls with TS, and women with TS who have shared their sometimes painful experiences at school, in order that the younger girls with TS would not suffer as they did. Special thanks to Arlene Smyth and Amy Holmes, for their determination to see this information in print and circulated to teachers.

What is Turner Syndrome?

A Brief Explanation

Turner syndrome is a genetic disorder that affects about 1 in every 2,000 female births. A girl with Turner syndrome has 1 of the usual 2 X chromosomes either missing or incomplete. Consequently, girls with Turner syndrome often have a wide range of symptoms and some distinctive characteristics. However, almost all girls with TS are shorter than average and have non- functioning ovaries.

Although diagnosis can be made during pregnancy or at birth, as height and sexual development are the two main characteristics, Turner syndrome may not be diagnosed until early childhood when growth declines or when a girl fails to show sexual development associated with puberty, usually between the ages of 8 and 14 years.

Girls with Turner syndrome are entitled to receive high-dose growth hormone therapy as soon as it becomes apparent that growth has declined. Growth hormone therapy is administered through a daily injection, usually in the evening, started at around five years of age or later if undiagnosed. Additional growth stimulating treatment may be prescribed alongside the injections and is usually in tablet form. Pubertal induction is achieved through hormone treatment in the form of tablets or patches. The age at which this is started varies but could be from age 10 onwards and will continue throughout adulthood. If attending a residential trip, arrangements will need to be made and agreed with parents and carers with regards to the storage and administration of the injections, tablets or patches.

Physical characteristics associated with Turner syndrome can vary significantly between individuals but can include: a short, wide neck, a webbed neck, a broad chest and widely spaced nipples, arms that turn out slightly at the elbows, a low hairline, mouth abnormalities, which can cause problems with the teeth and speech development, a large number of moles, small, spoon-shaped nails, a short fourth finger or toe, eyes that slant downwards, droopy eyelids, a squint, short sightedness, low-set ears, recurring middle ear infections, glue ear and hearing loss.

Due to the potential complexities of the condition girls with Turner syndrome will need to have regular health checks of their heart, kidneys and reproductive system, amongst other related checks, throughout their lives. Many also suffer with the symptoms of menopause due to premature ovarian failure e.g. hot flushes and fatigue.

Most girls with Turner syndrome have good language and reading skills. However, some have behaviour, social and specific learning difficulties. Some girls with Turner syndrome may have problems understanding social relationships because of the way their brain develops. Spatial awareness is the ability to understand where you are in relation to objects or other people. More than 8 out of 10 girls with Turner syndrome have difficulty understanding spatial relationships.

Some girls with Turner syndrome can experience a phase in childhood that involves: hyperactivity, such as constant fidgeting and restlessness, acting impulsively, having no sense of danger, having a short attention span and being easily distracted. Others show no signs of any of these issues.

As with all medical conditions there is a wealth of information and research associated with Turner Syndrome. The information provided above is a summary of the main characteristics and symptoms. Again, it is important to reiterate that all girls with TS are individual and as such the condition will affect them differently. This is why it is essential to gather as much information about the girl with TS and how her condition affects her personally as early as possible from when she starts or before she starts school. It is worth noting that some biology teaching about TS is sometimes out of date and it is essential to use recommended websites for research purposes.

Please access the following website for further information: www.tss.org.uk

Teachers and other school staff reading this information may subsequently suspect that a child known to them has Turner syndrome and is as yet undiagnosed. Research shows that this would not be uncommon as many girls go undiagnosed for years or are not diagnosed at all. However due to the confidentiality, sensitivities and complexities surrounding the diagnosis for the parent, carer and child it is important to refer all possible concerns to a senior member of staff. They will then request a referral to be made to the school nursing team or another appropriate health professional so that they can deal with the medical investigations needed directly and appropriately, if deemed necessary. At this point when seeking the consent of the parent or carer for the referral short stature and stilted growth would be the reason for the involvement of health professionals. School based staff are not equipped to suggest otherwise but are well placed to identify girls with TS who have not been diagnosed.

