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Who is the woman that I am less than anyway?

An information leaflet for women
who have TS looking at self esteem
and how to improve it.

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This leaflet is intended as a guide for women who have Turner Syndrome (TS) with self esteem feelings and issues they face. It has been produced by Dr Paul Chadwick, a Clinical Psychologist with expertise in TS, and members of the Turner Syndrome Support Society (TSSS).



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The leaflet is provided as a guide only and is by no means definitive. More comprehensive medical information can be obtained by reading "Turner Syndrome Lifelong Guidance & Support" available from the TSSS office. For additional reading refer to the Bibliography.

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Abbreviations

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

TS = Turner syndrome

TSSS = Turner Syndrome Support Society (UK)

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Background

In 2008, thirty women with TS participated in Living with Turner Syndrome workshops held in London and Manchester. They met as a group to discuss the challenges of living with TS. Some of the women talked about how feeling 'different' had prevented them from appreciating themselves and living their lives more fully. They felt that other women with TS might benefit from what they had learned and this leaflet has been produced as a way of sharing their experiences.



Living Well With Turner Syndrome

Turner syndrome is a complex genetic disorder arising from the complete or partial absence of the X chromosome in typical females. Living with Turner Syndrome as an adult woman has its own unique set of challenges, whilst others are shared with all women, regardless of genetic make-up. The key to Living Well With Turner Syndrome may lie – in part - in appreciating how women, parents, friends and the general public think about the differences between women with and without TS.

Empty Labels

Variations in the make up of genes keeps the human race thriving. Unfortunately, public understanding of this entirely normal genetic variation is poor, and is often laced with prejudice. Without meaning to, science and medicine can contribute to such social prejudice by scrutinising people with genetic conditions to establish how they are different from those that are so-called ‘genetically normal’. In research, it is mostly the differences between people that get emphasised and publicised and sometimes those who are the objects of such studies come to see themselves in the same way; as a collection of ‘deficits’ or ‘differences’. It is no wonder that many people with genetic conditions find it hard to maintain a strong sense of positive self worth.

Although it is important to understand the influence of genes on personal, social and medical development, this search for ‘difference’ can obscure the most important fact of all: that people with genetic conditions and those without are actually far more similar to each other than they are different. Women with TS are Women First and as women they share all of the same opportunities, challenges, hardships and joys faced by women without TS.

Women usually have two X chromosomes. In TS, part or all of one of them is absent. Because of this, some women with TS say they feel confused about whether or not they are ‘real’ women. This self doubt and an associated sense of shame can prevent them from being open about TS. For some women this has had a negative effect on their lives – causing them to avoid friendships and romantic relationships for fear of being rejected. But being a ‘real’ woman is much more than having a particular set of chromosomes arranged in a particular way – there are plenty of women with two X chromosomes that don’t fit into conventional definitions of femininity, and genes

do not mean gender. Women with TS are a very diverse group with a wide range of skills and abilities – they can, and do, live rich and rewarding lives.

Some women with TS say that compared to their peers, they seem to have more difficulties in social understanding and communication, whilst others say that they have more difficulties with planning and organising themselves. It can help to be more aware of these very specific needs and seek help and support from other women with TS.

Women with TS have shown themselves to be an extremely resourceful group who are particularly good at problem solving. Most of the difficulties with social communication and planning can be addressed with the right support and strategies – but many women with TS are not aware of this and struggle on in silence. As the awareness and understanding of these difficulties grows so too does the possibility of help. The TSSS has a lot of experience of helping women successfully overcome these challenges.





Who exactly am I comparing myself to?

From a young age girls are trained to scrutinise themselves for imperfections. As they grow up, they become more prone than boys and men to compare themselves unfavourably against idealised but impossible standards. For women, advertising and media images of the ‘perfect woman’ are specifically designed to create feelings of anxiety and inadequacy which stimulate the desire to purchase the products marketed to help

them feel better about themselves. Repeated exposure to such idealised images can make women – regardless of whether they have TS or not – feel unnecessarily diminished and inadequate.

It may be good for self esteem if women, with or without TS, were to regularly ask themselves what kind of ‘femaleness’ benchmarks are they hoping to reach? In fact, experts on women’s emotional well-being recommend that this is essential for successful psychological development for any female. The airbrushed image of the tall, young, slim woman with flawless skin, hair and teeth and impossibly long and slender legs is not a real person; it’s a manufactured and biologically impossible image. But, whilst most women know this for a fact, almost all continue to judge themselves for failing to live up to unrealistic ideals.

All women – whatever their genetic make-up – have to find their own response to the pressure generated by this narrow and restrictive view of femaleness. Women with TS are no different.

So, women with TS face many of the same challenges as other women, alongside the unique challenge of living with TS. They also need to ask the same searching questions – of themselves, but also of the society in which they live. It is harder to devalue yourself if you can keep reminding yourself that there are many kinds of women in the world living many different kinds of lives. TS offers women the rare opportunity to reflect on just how many different ways there are to be a woman, and to decide on what kind of woman she wants to be. This is an opportunity that many women without TS do not have – with the result that many feel trapped by the limitations that society imposes on their gender.

Top 10 Tips on learning How to Value Yourself

Women taking part in the ‘Living With Turner Syndrome Workshops’ were asked to share their most effective strategies for dealing with the challenges of adult life with TS. These are their 10 top tips:

- 1** All human beings are unique yet equal - remind yourself of this as often as you can.
- 2** Focus on what you have to offer. Ask yourself how you can best play to your strengths – and be pro-active in making sure that others do the same.
- 3** Learn to accept and return compliments. Others will see positives in you that you don’t recognise in yourself – listen to them and make a pledge to integrate what they see into your own sense of yourself.
- 4** Apologise for your mistakes, not for being who you are.
- 5** Good things in life involve risk. The “if you don’t try, you can’t fail” philosophy can keep you stuck.
- 6** Making effective changes in your life is a skill that requires practice. Start with a willingness to step out of your comfort zone, cut the task into small chunks and take it one step at a time.
- 7** If you need help, ask for it clearly and honestly. Don’t wait to be rescued – this is a sexist stereotype that you definitely don’t need to live up to.
- 8** