


# Turner Syndrome & Education



a guide for parents and teachers



Turner Syndrome Support Society



**TSSS** This booklet is published by the Turner Syndrome Support Society (TSSS) as an aid to both parents and teachers of girls with Turner syndrome (TS).

It is not definitive, but written as a result of many shared experiences of those with TS, their parents and teachers. The booklet is intended to provide help when dealing with problems or difficulties that may be faced by girls with TS during their school years.

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**how to help your child  
survive and succeed at school**

a guide for parents and teachers

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# Introduction

Thank you for taking the time to read about Turner Syndrome (TS) and Education. We do appreciate how busy you are and how many demands there are on your time, but we hope that this leaflet will help you understand some of the characteristics of a girl with TS and how they may affect her abilities in the classroom.

This leaflet is intended as a guide only, as no two girls with Turner syndrome are the same, each is an individual with individual needs. There is no one method or approach, which will be guaranteed to produce the best results for every girl with TS, and it is difficult, if not impossible, to give general educational guidelines about their needs. They are all different and, like the general population, they have different skills, strengths and weaknesses of their own, which have nothing to do with TS and don't always follow a general pattern. It is perhaps because they are not all exactly similar in their physical and psychological needs that we have not always seen these needs catered for properly in the past, inside school and out. It is sometimes difficult to recognise and understand patterns of behaviour within a busy home or school situation. There are, however, a number of specific problems which may need to be addressed, and these may only become clear if you have the chance to meet a number of girls with TS and see a "big picture" begin to emerge.

This leaflet is intended to provide some information for both parents and professionals working within school. We hope that it may help you to understand and cater for the needs of a girl with TS more successfully, and get the best out of the school system. Some of the information will already be familiar to those working within school, but it is included for the benefit of those parents who are new to the education system and need to know how it works. Please do not hesitate to let us know if you think we have omitted anything of importance or if you have any information that you feel would help others.

The TSSS would like to thank all those who helped in the compiling and writing of 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 the older women with TS, who shared their sometimes-painful experiences at school, in order that the younger girls with TS would not suffer as they did. Special thanks are due to parents Arlene Smyth and Lynne Taylor, and to Pat Rogers, a retired head teacher with TS, for their determination to see this information in print and circulated to teachers, as well as to the girls with TS and their parents whose shared experiences have

# What is Turner Syndrome?

## A brief explanation

Turner syndrome [TS] is a chromosome abnormality affecting only females, caused by the complete or partial deletion of the X chromosome. The incidence of TS is approximately 1:2000 live female births.

Confirmation of a diagnosis of TS is by karyotype but a suspected diagnosis can be made by a series of characteristic physical features i.e. web neck, broad chest and widely spaced nipples, low hairline and increased carrying angle of the elbows and other features. Two main clinical features of TS are short stature and non-functioning ovaries. Diagnosis can be made at birth; however, most girls are diagnosed in early childhood when growth fails or later when the absence of a pubertal growth spurt and lack of development of secondary sexual characteristics become apparent.

Girls with TS may have only a few or several of the features associated with TS, but short stature and infertility are nearly always present. Further detailed information about TS can be obtained from the Society. However, it may be helpful here to mention several aspects of the syndrome that could possibly affect the school life of a young girl with TS. Girls with TS are prone to recurrent ear infections and these can lead to hearing problems. Short stature and fine motor co-ordination skills can be a problem in games or PE lessons, and can also lead to low self esteem particularly if a girl with TS is constantly not picked by others for their team. Misunderstanding can occur because those with TS have difficulty in reading facial expressions and this in turn can lead to difficulties with friendships. The girls need constant reassurance, this can be annoying at times and thought of as attention seeking. You will read further on that good verbal understanding and ability does not necessarily lead to a girl being able to express herself as well in writing, this can possibly lead to a child being wrongly classed as lazy. Spatial awareness problems are covered elsewhere in this booklet but they can normally be overcome with extra help. Girls with TS like routine and can be stubborn if changes are made without an explanation being given. All of these aspects are covered in more detail in this booklet, and the majority of girls and women with TS are healthy, happy and lead normal lives.

# Coping with the social aspects of life in school

## Self-image and confidence

Girls with TS can find the social side of school life challenging. Some of the possible reasons for this are looked at in this section. The areas noted are things to be aware of, and look out for, rather than to expect.

Many girls with TS have a poor self-image and are easily hurt or discouraged by someone with an unsympathetic or hostile approach. They can tend to accept other people's assessment of their qualities far too easily- even in the face of concrete evidence to the contrary. If a teacher perceives a child who is tired, or finding something difficult which someone of their ability level should be able to cope with, as lazy or uncooperative then you have a potential personality clash waiting to happen. Most children tend to live up to the expectations of their teacher and their peers, and if a child hears often enough that they are clever/kind/talented then they may well end up being just that! The opposite is also true. Many adults with TS have gone on to succeed in something they were unsuccessful at in school. Children can be very cruel, and what may be normal playground banter to most can hurt terribly if your self-image is poor. Girls with TS don't always seem to be able to shrug off unkind remarks or "give as good as they get" as easily as they might. Self-confidence isn't just something that gives you a kind of helpful glow to get you through life; lack of it can actively stop you achieving things that you are capable of. Girls with TS tend to need lots of reassurance and while this may be frustrating responding positively to their worries and giving reassurance is an important way for those around them to help build up the child's confidence.

## Response to pressure

Sometimes time and space may need to be given so that the child can learn in her own way and at her own pace. Girls with TS don't always respond to pressure of any kind well. Clearly, this is not going to fit into a school routine that is becoming more and more pressured and test centred at an earlier age. The national curriculum makes it harder for the teacher to teach in their own way and adapt to fit the pupil's needs. A formal numeracy hour may not be the best means of delivery when it comes to teaching a girl with TS maths, for example.

## **Day to day routine**

Most girls with TS respond well and work best in a structured and well-ordered day. They need to know exactly what they will be doing during the day, not only in terms of the lessons or topics to be covered, but also the order that information will be covered within each topic or subject area. If the teacher gives a brief outline of what will be covered at the start of the day or lesson, this will go a long way to help the girl with TS know what to expect, and she will feel more confident and able to cope from the outset. Handouts summarising the work to be covered are of great reassurance and this often alleviates the need for the child to constantly ask her teacher. Similarly, visual aids can be particularly helpful. Also, girls with TS often respond well to realistic target setting and reward schemes.

Some girls with TS may find any sudden change to routine difficult to deal with. For example, in the case of the younger child, if the child's usual class teacher is ill, and a supply teacher with whom the child is unfamiliar will be taking the class, it would always be helpful if the girl with TS could be made aware of this beforehand.

Some girls benefit from a slight adjustment to the timing of certain subjects as, like many children, they are often more productive in the morning. Although we recognise that changes to time-tabling, even for Primary age groups, can now be extremely difficult to arrange, it may be helpful if the subjects the girl with TS finds most difficult are studied during the first part of the day.

## **Social skills**

Dealing with other children and adults in a social setting can be difficult for girls with TS. Workshop drama may be useful, as acting out relationships and situations can help them to understand social interactions in a way that someone with TS might not in "real life". It may also be easier for them to build relationships with others in a structured setting where there is a reason for being there and a focus. Things can often be understood indirectly through a book, TV or the theatre that would not be picked up if they actually happened to the child directly. Try to talk about what is seen and heard with them as much as possible.

## **Recognising social cues and responding to them**

Girls with TS sometimes have difficulty recognising and responding to social cues. Don't assume that what you meant to get across is what was actually understood. Be exact and specific. Most teacher/child interactions are quite short and pressured and there may not be an opportunity for the teacher to



realise that they have been misunderstood. This may also lead to problems with peer relationships. Teasing may be misunderstood and taken seriously rather than laughed off. It is not always easy for a girl with TS to recognise and respond to facial expressions, and this can lead to misunderstandings when they are in social situations.

### **Being perceived as the age they are**

Given their small stature there may be a danger of a girl with TS either being picked on as someone small and vulnerable, or patronised and treated as a mascot by peers. While the child may enjoy being “babied” for a time and find it comfortable and reassuring, neither situation is helpful to the child as they grow towards maturity and independence. In conversation with girls, and even women, with TS this is an important issue for them.

### **Bullying**

Girls with TS appear to pass through a stage where they seem to be immature for their age and they find it hard to maintain friendships with their peers. This can lead to isolation and increasing loneliness, particularly at playtime and during breaks. Bullying is one of the most common problems experienced by most girls with TS. They are easy targets and find it difficult to tell someone if anything is happening to them. The girls are very good at pretending that everything is fine when it is not. They often display what is classed as attention seeking behaviour, when what they are trying to do is spend time with a teacher or other adult to find a way to tell them they are being bullied.