Medical Conditions Statutory Guidance & Disclosure Advice

Disclosure of any medical condition to a school can be potentially difficult and daunting for parents and carers. However, all involved should be aware that section 100 of the Children and Families Act 2014 places a duty on governing bodies of maintained schools, proprietors of academies and management committees of PRUs (Pupil Referral Units) to make arrangements for supporting pupils at their schools with medical conditions. This statutory legislation has raised the profile of medical conditions provision in schools. Therefore there should be medical conditions systems and procedures in place in all schools to support parents and carers in disclosing confidential information and then plan accordingly to support the child.

'The governing body should ensure that its arrangements give parents and pupils confidence in the school's ability to provide effective support for medical conditions in school. The arrangements should show an understanding of how medical conditions impact on a child's ability to learn, as well as increase confidence and promote self-care. They should ensure that staff are properly trained to provide the support that pupils need.'

'Supporting Pupils at School with Medical Conditions' Statutory Guidance, Department of Education December 2015

Schools often publish their Medical Conditions Policy on the school website and as such parents and carers can access this information and be reassured that the school will focus on the individual needs of their child and how their medical condition impacts or could impact on their school life. If the medical conditions policy is not published parents or carers could approach the school to request a paper copy.

To support the school in meeting the needs of the girl with TS from the outset, disclosure of TS should be part of the admission procedure when joining the school or as soon as possible in the case of a delayed diagnosis. At this point it is advisable to request a meeting with the person in charge of supporting children with medical conditions or the class teacher to **confidentially** inform them. Parents or carers may wish to provide some information about TS before or at the meeting so that the relevant school staff members can read about TS in preparation for admission, as it is unlikely that they will be aware of the condition. This will also make the process easier and more productive for both parties and ensure absolute confidentiality is in place from the outset.

At the first meeting it should be made clear to school staff whether or not the child is aware of her condition and if this has been disclosed to friends and family. This is a personal preference but one that needs to be shared directly as some families disclose to their child earlier than others and their choice in doing so must be respected by all concerned. There are also confidentiality implications if the family or child does not wish the disclosure to be wider than the professionals involved. Again, as the girl gets older the situation may change; either way this needs to be made clear at the annual medical conditions review. If the girl wishes to disclose to friends the school should be involved and support the family and child to do so appropriately and sensitively.

Ideally, once the school is aware that a girl in their care has TS, an informal meeting should be arranged so an Individual Health Care Plan (IHCP) or medical conditions form can be completed. A copy of this form can be downloaded from the TSSS website. The discussion at the meeting should be focused around how TS may or already does impact on the ability of the girl with TS to learn, socialise and develop in confidence. The main source of information to do so will be the parent or carer and, where appropriate, the girl herself. As mentioned previously this information will be individual to each girl with TS and it may be that there are no concerns to raise at that point but by informing the school staff have a duty to monitor the situation and also will know what to look out for e.g. possible socialisation issues or difficulty following instructions promptly etc.

The IHCP or medical conditions form should then be reviewed at least annually so that school staff are kept fully informed of any new information or complexities that may have come to light. In addition parent and carers are then also provided with an opportunity to discuss any medical, social or educational concerns.

The government guidance with regards to medical conditions also recommends that training should be made available for staff so they can provide effective support. Some hospitals will support this process if contacted directly (endocrine department).

For additional information the Department for Education guidance provides full details with regard to entitlements and 'best practice' in schools:
<https://www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions--3>

Sex Education

This is a potentially sensitive topic for girls with TS and their families and it is essential that school based staff are aware of the physiological aspects of infertility and the psychological affects this can have. Whether or not the individual girl has disclosed to her friends or not at all this subject would need to be discussed with the family and the individual girl prior to being taught so that all involved are prepared and can express their views. In terms of the delivery of the sex education session it is essential that generalisations are not made such as, 'All girls have periods etc.' Therefore the preparation for the meeting must be planned in detail so that comments such as this are avoided, just adding the word 'most' provides a much more sensitive approach. In addition, it is worth considering that after the sex education sessions have taken place the girl may want to ask further questions and, as a minimum, should be given an opportunity to do so privately with due regard for her emotional well-being.

