So you are considering a partnership! What does Turner syndrome mean for "us"? has been produced for couples where the female partner has TS. It is a general information booklet and introductory guide for couples who have reached the point in their relationship at which they are looking to make a commitment to each other. Based on a balance of medical facts, comments from group discussions and personal accounts, it endeavours to show just how normal life can be for those with TS and their partners.

The TSSS aims to offer support, social contact and information on all aspects of Turner syndrome to girls and women with TS and their families.

Turner Syndrome Support Society
12 Simpson Court, 11 South Avenue
Clydebank Business Park, Clydebank
West Dunbartonshire G81 2NR
Tel 0141 952 8006
Fax 0141 952 8025
Helpline 0300 111 7520
Email Turner.Syndrome@tss.org.uk
www.tss.org.uk
TSSS Charity Registration Number: 1080507

So you are considering a partnership!

What might Turner Syndrome mean for "us"?

A general information leaflet for partners ©

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Adoption UK
Manor Farm
Appletree Road
Chipping Warden
Banbury
Oxon OX17 1LH
Tel 01295 660121
www.adoptionuk.org.uk
Information for adoptive families, local support groups & self help support

Child Growth Foundation
2 Mayfield Avenue
Chiswick
London W4 1PW
Tel 020 8994 7625
Email cgflondon@aol.com

The National Osteoporosis Society
Camerton
Bath
Avon
BA2 0PJ
Tel 01761 471771
www.nos.org.uk
Advice on osteoporosis

The Human Fertilisation & Embryology Authority
21 Bloomsbury
London
WC1B 3HF
Tel 020 7291 8200
www.hfea.gov.uk
Information on Clinics and IVF with egg donation

Bibliography

Turner syndrome – lifelong guidance & support available from the TSSS

Talking about Turner syndrome CD Rom/DVD & accompanying booklet available from the TSSS

Turner Syndrome A Guide for Families can be downloaded in pdf format from the resource section on the American TSS website www.turner-syndrome-us.org

A list of further reading and information sheets held by the TSSS on all aspects of TS can be provided by the Office. A publication list can be downloaded from www.tss.org.uk

Useful addresses and contacts

Turner Syndrome Support Society (UK)
12 Simpson Court, 11 South Avenue
Clydebank Business Park, Clydebank
West Dunbartonshire G81 2NR
Tel 0141 952 8006
Fax 0141 952 8025
Email Turner.Syndrome@tss.org.uk
www.tss.org.uk

British Agencies for Adoption & Fostering (BAAF)
Skyline House, 200 Union Street
London SE1 0LX
Tel 020 7593 2000
www.BAAF.org.uk
Information on Adoption & Fostering

Infertility Network UK (formed from amalgamation of CHILD and ISSUE)
Charterhouse,
43 St Leonards Road,
Bexhill on Sea
East Sussex TN40 1JA
Tel 08701 188088
www.infertilitynetworkuk.com
Infertility education, advice & counselling

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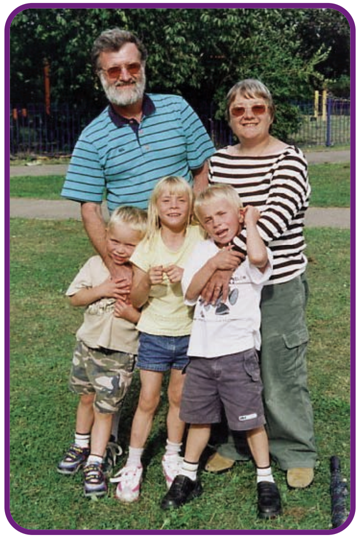

The Editor: Gavin Holmes, and family

Abbreviations

The following abbreviations are used throughout the text and the meanings below relate solely to their use in this booklet:

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

Are there health issues we should be aware of?

Yes possibly.

It is important to stress that not every woman with TS will have health problems in all the areas that have been mentioned but forewarned is forearmed. As highlighted elsewhere it is important for all women with TS to be encouraged to have regular health checks. If your partner attends an Adult TS Clinic (described below) she should be receiving the health checks/monitoring she needs.

Adult TS Clinic health checks

The first Clinic visit could possibly include an up-to-date karyotype test, (modern technology enables more precise testing). Renal and pelvic ultrasound and thyroid autoantibody testing plus a physical examination, height and weight measurement to calculate body mass index (BMI); blood pressure check; cardiovascular assessment etc. and almost certainly thyroid function, lipid analysis, blood sugar (glucose) levels, liver and renal function. Most of these should be repeated annually. An echocardiograph (heart), bone density scan (DEXA) and audiogram (hearing test) should be repeated every 3-5 years.

Some problems which are known to be particularly common in TS are preventable if simple health checks, as above, are undertaken; prevention always being better than cure.

You should strenuously encourage your partner, with her GP's blessing/referral to regularly attend an Adult Turner Clinic if at all possible – distance should not be seen as an obstacle as the benefits of regular health monitoring (see page 7 for health matters) cannot be over emphasised.

Diabetes can be a risk for those with TS and may exist for many years before it becomes obvious. As with the general population there is more risk if you are overweight and have a diet high in sugar.

It would also appear that there is an increased incidence of both inflammatory bowel disease and coeliac disease in girls and women with TS. The reasons for this are unclear and research continues in this area. Any woman with TS who has unexplained diarrhoea or rectal bleeding should be referred to a Gastroenterologist to rule out a diagnosis of ulcerative colitis, Crohn's disease or coeliac disease.

Partner quote: "The best things come in small parcels"

Note:- The Editor would welcome, via the TSSS Office (see details on page 18), any comments along with suggestions for items which anyone feels may be required to be added to the booklet in future editions.

It was a big decision, especially for Lisa, but we agreed that we could not put ourselves through all that pain again.

Early in 2000 we contacted our local Social Services and, after what seemed like an eternity of interviews, meetings and courses, we were accepted as adoptive parents. The adoption process is not an easy one but in 2002 we became the proud parents of a grand little 4-month-old boy, now 3½ years old.

Every relationship comes with its own baggage Turner syndrome is just part of ours. I heard it said by a woman with TS at 2003's conference that the partners of women with TS are special people. It's not true – we're just ordinary guys who were lucky enough to fall in love with someone special. Well I did anyway!!

Ed's note: Lisa and Les's story, above, is fairly typical of the experiences of other TSSS members who have been down the IVF and then adoption route. A point to bear in mind is that the Adoption Agency's will require a couple who have been through the treadmill that is IVF to have had a reasonable "grieving" period before commencing with adoption.

First edition August 2001

Second edition (updated with additional material) September 2005

The 2nd edition of this booklet has seen it move towards a more stand-alone form but it is still provided only as a guide and is by no means definitive. It remains intended for general information and as an introductory guide for couples who have reached the point in their relationship at which they are looking to make a commitment to each other and where the male partner has just learnt of their female partner's Turner syndrome (TS). More comprehensive information specifically about Turner syndrome can be obtained by reading "Turner Syndrome – lifelong guidance & support" available from the TSSS. With your partner's permission her GP or Specialist should be consulted if you have more specific questions.

This booklet has been written in the form of short paragraphs to enable you to put it down and then return to it subsequently when you feel ready. It has been edited by Gavin Holmes, who has been married to a woman with TS since December 1994, in conjunction with Lynne Morris and in collaboration with other couples, all members of the Turner Syndrome Support Society (TSSS). Since the first edition Ruth and Gavin have become the proud but over worked parents of a sibling group of three delightful adopted children.

The TSSS would like to thank Dr Gerard Conway and Miss Melanie Davies from the Middlesex Hospital, London, and Mr Keith Masters for their helpful guidance during the initial writing of this booklet and the above along with, Professor Anne Garden, for their advice in its subsequent updating.

Partner quote: "I didn't know whether to laugh or cry, but now we are laughing together."

Partner quote: “The courage it must have taken to tell me of her TS still amazes me”

Disclosure

The fact that you are reading this means that your partner will already have made an extremely courageous and potentially life changing decision. She will almost certainly have thought long and hard, and undoubtedly put herself through a great deal of heartache and soul searching before deciding to tell you that she has Turner syndrome. You may not even have noticed that she is different, which is a good thing, and she is certainly not going to change from the woman you know now to someone else as a result of your reading this booklet. The aim of the booklet is to give you an understanding of and background for sharing your life with someone who has TS. We hope that you will find it useful in trying to understand what makes her tick and are able to discuss the syndrome with your partner, especially how she feels about having TS and coping with it on a daily basis.

What is Turner syndrome?