### **Social Problems related to Spatial Understanding**

If the girl with TS is spatially disordered this may affect their social relationships. They may be rigid and inflexible with regard to the behaviour of others. They may have poor manners. They may invade someone else’s personal space, and not be able to understand the effect on others of something they have said or done. This can make relationships with teachers difficult as they may need a rigid adherence to a pattern and have difficulty understanding exactly what is expected of them.

The spatially disordered person struggles with order in the environment and may either give up trying to maintain order completely and live in chaos, or try to impose a rigid and inflexible order on their world. This can have social implications as well as academic ones.

# General Learning Issues

There are some learning issues of a general nature, which may cause difficulties within the classroom for a girl with TS.

## Difficulty in concentration

Repetition and short bursts of information may be more productive than a long tiring slog. Girls with TS can also be creative, thinking in an original way, and going off at a tangent when they are meant to be thinking about something else. This can be positive as well as negative, leading to progress. It is important to try to ensure that the learning environment is quiet, calm, and free from distractions.

## Memory

Girls with TS may have short-term memory problems. However long term memory is often very good, for instance in recalling historical events and dates.

## Co-ordination.

This can be a problem, and may make a child a target for teasing. Practice will help.

## Lack of stamina

Girls with TS are often able to make a great effort and get through something, 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 problems that a child has are going to be magnified when they are very tired. They don't always know how to pace themselves, and may well go on till they drop if you allow them to!

## Uneven skills

It is important that a teacher realises that some girls have genuine difficulties with certain aspects of some subjects and that these might be unexpected when taking account of either their age or their abilities in other subject areas. The child is not necessarily being awkward or lazy and it may be necessary to allow extra time or even a fresh approach to the subject before the child makes progress. Occasionally the child may need extra time so that

she can learn in her own way and at her own pace. For girls with TS repetition of facts and short bursts of information may be more productive than a long “slog” through a particular topic.

### **Difficulty following instructions**

It may be harder for some girls with TS to follow instructions, particularly if they are partially implied. You may need to state the obvious! Instructions need to be full, if not laboured, and often clarification may be required. Inferred language may be difficult for the girls to follow and they often give the impression that they have understood when they have not. This is something that the teacher may not expect once the child has reached a certain level of education and a girl with TS may appear disobedient in not starting a set task, when really she hasn't understood what is being asked of her. Teachers need to be exact and specific, and asking the girl to repeat the instructions for the task that they have set may also help. Older girls might find it helpful to make notes. It should also be noted that it may be harder for some girls with TS to perform tasks that require several steps to be linked, even if the individual steps can be done with ease.

### **From Susie**

“Something that helped me was a Dictaphone. When preparing 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.”

### **From Kylie**

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

(For more information about extra time during examinations the SENCO [see page 15] will have details.)

### **From a Mother**

“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 whilst going to sleep listening to it. It certainly worked for her.”

# Specific Learning Issues

Girls with TS may have some subtle and quite specific learning difficulties.

## Maths

Girls with TS can be very articulate with a natural flair for English and other languages but maths, in particular, may cause problems. They seem to be able to cope quite well with the problem solving area of maths, but have great difficulty with abstract concepts and spatial awareness. They seem to have particular difficulty visualising a 3-Dimensional object in a 2-Dimensional format and in secondary school, anything trigonometry based for example can cause problems.

## Spatial Awareness

Spatial understanding is important in many areas, including mathematics, spelling, punctuation and capitalisation, mapping, understanding time, drawing, copying, ordering, changing point of view and handwriting.

Reading comprehension requires spatial skill. In order to understand grammar and sentence structure the ability to track meaning through a text is needed. This is true both in terms of an individual sentence and in terms of following a storyline, as well as understanding the development of an argument in an essay.

Mathematics requires a great deal of spatial skill, in order to understand concepts like place value, signs, borrowing and division. The ability to sequence and keep to a set of sequential rules while solving problems is a spatial skill. Time is spatial. It requires understanding of ordered sequences. Geometry also requires understanding.

Punctuation may be a problem for somebody with poor spatial understanding. If a person does not perceive the pauses of speech in everyday life they may not see the need for punctuation when writing. Handwriting is easy and effortless with accurate motor-spatial control, and very difficult without it. Writing and drawing require both visual spatial skills (knowing where to send the pencil) and motor spatial control (being able to make the pencil go where you want it to).

Many more everyday tasks require spatial skills: reading maps, tying shoelaces, driving, giving and receiving change, and finding your way around an unfamiliar place are a few examples.