Learning Support

In all schools if any child is having difficulties that are affecting their progress and ability to reach age related expectations, whether this is learning related or social, emotional or mental health difficulties, they should be in receipt of additional support or intervention to 'catch up'. If this support does not have the intended effect the school SENDCo (Special Educational Needs or Disabilities Co-ordinator) will contact the parent or carers to discuss further adjustments at SEND support level, which may involve increased support in or outside of the classroom to address the identified needs by school based or external specialist support staff.

However, if this additional provision is not effective over time and there are continued concerns it may be necessary to apply for a EHCP (Education Health Care Plan), which would provide a unique plan of additional support which would be reviewed annually with the child and parents or carer. The reasons for the EHCP may or may not be related to TS but the IHCP (Individual Health Care Plan) or Medical Conditions form should be incorporated into the EHCP should the application be successful. Further information regarding SEND support and EHCP applications can be found on the Department for Education website

<https://www.gov.uk/children-with-special-educational-needs>

It would be unusual for the school SENDCo not to be involved with a girl with TS in terms of tracking their progress and social, emotional and mental health as a minimum. Again, it is advisable for parents and carers to approach the school directly if this is not the case. All schools have a statutory duty to publish their SEND Information Report on their school website. This document will contain all their information with regards to the SEND provision in the school and who to contact.

Access arrangements for all tests and exams needs to be discussed with the school SENDCo at the earliest opportunity. If you have any difficulties with this contact the Turner Syndrome Support Society directly for support and advice. Please note that access arrangements for tests (SATs) and exams can include: additional time (25%), being tested in isolation, using a laptop, being provided with a reader, prompter or a scribe or having 'rest breaks', which means the child does not get additional time but that she can stop at different points and have a break. The suitability of each type of access arrangements mentioned may or may not be appropriate for each girl. Each is dependent on their individual ability or learning needs and will be assessed by the school. The list provided is not exhaustive, just be aware that the fact that the girl has TS means that they must at the very least be considered for access arrangements.

It should be noted that, from the point of view of the school, if the girl with TS has not disclosed to her peers there is a confidentiality issue involved with organising and providing access arrangements but there are many reasons for access arrangements so this just needs to be sensitively discussed with the family and the girl herself.

Kylie's View

'Having extra time whilst taking exams gave me confidence to read through the instructions and follow them correctly without panicking. I am sure it helped me pass my exams.'

It is difficult to list or summarise how TS could affect the learning of each girl, as this will be unique to each individual. However there are some aspects of the condition, which could cause difficulties that it is important to be aware of so action can be taken and support provided.

Processing Speed Difficulties

There has been much research into how some girls with TS have difficulties with processing speed and this has also been related to the issues some girls experience with socialisation and particularly not being able to keep with the speed of conversation or respond to questioning as quickly as their peers, which can make them appear 'slow' or like they have not heard. If they do have a hearing difficulty this is further compounded by the issue as this is the assumption made whereas the real reason is much more complex.

A Mother's View

'Lily was a late diagnosis; we discovered she had TS when the consultant at the hearing clinic noticed her short stature and referred her to a paediatrician for further tests. In terms of her education Lily did struggle a little during her primary years and although she reached the expectations for her age she found it hard at times and this was put down to her intermittent hearing loss from 'glue ear'. When she no longer had 'glue ear', but her hearing did not improve, she was diagnosed with permanent, moderate hearing loss. After a battery of tests, her hearing impairment was linked to TS and she was given a hearing aid in Y7. She has always hesitated before responding in conversation and although this worried me at times, as it affected her socially, I put it down to her hearing loss.