It is a genetic abnormality affecting the X chromosome of approximately 1 in 2,000 live female births. The feature common to almost all women with TS is premature ovarian failure resulting in infertility; reduced stature is also quite frequent. Beyond this there are a general range of characteristics some of which your partner may exhibit, to a greater or lesser extent.

There is no typical woman with TS; just as with women without TS they are unique individuals.

Can Turner syndrome be prevented?

No, not at present but as with any medical condition research is ongoing.

What about life expectancy?

Some women with TS may have more health problems than others, which can affect life expectancy, but again the general population can suffer similarly. The medical specialists believe that the use of HRT can be of long-term benefit. Like you, your partner should be encouraged to maintain a healthy diet and take regular exercise. Reports suggest, however, heart disease is more common in women with TS but with modern treatments life expectancy is probably much as that of the general population (see page 17 for health issue details).

Partner quote: “It is what is there that counts – not what is missing”

me down and told me that she had Turner syndrome and that she could not have children. I don’t remember my exact response to this news. I only knew that I loved her and nothing could change that. I would stay with her through anything.

I decided to find out more about Turner syndrome but the local library only came up with a contact number. However, ringing this number put me in touch with the support group and this was a great help. They supplied me with a lot of information on TS by post, on the condition that I told Lisa that I had contacted them. When this information arrived it made interesting reading but it only told half the story. It wasn’t until we went to our first convention in 1993 and talked to other women with TS and their partners that everything fell into place.

Lisa and I moved in together in 1994 and I was amazed at how easy it was to settle into a new way of life. Naturally the question of marriage came up and we set a date in September 1995. It was a very special day! Since the day Lisa told me about Turner syndrome we had discussed the possibility of IVF and after the wedding we started to talk seriously about it. We were lucky that in our area we could get treatment on the NHS and put our names on the waiting list for funding. We waited and waited! It took about a year but they agreed to give us three attempts. Then we were put on the waiting list for a suitable egg donor and waited and waited again!

Finally, between Christmas and New Year in 1998 we got a call to say we were top of the list. We both had a number of tests done and in April 1999 the big day arrived. I was at Lisa’s side when she had three embryos implanted. From the very first day Lisa felt pregnant but sadly by the end of the week she started to bleed and we were devastated when she lost all three embryos. It took us a long time to get over this blow. Six months later we went to a convention in Coventry and for the first time talked openly to a few friends who knew what we had been through. It was there that we decided not to try IVF again.

The TSSS publishes four newsletters a year covering issues relating to TS, often including articles written by members themselves, parents or partners. The Society also has a Couples Contact Network enabling couples to make contact at times of need or just swap notes by telephone. There are also some local groups around the country, which hold social and fundraising events.

Les and Lisa's IVF and adoption story

I met Lisa at work early in 1992. She was a quiet person and although we exchanged pleasantries I didn't take much notice of her until, a few months later, at a fundraising event at a local club. The drinks flowed freely and at the evenings end a crowd of us went to a local pizza parlour for something to eat. One by one people set off for home and eventually we were the last left and, being a gentleman, I suggested escorting her home. To my surprise, she said yes. We talked for hours about everything – home, the job, life in general. It was easy. I had never opened up like that before and very soon she knew all there was to know about me. I can remember walking home thinking 'She's the one for me'.

In the next couple of weeks we went out for a drink, then a meal, the cinema, and a shopping trip. We enjoyed each other's company and I quickly fell in love. The biggest problem we had to endure came from Lisa's parents. For some reason that I did not understand they didn't like me and seemed unable to see past the fact that I was 13 years Lisa's senior, this may seem like a big age gap but it has never been an issue in our relationship. When Lisa went on holiday with her sister I took the opportunity to go and see her Mum and Dad. Sitting round the kitchen table I tried to tell them how much I loved their daughter and I think I finally got through to them.

My first inkling that there was something that Lisa was not telling me came one day while walking on the beach. We'd been together a couple of weeks at that time and she asked how I saw my future. I told her I saw a nice house, a good job and a couple of kids. Lisa went very quiet and into what I now know as one of her sulks. I couldn't work out what I had done. Finally six weeks later Lisa sat

Health matters

Most women with TS live long, happy and healthy lives and develop no unusual health problems as they grow older. There are some issues, however, that are more common for women with TS and simple health screening measures should prevent these from becoming problems. An underactive thyroid gland and high blood pressure, for instance, are more common in women with TS than average making it advisable for them to have a yearly blood test for thyroid function and have their blood pressure checked.