It has been difficult for the Society to find a good explanation of the difficulties

faced by children who have spatial awareness problems. We have recently come across an American article, which you may find useful. A copy can be obtained by sending a large SAE to the TSSS office for a photocopy. Please also enclose 4 loose 1st class stamps to help cover the cost of photocopying. It is well worth reading and may help you to help your pupil.

## **Fine motor skills**

Girls with TS may have difficulty with “fiddly” tasks requiring dexterity. Gentle patient encouragement is needed, with realistic expectations. If the child is allowed the time to repeat the task their determination usually serves them well, and they will manage eventually. Specifically, getting changed for PE may be difficult if she can’t manage buttons, tie-up a tie, or manage the buckle on her shoes. Careful shopping on the parent’s behalf should avoid some problems here. It is sometimes the case that the child’s ability to write may not match her ability at reading, or her verbal skills, particularly in the early stages of learning. Speed and neatness may be a problem in later school years.

## **Gross motor skills**

Some girls may have problems controlling their gross motor skills. They may appear clumsy and their hand-eye co-ordination is often very poor.

PE is an obvious example where a girl with TS is unlikely to shine. PE staff should be aware that the problems encountered by girls with TS are of a physiological and neurological nature and persistent criticism is simply likely to be counter-productive. Constant encouragement is needed and it is important that the girls with TS is aware that the often-tremendous efforts she is making to improve have at least been acknowledged, even if they don’t seem to bear much fruit! Team games can be a nightmare for girls with TS and they often prefer individual sports. If given a chance they can do very well in swimming, dancing, gymnastics, and field events.

Science and cookery is also an area where the teacher needs to be aware of possible clumsiness. The use of boiling water and chemicals is something that needs to be monitored; although it is only through practice in handling such things that progress can be made.

## **Planning and structuring tasks**

Girls with TS may find it difficult to plan and structure their work. Self-organisation may not come naturally for some of them, although it is a skill that, to a certain extent, can be taught. This may become more apparent in later school years, where pupils are expected to plan their approach to tasks

and manage their workload themselves. However, the reverse can also be true. The girl with TS may have a need, possibly bordering on obsession, to know what is going to happen and when, in order to feel they can cope. This can make the people around them feel uncomfortable and if this starts to interfere with their education it would be wise to seek the help of a psychologist.

## Thoughts on school

"I am now fifteen years old and when I started school, just before my 5th birthday a lot of what I can remember was just playing in the play corner and writing lots of extremely short stories with terribly scribbled pictures.

At primary school, which was mixed-sex, the subjects I enjoyed most were English & Drama, even though we didn't do a lot of drama. Having said this, I never seemed to get the hang of comprehensions very well, stories and creative writing were fine but comprehensions were just terrible. My handwriting was appalling and when I reached Year 4 I was the only child in the class not allowed to write in ink. In the end, it was only at Mum's insistence that I was allowed to write with a pen and from that day onwards my handwriting improved tremendously. Within six months I was writing more neatly than most of my friends. I can always remember dreading the days when I had P.E. I was without any doubt the least athletic and sporty person in the class. Another subject I was never any good at was art and design technology. I was constantly being told by the teachers to redo pieces of artwork. I wasn't a great fan of Maths, but I didn't dread it. I could answer the questions and because I was in one of the higher groups I didn't feel that I wasn't capable of doing the questions. As far as friendships were concerned I always felt slightly removed from the rest of my class. There were an odd number of girls and when we had to pair up I always seemed to be the one that was just left there because everyone else had their own "best-friend" who they would pair up with. I was friendly with the other girls in my class, but I was never really that close to anyone.

I've now been at secondary school for 4 years and I have literally loved every minute of it. It has been so different to primary school. There are so many more subjects and you cover so many more aspects of life than you do at primary school. I settled in straight away and I made lots of really nice friends. At first I was a bit frightened because I was the only girl from my primary school that went to my secondary school. The truth is that the friends I

have made here are much more like me than my friends at primary school. We all have a lot more in common because we come from similar backgrounds. Occasionally I can feel rather ignored but this never lasts long and probably isn't that different to other girls of my age.