Lily left primary school with age related results but when she joined secondary school she became very driven. She worked fantastically hard achieving excellent progress due to her amazing work ethic and determination to succeed. It was hard to get her to 'switch off' and she spent hours after school working. Although I knew she was entitled to additional time in all her exams, including her primary SATs, I didn't request it as I was trying to make sure she achieved what she could and then had a realistic starting point to move on from. This was mainly as I knew she always tried her best and I wanted to relieve the pressure. Although this approach worked initially, in Y10 when she had her mocks she worked tirelessly and was anxious despite my assurances that it didn't matter what grades she got. Then in the Autumn of Y11 when revising for her mock exams she became increasingly anxious, developed alopecia and lost some hair. At this point I approached the school to apply for additional time on the grounds of anxiety and because she had TS, as I was aware that others had been granted the time without question or further tests due to the condition.

As Lily had such high achievement results and excellent predicted grades the school were surprised at my request but agreed, after some persuasion, to put in the application for access arrangements. I was advised that the guidelines had changed and she was, in their opinion, unlikely to be granted additional time because she was 'so clever'. There were also some tests she had to complete to ascertain whether or not she met the criteria for the application. I was poised to ring Arlene as I thought she would pass with flying colours and I would need to go down a different route to get what she needed. What came back floored me, my intelligent, hard working and incredibly resilient girl had cognitive processing scores that put her in the 'extremely low' percentile and she would definitely be granted the time on those grounds despite being predicted As and Bs.

The key message to sharing our story is that if you have any concerns or worries with regards to this issue, and think your daughter may have processing difficulties, please share them with the school and request a referral to an Educational Psychologist. There are lots of ways to support your child and reduce the anxiety caused by this difficulty and the sooner the better.

Processing speed is not just how fast we write, how rapidly we can come up with an answer to a question or how quickly we are able to get dressed for work or school. Processing speed can be a mix of factors. One of them is the ability to process verbal information, listen to information and then react to it in a timely fashion, without delay. Another is the ability to process visual information, e.g. scanning and skimming a text. A third factor is how quickly we are able to respond with quick motor speed i.e. the time needed to complete a task.

- Having slow processing speed **has nothing to do with how smart you are.** It is not unusual for gifted students to have slow processing speed, which is just how fast you can take in and use information, make sense of it and begin to respond i.e. thinking time.
- This information can be visual, such as letters and numbers. It can also be auditory, such as spoken language.
- Slow processing speed makes it very hard for you to keep up in class time and then can cause anxiety.
- It may take you a lot longer than others to perform tasks that are school-related particularly.

- Responding to many things at once can also pose a challenge e.g. if someone gives you multiple-step directions -“When you come downstairs bring your notebook, can you also bring down the dirty plates and put them in the dishwasher?” or being part of a fast paced discussion. Having slow processing speed makes it hard to digest information quickly enough to know what to do or sometimes how to respond.

Signs of Processing Speed Difficulties

- Struggling to finish tests in the allocated time, classwork in the lesson or finishing homework in a reasonable time frame
- Having to listen intently or take notes when a teacher is speaking- writing all information down on paper
- An inability to solve simple maths problems in your head quickly
- Completing multi-step maths problems in the recommended time
- Keeping up with conversations
- Becoming overwhelmed by too much information at once
- Needing more time to make decisions or give answers
- Needing to read information more than once for comprehension
- Often feeling anxious

The information provided with regards to processing speed difficulties is quite common to the issues faced by many girls with TS, therefore if this is the case there should be a referral made to an Educational Psychologist for a full assessment via the school SENDCo wherever deemed necessary.

Self Help Strategies

- Practising a specific skill can help improve your speed at that skill. Research shows that repeating a task makes it become more automatic and thus quicker to process. This applies to everything from learning multiplication tables or taking notes to help you remember. The more you do a task, the faster you get at it.
- Try to cut down the time it takes to do a homework assignment, make a list of what is required for the assignment and work through it step by step.
- Work on planning and organisation skills, e.g. by estimating how long a project will take and then tracking whether you are on track.
- Break assignments and homework into chunks, breaking down tasks can make them appear more manageable. Try not be overwhelmed by the amount of information presented on revision tasks or you might fear they will not get it done, which will aggravate anxiety levels.
- Ask for pre-printed notes you can 'pre read' but still take your own notes in class; research shows that writing down new information helps you to remember it.
- Consider using a keyboard rather than writing, for some people with slow processing speed using a computer to take class notes is faster and easier than handwriting.
- Practice handwriting - the more you write by hand, the faster and clearer note taking will be.
- If reading is assigned before a class make it a priority, this way you will already be familiar with what you are hearing in a lesson. It can help keep you from falling behind when trying to process new words and concepts.
- Review class notes every night, even a quick glance will help pick out spots where information is missing or notes are unclear. The chances are you will be able to fill in the gaps when the information is still fresh.
- Cover all questions but one at a time, focus attention on that one, do not worry about the others until you come to them.
- Use sticky notes or highlighters in active revision.