In most women with TS the ovaries do not contain any eggs and do not make oestrogen. Because of this women with TS can rarely become pregnant by using their own eggs and will need to take oestrogen for most of their lives. The lack of oestrogen affects each woman differently and there are many different products available so that with experimentation, the best one for each individual can be found.

Perhaps the most important health issue concerns the heart and aorta. There is a rare but possibly serious stretching of the aorta that can cause weakness and rupture. All women with TS should have an echocardiogram of the heart every 3-5 years to check for this risk.

Although your partner will be under the care of a GP it is unlikely the GP will have the specialist knowledge required for the overall care of a woman with TS. Ideally women with Turner syndrome should be under the care of a Specialist TS Clinic with a multi-disciplinary team equipped to manage the specific medical problems associated with the syndrome (see page 17 for details). A list of health checks is available from the TSSS office or can be downloaded from the website.

What medical treatment is available?

Women with TS are, where possible, encouraged to attend an Adult TS Clinic (see page 17) annually to regularly monitor their health and help maintain a generally healthy well being. The TSSS Office can provide the location of your nearest Clinic (see contacts page 18). An amenable, understanding GP is also extremely helpful.

Medical opinion suggests that women with TS benefit from replacement of the hormone oestrogen and progesterone, which are normally produced by the ovaries. This keeps the uterus healthy, assists in the prevention of heart disease and helps combat brittle bones (Osteoporosis*).

*Osteoporosis is more common in TS because of lack of oestrogen and is mostly preventable by taking an oestrogen replacement. All women with TS who don't have periods should take HRT which is available in many different forms. Experimenting with the type of HRT may be necessary before finding the one that suits an individual. As well as taking HRT, weight bearing exercise and a good calcium diet will help.

Can women with Turner syndrome have a sexual relationship?

Yes!

A woman with TS is physically completely female. Although most women with TS do not need to observe birth control from a purely practical standpoint, as with the rest of society, it is sensible to take precautions to avoid sexually transmitted diseases. The use of HRT has the additional benefit in that it allows more comfortable intercourse by increasing vaginal lubrication. (For some women additional water soluble lubricant jelly may also be required to prevent discomfort). Experimentation with various positions for intercourse may be necessary to achieve comfort for both partners and is part of the process of consolidating an ongoing relationship.

Will we be able to have children?

Yes!

The fact is that as many as 10% of couples in the general population are infertile due to other conditions or for a variety of other reasons. In women with TS, however, it is unfortunately extremely unlikely that pregnancy will be achieved via traditionally practiced natural methods. The TSSS is aware of a very few natural pregnancies (i.e. not IVF assisted) occurring in the UK and elsewhere to women with TS but these are extremely rare! Pregnancies are only probable in those having spontaneous menstrual cycles and are exceedingly rare if the cycle is not intact. Additionally you should be aware that if you do decide to proceed towards the desired state of parenthood it will not be achieved without a great deal of commitment, effort, expense, distress, pain, patience and persistence from you both. The other thing to consider is that once you have got children there is the possible eventuality that you might just be presented with grandchildren who can be an added joy!

Do we actually want to have children?

This is something only the two of you can and should decide and will entail considerable discussion and soul-searching, possibly over an extended period. External peer/parental and family pressure should be ignored if at all possible. Indeed many fertile couples choose not to have children for one reason or another so if this is the decision you jointly come to as long as you are completely comfortable with it then any external pressure or comments can and should be ignored. Some women with TS are vulnerable and could be pressurised into undergoing IVF/Adoption against their better judgement just to please when personally it may not actually be what they want to do.

Partner quote: "We found how to love each other for what we are"

7. They may exhibit an inability to see alternative points of view to their own. This is not because they do not want to but that they did not anticipate there could be a different one. Listening, hearing and understanding what is said is as important as talking. Great patience and tact may be necessary to gain their understanding of another view.
8. Mood swings are common with HRT. Often women will not be aware that the HRT cycle causes mood changes so this is an important area for open discussion. By experimentation with the many types of HRT it should be possible to find one with few side effects.

A woman with TS cannot change how she was born however she can be encouraged to develop skills to help overcome some of the above. Inevitably "Turner" traits are discussed at TSSS Conferences most years.

What benefits does Turner Syndrome Support Society membership give?