My favourite subjects are English and Religious Studies. Since I started my GCSE courses in September, I have completely dropped Art, Design Technology, Music, French, History & Geography. I'm doing 9 subjects altogether, which are English, Maths, Chemistry, Physics, Biology, German, Latin, Religious Studies and Information Technology. I appear to be quite good at languages, but I made the decision to drop French because I wanted to do Religious Studies and Information Technology. I dropped History as I found it tedious and I dropped Geography because, although I wasn't bad at it, I never seemed to click with the subject. I'm much happier now that I have chosen the subjects that I enjoy and I'm loving every minute of school. I am still the least athletic person in the form, and probably the whole year, but I don't worry now because I know that it isn't really that important to my future. I still dread games but not as much as I used to. I can't stand hockey, but badminton and netball are not too bad. I'm not particularly good at tennis either. I also really used to dread music, because I've never managed to grasp how to read music and so I was never any good in the lessons. However in spite of this I have achieved Grade 3 at singing and am shortly to take my Grade 4 examination.

At the end of the day I always say to myself that as long as I've tried my hardest at something that is all I can do and that is all anybody can expect of me."

Joy

## Sex Education

This will be a particularly sensitive topic for girls with TS and their families and it is very important that the teacher is aware of the physiological aspects of fertility for girls with Turner Syndrome. When talking about this subject, whether in a dedicated lesson or as part of a topic in Science, it is helpful to mention that there are also some women without TS who may not be able to have children by the traditional method. While some may use IVF treatment, many choose not to have children at all. In biology genetics may be taught and teachers should be aware that some information about TS might be out of date. A degree of sensitivity is required when these topics are covered. Parents need to be aware well in advance that the topic is going to be covered, as it may be earlier than some parents would expect, and they may wish to discuss the subject with their daughter beforehand. If a video is to be used it may be helpful to offer it to the parents to preview at home as they may wish to prepare themselves for any questions which their daughter asks. It is also important to make sure that any information given in school regarding TS is accurate and up to date.

## Medical Issues

There may be certain relevant medical conditions, linked to her TS, that the child has, which would affect her schooling, such as hearing loss, squints etc, and it is obviously important that her teachers are aware of these. It may be helpful if the child's teacher is aware of any treatment she is having in order to promote her growth (such as growth hormone injections), should she talk about it at school. There may be a time that fits in with the curriculum, when it is possible for her to talk to the class about her condition or treatment. Possible times might be when a nurse is visiting to talk to the class, if the topic of inoculations is being discussed, or if height/growth is a topic for the year.

### From Emma

"Everyone involved with a girl with TS should be told that each girl is different so nobody knows how it is going to affect each individual. So I reckon that every girl should just be told to go for what they want and to try their best and reach their potential. From when I went to secondary school and started doing experiments in the lab I have loved science. I'm glad that I am doing a pharmacy degree, I'm going to be the first professional in my family."



# 10 tips that can be easily applied when teaching a child with Turner syndrome

- Try to ensure that the child is seated so that she is facing the teacher for the majority of the time.
- Make eye contact with the girl whenever possible. (This may not be easy for her)
- Use handouts, rather than the blackboard, whenever possible.
- Try to keep background noise to a minimum.
- When giving an instruction start with the girl's name and finish with her name.
- Give full and detailed instructions and repeat if possible.
- Encourage the use of visual aids and colour to aid memory.
- Set realistic targets and award with lots of praise.
- If not reaching academic targets then praise helpfulness etc.
- Listen to her concerns and treat her fairly and this will help the girl with TS reach her full potential and become a valued member of the class.

## 10 tips for parents which may help at home

- Take time to help your daughter plan her day, especially if there is a change.
- State the obvious. Do not expect her to know what you want without saying it.
- Use her name at the beginning and the end of a sentence when asking her to do something for you.
- Encourage the use of a diary, wall planner, calendar or notebook.
- Write a list if you want her to complete a few tasks.
- Give lots of praise and encouragement, even when repeatedly asking you the same thing. They are seeking reassurance that what they think will happen will.
- Be firm and fair say yes or no, they find it difficult to respond to “in a minute” or “maybe”.
- When asking them to get something for you, mention the colour and the name. It helps them be sure they are getting the correct thing.
- Do homework in short bursts with a break in between subjects.
- If possible allow them to complete one task before starting the next one.

# The Special Needs System

This section is an overview of the ways help can be provided within the system for those children who need it. The child may need to access help throughout their school career, or for only a part of the time they are at school. They may need help in one specific area, or they may have several specific learning problems. They may have no special needs at all within the classroom, but find the social side of school very difficult to handle. Whatever their needs this is an outline of the channels which are there to enable you to find support. As you may know it can be difficult and take a long time, given that the system is overstretched, so you will need to flag up the child's needs as early as you can, and be patient and persistent. The most important thing is to keep a dialogue going between the school and the child's parents, and make sure that everyone involved knows what is happening. Don't assume problems, as you may experience none at all, but be ready for them if and when they happen. You also need to be aware that different LEA's may not always follow exactly the same procedure.

## Pre-School Education

### **Educational assessments for children under two**

If your child has a particular problem, which has caused concern they can be referred to the local authority for an assessment. If the Local Education Authority [LEA] agrees that your child has \*Special Education Needs [SEN] and there may be a need for extra educational provision it may decide to assess your child. Your consent will be needed for this if your child is under two. You can also request an assessment for your child on your own behalf if they are under two. All nursery settings, which receive government funding, must have a written SEN policy and a Special Educational Needs Co-ordinator (SENCO). [\* also known as children with additional support needs] Help may be given in a variety of ways.

### **Early Years Action**

If it is felt that your child needs extra help, which the usual nursery curriculum is not able to offer, the SENCO and the child's teacher may discuss with the parents how extra support may be provided.

### **Early Years Action Plus**

If the additional help provided proves not to be enough to help the child progress successfully outside help from support services and/or specialist advice may be sought. This may be an Educational Psychologist or specialist teacher. Again, this will be done in consultation with the child's parents.

## Request for a statutory assessment

If the help is still not enough to meet the child's needs a request for a statutory assessment can be made. This can come from the parents, or from one of the professionals working with the child, and the LEA must carry it out.

## Portage

This is home-based educational support for pre-school children with special educational needs. Usually a teacher will visit you and your child. They will suggest ways in which parents can help the child, make a note of specific areas where they have difficulty, and suggest work for the parents to do with the child between visits (see useful addresses).

## Toy and Leisure Libraries

These provide toys to borrow, play sessions, and a useful meeting place where parents can chat to each other. It is very important that the child has as many opportunities as possible to interact socially with other children before they start school. Networks can be found, both formal ones, within the system, and informal ones, which grow as a group of parents get to know each other. It is a good place to share advice and prevents the parent from being isolated.

If the child has a statement before they start school the authority will include the name and type of school they will be attending in part 4. The parent may state a preference and this will be taken into account. The LEA must comply with this preference unless it is shown to be unsuitable for the child, or incompatible with the efficient education of others, or the efficient use of resources.

## From Louise

"For my last three years at school I attended a special school, on leaving, my teacher said she thought it best for me to go to college to learn "Life skills" e.g. making cups of tea etc. But I fought against it and I said I wanted to do a BTEC in Performing Arts, and I am glad I decided to. I am studying this at the Chicken Shed Theatre Company where I have been a member for the past five years. The theatre has helped me gain in confidence and independence, gain friendships and an understanding of others. I am currently working towards a final end of year production of Federico Lorca's passionate and intense play "Blood Wedding" which combines dance drama and music."

# Choosing a School

It is important for the parent to visit a variety of schools in the area before deciding where they would like their child to go, and gather as much information as they can.

Here are some points to help.

- Ask to see the schools SEN policy and find out which governor has responsibility for special educational needs within the school.
- Have a look at the school's prospectus.
- Find out about the school's admission policy.
- Have a talk to the school's SENCO.
- Find out how the school involves parents and communicates with them.
- Have a look around the school. Notice class sizes particularly.
- Speak to parents who already have children at the school- especially if their children have special needs.

## When your child has started school

If the parent or the child's teacher is concerned about the child's progress the first step is for them to talk together and see what can be done. They may then feel that the school SENCO needs to be involved.

## School Action

The SENCO will assess the child's difficulties and decide what support is needed to help the child's progress. This will be done in consultation with the parents and the child's teacher. An Individual Education Plan [IEP] will be written which should say what targets the child will be aiming to achieve, how they will be helped to do this, and when their progress will next be reviewed. This should happen at least twice a year.

## School Action Plus

If the action taken using the resources available within school proves not to be enough the school may ask for extra support from outside agencies such as an Educational Psychologist or a specialist teacher. This is known as School Action Plus. A new IEP will be written to take account of this.

## Statutory Assessment

A few children may need further help to make sure that they progress. If this is the case, the school or the child's parents may ask the LEA for a Statutory Assessment. This is a detailed assessment of a child's needs and difficulties. All those who have worked with the child, as well as the child's parents, will contribute. There are time limits for this procedure. It should take 26 weeks, but may in fact take longer.