- Use mind mapping for note taking- reducing the amount of writing.
- Use technology for note taking and mind mapping etc.
- Try brain training apps, etc. to try to develop and improve speed of processing.
- Be aware of the emotional factors linked to slow processing. It can all feel too much and this is when you need to stop and ask for help.

Teacher Support Suggestions

- Ensure the girl is sitting near the front of the class.
- Check they understand the intended lesson outcomes.
- Always discreetly give extra time for the girl to respond to a question by asking the question but then coming back to them.
- Sensitively provide extra time to complete a task when needed.
- Provide written instructions to be looked back on.
- Give copies of power points or written notes that can be highlighted or annotated to alleviate their additional note taking workload.
- Always break down tasks into chunks with clear instructions.
- Give extra time for homework, tasks and exams and support additional time applications.
- Support the girl with her feelings of anxiety and reassure her that it is normal to feel that way.

Susie's View

'Something that helped me was a Dictaphone. When preparing for an essay I used to say what I wanted to write into the Dictaphone and then refer to it when I was writing the essay, it helped enormously.'

A Mother's View

'Revision is stressful for any student and my daughter was helped by putting the subject information onto a tape and playing it back through earphones. It certainly worked for her.'

Fatigue

Many girls with TS suffer from fatigue but can also be determined to 'keep up' with their peers and will often put in tremendous amounts of effort into their school day and homework. However in time they can then become tired and unable to perform to the best of their ability and concessions should be made for this whilst never lowering expectations of what the girl with TS can achieve.

Strategies to overcome this issue could include shortening tasks where appropriate but also sometimes using an egg timer or stop watch so they can plan their time to complete questions. This could help them complete their work, pacing themselves without adding too much pressure. Home - school communication links are important with regards to reporting signs of fatigue so that both parties can be mutually supportive and informed. For example if the girl with TS has had very little sleep the previous night or she has appeared particularly tired during the school day it is advisable to share this information via a reading record, home - school diary or a brief discussion at the start or the end of the school day.

Hearing Impairment

This may be caused by repeated 'glue ear' or be more permanent or degenerative. In both cases the child should be referred to the local hearing clinic, through the GP, and will then be supported if necessary through the local hearing impairment support service. Generally, the child should be seated at the front of the class, encouraged to make eye contact with the person speaking and time should be taken following the main lesson input to ensure she knows what she needs to do to complete the task set. A calm, settled classroom will also benefit any child with hearing loss or a hearing aid as any noise is amplified by the device and can make concentration difficult.

Spatial Awareness

Some girls with TS have had difficulty with spatial awareness and abstract concepts. Spatial understanding is important in maths, spelling, punctuation, mapping, understanding time, drawing, copying, ordering, changing points of view and handwriting. This difficulty can also apply to everyday tasks such as: reading maps, tying shoelaces, driving, using money correctly or finding your way around unfamiliar spaces. These are issues to be aware of and discuss or raise with school staff or parents and carers in terms of how they are affecting learning and again whether a referral to a specialist is required for further advice and support.

Comprehending Instructions

It is advisable for school based staff and parent or carers to ensure that instructions are clear and not implied as some girls with TS find it hard to follow instructions without further clarification and explanation. Once aware of this issue discreetly asking the girl to repeat what she needs to do is a sensitive and useful strategy to employ as not to cause her anxiety. Older girls find it helpful to make notes as mentioned previously to help them remember what to do particularly when receiving multi step instructions.