The TSSS holds an Annual Conference, giving updates on Clinics, research and treatment management along with workshops on areas of special interest for example adoption, driving instruction, hearing, IVF, psychological issues or sexuality. You should be aware that your partner may find these intensive sessions stressful and could become emotional at some point. Despite this they appreciate attending and you should continue to maintain your encouragement.

Additionally attending conference allows social interaction; meeting and chatting are good therapy and talking is something most women warm to. Swapping notes with other women with TS reinforces that they are not alone in their troubles and can also produce solutions in areas they are having difficulties overcoming.

To this point the booklet may seem to have been just about women with TS but a relationship has to be a two-way thing and to make it work needs a Couple. We men have the benefit of the TSSS being the only Turner Society world wide, that includes men in its Conference sessions which also just happen to be enjoyable social occasions. Conferences are also a great way of making long term friendships and exchanging experiences of living day to day with TS.

The Society also holds a series of Open Days throughout the country (between three and four a year), quite often with a specific theme suggested by members locally. The main purposes of these, however, is to provide opportunities for members to get together socially, exchange ideas, and discuss all aspects of living with TS day to day.

Partner quote: "I was attracted by what you are – not what you are not."

Endeavour to encourage her to attend local group social events and if appropriate participate yourself. Meeting up with a group of like-minded people can be most enjoyable and rewarding.

Can assistance be gained from other sources?

Yes

Some women with TS, in particular those who have had a late diagnosis of TS may benefit from counselling.

Are there typical "Turner" traits?

Possibly! The following list give traits that may be emphasised in some women with TS but not all.

Ed's note: At the risk of seeming a wanton male chauvinist I am led to believe that many of the following traits are not solely restricted to women with TS but I'm led to believe may apply to the male species also:-

1. A lack of self-confidence stemming in part at least from delayed puberty and reduced stature, which, during the sensitive teenage years, may have given rise to feelings of difference from their peers. They may also feel a sense of feminine incompleteness owing to their infertility. This lack of self-confidence can result in a sense of insecurity leading, in some women, to compulsive/irrational behaviour.
2. Conversely to 1. above they may instead be strong willed if their parents have encouraged them to be independent.
3. Low self image/self-esteem. This can be laid at the door of their short stature, which serves to accentuate any gains in weight, which they may undergo. Low self esteem and lack of assertiveness can make women with TS particularly vulnerable in the workplace, especially where there is sexism and bullying involved.
4. Spatial awareness problems:- a lack of hand-eye co-ordination can make ball sports more difficult and also lead to problems with driving (a lack of confidence in judging distances). They may give the appearance of being accident prone and/or clumsy; this is just the way they are!
5. Underdeveloped social skills and difficulty in reading facial expressions/ misreading body language. This can lead to misunderstandings in social situations.
6. Inflexibility in coping with changes of plan in a daily routine, arising from a fear of the unknown, can lead to confusion or panic and refusal to do anything different.

The TSSS is aware of couples within the Society who have consciously decided not to have children and are comfortable with their choice and getting on with living their lives so please bear with us, or indeed skip the following section if having children is not your choice. Be aware, and this does not necessarily depend on what your decision relating to having children is, that external events such as a sister or friend becoming pregnant or someone you know having a baby, for example, can serve to be painful reminders to your partner of her sense of feminine incompleteness; Mothering Sunday, for example, could have the same effect.

What options are available to a couple wishing to have children?

Broadly speaking there are three routes to achieve this. These being: Adoption, Fostering and Invitro-fertilisation (IVF). Adoption is regarded by the majority of the current TSSS Couples Group as 'when' you will have children, whereas IVF is viewed as 'if' you might have a child. Unplanned pregnancies are a remote possibility and it is therefore recommended that barrier (condom) contraception should be practiced if only as a sensible general health measure.

Women with TS considering pregnancy must have a full cardiological assessment before attempting to become pregnant. Any women with TS who has the potential of a natural pregnancy should seek the advice of a Genetic Counsellor, it is important that they are informed of the possible increased chance of the baby having a chromosome abnormality i.e. Down's syndrome or TS itself. Those contemplating IVF together with their partner, should in most cases, be offered genetic counselling as part of the IVF process. Genetics is a complicated subject and therefore best explained by a geneticist. Ideally women with TS who are pregnant should be cared for in a specialist obstetric centre.