Considering whether a Statutory Assessment is necessary	6 weeks
Making the Assessment	10 weeks
Drafting the proposed Assessment	2 weeks
Finalising the Statement	8 weeks

A Statement is a legal document and sets out the child's needs and how they will be met. The child has a legal right to the help stated within it. It is very important therefore to make sure that it is accurate and represents the best possible support for the child.

Further details of the system and how it works will be found in the SEN Code of Practice 2001. You can get copies and a guide for parents free from the Department for Education [see useful addresses.]

## Getting Ready for Life After School

It is not always easy for a young woman with TS to make the break from home and a familiar school environment and settle into a new more independent routine at work or college. While they are all individuals, and circumstances leading up to this point will be different for each of them, there are perhaps a few general words of advice that may help make the transition an easier process.

- It may be better to choose a course which is far enough away from home to encourage independence, but not so far that it is too difficult to return home from time to time when in need of a few home comforts.
- It may be helpful to choose a smaller college or university. A large campus may seem rather daunting and difficult to settle into.
- When choosing a course find out what arrangements exist for pastoral care, personal tutoring etc. Try to meet people and students within the department and get a feel of the atmosphere. Is it friendly, personal and welcoming?
- Prepare the ground carefully in the few years leading up to further education. If they have not been encouraged towards independence during later teenage years, the break will be harder. It may be that the girl with TS doesn't branch out towards independence naturally in the way that most teenagers do. It is easy to be overprotective.

As a young adult making a start in a new environment it is particularly important that the girl with TS is not labelled as somebody different. While you may need to keep an eye on progress as she settles into a new social life and gets used to a new more independent way of working, try to do this as unobtrusively as you can.

### From Katy

"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 any height problems than people 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 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."

## Some Final General Points

The most important thing of all is that the child has a positive self-image and a positive view of what they can do. This will need to be stressed over and over as girls with TS tend to need lots of reassurance and don't always "hear" and take in compliments as well as they should. It's a fine line between giving a child the help and support which they need and overprotecting them and assuming difficulties which can be worked around are going to stop them doing things.

If it is possible, it may be helpful for the child to be evaluated by a child psychologist, to see what problems, among those which might be expected in a child with TS, are actually present. An individual assessment is the only way to combat the fact that there is no "blueprint" for educating a girl with TS, which is going to tell every parent or teacher what to expect. At the very least, even where there seem to be no difficulties at present, it is important to make sure that both the child's parents and their teacher have a general grasp of the problems that might come up. Any change in school/class teacher may lead to a change in the child's performance if, for whatever reason, they no longer feel secure and comfortable. Keep a watching brief.

The people around the child are going to be crucial. The girl with TS may tend to keep things to herself and you may need to ask to find out what the root of a problem is. When you know that the child has been misjudged, either in passing by somebody who may not know them at all, or by one of the adults in school who does not have a detailed knowledge of them but has to work with them at some point, then challenge the assumption which has been made in discussion with the child and let them know that it has been unjust or incorrect. If left to themselves they may believe it. This is true of well meaning "positive" misjudgements as well as the negative. It may be very comfortable and pleasant for the girl to be "babied" but it doesn't help her grow and mature. This applies right through school life, from a girl's early efforts at independence in nursery school, to life as a developing teenager. Remember that women with TS are not often assertive and if they have to be it comes hard to them. The child will probably put up with a lot - especially from other children- before you see the hurt. Bullying can be a real issue for some girls with TS and this needs to be carefully watched for.

It is important to repeat that each girl with TS is an individual. The degree to which individual girls are affected by each of these issues we have mentioned varies greatly. Some girls may need only slight adjustment of the curriculum and teaching approaches to meet their needs, while others may have significant and sustained needs, requiring assistance from the Local Education Authority or other outside agencies. Not all girls will require a



statement/record of needs but to ensure continuity an Individual Education Programme will benefit both teacher and pupil. However, some girls with TS do have a poor short-term memory and concentration and it is important not to think that this will automatically improve with age and maturity, as it might in other children. It tends to be a problem that continues into adult life. Girls and women with TS are very good at finding ways to cope, if allowed the freedom to try different strategies.