Social Difficulties

Any child experiencing difficulties with friendships or bullying should always speak to an adult in school and if they are not confident enough to do so they should ask a friend to help or a parent or carer. However girls with TS, as with all children, may not always be confident to do so. Therefore it is essential that school based staff and parents and carers take the time to encourage her to talk about her school day and anything that might be upsetting her. As some girls with TS struggle to maintain friendships this is all the more important, as she may need intervention and support to overcome these difficulties such as being allocated a key worker or friendship group interventions.

Girls with TS are potentially vulnerable to unkind remarks from their peers and they may not have the skills to mediate when friendships have problems. This is all the more reason to monitor their socialisation as much as possible and intervene where necessary. It is also important for parents and carers to monitor social media use, without invading privacy, and if there any concerns regarding bullying or friendship issues they must contact the school immediately, who will be experienced in dealing with such issues.

Self Image

Generally, in modern day society, there is an enormous amount of pressure to look a certain way and this is at its most pronounced during teenage years. Depending on the success of growth hormone treatment and possible delay in pubertal development amongst other factors this puts additional pressure on girls with TS in an already challenging situation. If self-image is an issue this can affect self-confidence and self-esteem, which can lead to anxiety and depression. Therefore it is essential to seize all opportunities to raise self-esteem by offering encouragement and praise for the achievements and special personal qualities each girl has. It is also important to take the time to talk and listen so there are opportunities for girls with TS to express their feelings. The following website is useful for anyone who feels they may be suffering from anxiety or low mood: <http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/low-mood-stress-anxiety.aspx>

Routines

Most girls respond well and work to their potential in a structured and ordered day whereby they know exactly what they are going to be doing and when. A visual timetable in the classroom would be helpful to all children whilst incorporating the individual needs of a girl with TS.

Transition

Any transition to a new school is a daunting experience whether it is within the primary or secondary phase or moving from primary to high school or high school to sixth form. The current school can support parent and carers and the girl with TS to make this process as smooth as possible by meeting with or contacting the next school to discuss the provision currently in place, including access arrangements if applicable, so this can be taken into account when planning for admission. It is still advisable for the parents or carers to arrange a meeting with the new school pre admission to meet with key staff, usually the SENDCo to ease the process.

10 tips for supporting a child with TS in the classroom:

1. Try to ensure the child is facing the teacher whenever possible
2. Make eye contact as much as possible and encourage the child to do the same
3. Keep background noise to the minimum
4. Give full and clear instructions, using her name to gain attention
5. Use staggered inputs for 'pre-teaching' and confirm instructions are understood
6. Use visual aids and colour to aid memory
7. Set realistic but challenging targets
8. Ensure marking comments clearly highlight strengths and next steps
9. Praise often and try to find additional time to listen to her concerns
10. Have high expectations of what she can achieve, with support she has great potential

10 tips for parents and carers to support a child with TS at home:

1. Take the time to support your daughter to plan her day, especially if there is a change
2. Give clear explanations - state the obvious, never be vague
3. Use her name to gain her attention before speaking
4. Encourage the use of a diary, wall planner or calendar and notebook
5. Write a list if you want her to complete more than one task
6. Give lots of praise and encouragement and be patient
7. Encourage 'down time' in between homework tasks or after school
8. Support the development of friendships
9. Find time to let her talk about her day and encourage her to do so
10. Praise her for sharing anything with you that worries her

This quote should be kept at the forefront of our minds - the self fulfilling prophecy:

'If children are told often enough that they are good at something they will improve and if they hear enough negative feedback they will do the opposite.'