In respect of infertility TS should be viewed as a major benefit as the reason for your childlessness is known, and therefore requires no specific ongoing investigation to determine the reason for infertility. If, however, you do choose to explore the IVF option you will both be subject to some investigative procedures.

1. Adoption

Most couples with a partner who has TS achieve children via this route. Just because they are not genetically yours does not mean you will love them any less. It is unlikely that the choice of available children will include babies (due to changing moral values – a lot of single mother's retain their babies) but babies, when available are almost always offered to younger couples. Toddlers, however, are certainly possible and older children are definitely available to all. Couples have been known to go abroad to adopt babies and BAAF (see contacts page 18) can provide more information. Typically the approval/placement procedure can take between twelve to eighteen months.

Usually twelve months following a child's placement with adoptive parents the court process via which the child/ren legally become yours will commence. Some birth family contact can be required during and following adoption although this can be restricted to corresponding via an independent letterbox only. Face to face birth parent contact can be required and if at all possible, during the introductory period with prospective child/ren, Adoption Agencies may try to facilitate a face to face meeting with the birth family. Contact with siblings is usually face to face but may only be via letterbox. Every case is individual and contact will be discussed and agreed during the introductory period. For adoption agencies in your area contact the BAAF (see contacts page 18).

2. Fostering

If you are unable to entertain the commitment or expense that either adoption or IVF involve you might want to consider Fostering. The child/ren remains under Local Authority care and birth family contact is actively encouraged. The placement can be either short term, while the parents resolve their difficulties if possible or Social Services find an adoptive family or long term until the age of 18 if adoption is not considered by the Local Authority social workers to be in the child/ren's best interests.

3. Invitro Fertilisation (IVF)

With fertility treatment a child of your own is possible by IVF with eggs donated by another altruistic woman via an infertility Clinic. If successful this can lead to a live birth. In some Health Authority areas it may be possible, to receive IVF treatment on the NHS and it is always worth writing to them to explain your need for IVF with egg donation due to your partner's TS. However if circumstances mean that you might have to undertake IVF treatment as a private patient be aware that this will be a considerable financial commitment. If considering a private clinic then it would be wise to check its credentials with the HFEA or Infertility Network (see contacts page 18) IVF will require you to be well prepared psychologically as a couple as it can be very stressful and sadly not always successful.

Partner quote: "My husband knew about my having TS and the infertility as he was a friend long before we were married. We did discuss this and he said he didn't want children anyway and it has never been an issue between us. To love a child, to raise a child, and above all to do something meaningful in a child's life it does not have to come from your womb."

What research is currently being done in infertility treatment?

Research is constantly advancing the boundaries in the treatment of infertility. IVF with egg donation has only been in use since 1984. A team in America (Harvard University) are looking at the genes responsible for egg loss in females, which may have implications for the premature ovarian failure that occurs in TS. Another area of research, presently in its infancy, which may translate eventually to the human domain, is ovarian tissue removal for later re-implantation.

Every year we hear in the press of new breakthroughs in fertility treatment. Many of the new treatments will not be useful for women with TS because the eggs are absent from a very young age and cannot be retrieved. If some new treatment looks particularly interesting the TSSS will usually be able to find an expert to provide information.

What can a woman with Turner syndrome achieve?

Just as other women – anything she wants. A high proportion of women with TS seem to gravitate towards care professions however members of the TSSS work at a wide spread of different occupations. If she wants to achieve something she will, particularly with suitable encouragement and support from those close to her.

The TSSS has members who have now been married for a good number of years leading normal family lives, which for some has even included coping with grandchildren!

What can you do to help?

Any relationship requires commitment, honesty, openness, patience, tolerance and understanding from both parties, and everyone benefits from praise and encouragement.

You should never treat a woman with TS any differently to other women; be understanding but never condescending or patronising.

Most importantly you should support your partner in any efforts towards self-fulfilment and discourage her from using her Turner syndrome as an excuse for under achieving. Provide positive reassurance and permit her to do as much as possible for herself.

Show you are interested/care by offering to accompany your partner to medical appointments; she may turn you down but if you do not volunteer she will not know you are prepared to make the effort to go with her.

Where possible with Conferences/Open Days be prepared to get involved by attending with your partner. It encourages her to go and it is extremely beneficial for both of you to meet other people with TS, and their partners, to affirm that she is not alone in her condition.