It must be pointed out that girls with TS can also bring many positive aspects to the classroom, as they often have particularly lively and bubbly personalities. Many girls with TS possess a very kind and caring nature towards other children and will be the first to offer help and assistance if it is required. They will always try hard, and the reward of a firm and fair approach will be a happy contented pupil. We are still learning about many of the characteristics of girls with TS, but hopefully this booklet will help you if you should encounter any problems. Please do not hesitate to contact us at the TSSS if you have any general queries, as we are always happy to help and share information if we can. However, it is the development of a positive dialogue and partnership between the pupil, the school, and the parents that is most likely to ensure that the education of a girl with TS is a happy and rewarding experience for all those involved.

### **Self-fulfilling prophecy**

This educational research phrase is particularly true of girls with TS:

*"If children are told often enough that they are good at a particular thing they will improve, and if they hear enough negative feedback they will do the opposite".*

This can apply to both schoolwork and behaviour.

## Useful Contacts & Addresses

ACE [Advisory Centre for Education]  
1c Aberdeen Studios  
22 Highbury Grove  
London N2 2DQ  
Freephone Advice Line 0808 800 5793 Mon - Fri 2-5pm  
[www.ace-ed.org.uk](http://www.ace-ed.org.uk)

Contact A Family  
209-211 City Road  
London EC1V 1JN  
Freephone Helpline 0808 808 3555 Mon – Fri 10am – 4pm  
[www.cafamily.org.uk](http://www.cafamily.org.uk)

CSIE [Centre for Studies on Inclusive Education]  
Room 2S 203, S Block, Frenchay Campus  
Coldharbour Lane  
Bristol BS16 1QU  
Tel 0117 344 4007  
[www.inclusion.uwe.ac.uk/csie/](http://www.inclusion.uwe.ac.uk/csie/)

Disability Rights Commission  
DRC Helpline  
Freepost MID 02164  
Stratford upon Avon CV37 9BR  
Tel 08457 622633  
[www.drc-gb.org.uk](http://www.drc-gb.org.uk)

DfES [Department for Education & Skills]  
Sanctuary Buildings  
Great Smith Street  
London SW1P 3BT  
Public Enquiry Line 0870 000 2288 Mon – Fri 9am-5pm  
[www.dfes.gov.uk](http://www.dfes.gov.uk)

Scottish Executive  
Education Department  
Victoria Quay  
Edinburgh EH6 6QQ  
Helpline 08457 741741  
[www.scotland.gov.uk](http://www.scotland.gov.uk)

Welsh Assembly Government  
Schools Management Division 1  
CP2  
Cardiff CF10 3NQ  
Tel 029 20 825111  
[www.wales.gov.uk](http://www.wales.gov.uk)

IPSEA[Independent Panel for Special Education Advice]  
6 Carlow Mews  
Woodbridge IP12 1DH  
Freephone Advice Line 0800 018 4016  
[www.ipsea.or.uk](http://www.ipsea.or.uk)

National Toy & Leisure Libraries  
68 Churchway  
London NW1 1LT  
Tel 020 7387 9592  
[www.natl.org.uk](http://www.natl.org.uk)

National Portage Association  
PO Box 3075  
Yeovil BA21 3 FB  
Tel 01935 471641 Mon – Thur 9am – 1pm  
[www.portage.org.uk](http://www.portage.org.uk)

Network 81  
1-7 Woodfield Terrace  
Stanstead CM24 8AJ  
0870 770 3306 Helpline Mon – Fri 10am – 2pm  
[www.network81.co.uk](http://www.network81.co.uk)  
[Offers information on Education Act and special education provision]

Parents for Inclusion  
Unit 2 Ground Floor  
70 south Lambeth Road  
London SW8 1RL  
Helpline 020 7582 5008 Tues – Thurs 10am – 12 noon & 1pm – 3pm

Pre school Learning Alliance  
69 Kings Cross Road  
London WC1X 9LL  
Tel 020 7833 0991  
[www.pre-school.org.uk](http://www.pre-school.org.uk)

Rathbone Special Education Needs  
4th Floor Churchgate house  
56 Oxford Stereo  
Manchester M1 6EU  
Special education Advice Line 0800 917 6790  
Asian Language Service 0800 085 4528

Skill –National Bureau for Students with Disabilities  
4th Floor Chapter House  
18-20 Crucifix Lane  
London SE1 3JW  
Tel 0800 328 5050  
[www.skill.or.uk](http://www.skill.or.uk)

Special Educational Needs & Disability Tribunal  
7th Floor Windsor House  
Victoria Street  
London SW1H 0NW  
Tribunal Helpline 01325 392555  
[www.sentribunal.gov.uk](http://www.sentribunal.gov.uk)