Preparation for Further Education

It may not be easy for a young woman with TS to make the break from home and a familiar school environment and settle into an unfamiliar more independent routine at work or college. Girls with TS are all individual and as such the circumstances leading up to this point will be different for each of them. However there are some general points that may support the transition for them:

- It may be advisable to encourage the girl with TS to apply for a job, university or college, which is far enough away from home to encourage independence but not so far away that it is too difficult to return to the family home when they need to.
- When deciding on a college or university course find out what arrangements are in place for pastoral care, personal tutoring etc. When visiting talk to staff and students within the course department and get a feel for the atmosphere - is it friendly, personal and welcoming?
- Contact the place of work or university well in advance of the start date to provide some background information about TS. If the condition has been disclosed, explain any additional support previously in place and establish if this can continue, making clear the access arrangements for exams that are already in place.
- Disabled student allowance can be accessed through student finance as part of the application process for further education and will result in the provision of learning support, learning mentors and technological aids to support learning and study. The resulting learning support plan will be individual to each girl so they need to be included in the process to ensure their plan is tailored to their needs.

- Be aware that the support provided will be discreet and protect the confidentiality of the girl but will 'level the playing field' and reduce some of the need to work excessively hard to keep up leaving more time to socialise and relax. This will provide a work - life balance and help to reduce anxiety.
- Prepare the ground carefully in the years leading up to further education. If the girl has not been encouraged towards independence during her teenage years the break will be harder.
- Encourage self-help skills as soon as possible e.g. being able to cook simple meals, use the washing machine, iron etc.
- As a young adult making a start in a new environment it is particularly important that she is not labelled as being different. Whilst as parents or carers it is understandable to want to keep an eye on your daughter as she settles into a new social life and an independent way of working it is essential to do so as unobtrusively as they can.
- However, advice, support and encouragement should be easily accessible during this transitional phase.

Katy's View

'In general I have found university life a challenge but not one that is beyond me, or anyone with TS. I have never really found my short stature a problem and if anything it is less so now that I am at university. At university people seem to be much more tolerant and understanding about my height problem than at school. I certainly found that my height has been less and less commented on as I have grown up. What I would like people to realise is that they shouldn't let having TS hold them back. If they think that they would like to give university a go they should not be afraid to do so. However, they should also not be afraid to ask for help should they need it.'

Conclusion

The most important message is all those involved must strive to ensure that all girls with TS have a positive self-image and a belief that they can succeed. Striking a balance between providing the appropriate level of support and ensuring they develop independence and self-confidence is essential. As mentioned previously whatever difficulties each individual girl may face, **they must never be underestimated or defined by their condition.** The degree to which the issues mentioned in this booklet affect each girl will vary considerably. Some girls may only need slight adjustments to meet their learning needs whilst others may have significant and sustained needs that require external agency support and an Education Health Care Plan (EHCP). Either way it is essential that every girl is regularly assessed in terms of the effectiveness of her current provision so that her needs are consistently met and she is enabled to achieve her full academic and personal potential.



photo credit: Thomas Murray

Useful Contacts & Websites

Turner Syndrome Support Society [UK]
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

ACE [Advisory Centre for Education]
Freephone Advice Line 0300 0115 142
www.ace-ed.org.uk

Anti Bullying
www.bullying.co.uk

Contact a Family
Freephone Helpline 0808 808 3555
www.cafamily.org.uk

Disability Rights Commission
DRC Helpline: 08457 622 633
Text phone: 08457 622 644
www.drc.org.uk

DfES [Department for Education & Skills]
www.dfes.gov.uk

Education Scotland
www.education.gov.scot

www.family-action.org.uk/schools-education

Joint council for qualifications
Rules on extra time for exams/access arrangements
www.jcq.org.uk/exams-office/access-arrangements-and-special-consideration

IPSEA [Independent Parental Special Education Advice]
www.ipsea.or.uk

National Portage Association

Tel: 0121 244 1807
www.portage.org.uk

National Bullying Helpline

www.nationalbullyinghelpline.co.uk

Pre-school Learning Alliance

www.pre-school.org.uk

Respect me – Bullying Support

www.respectme.org.uk

Scottish Government Education Department

Tel: +44 (0)131 244 4330
www.education.gov.scot

Welsh Assembly Government

www.wales.gov.uk

The above information was correct when printed.
There are lots of websites offering help and support in your local area.





Turner Syndrome Support Society [UK]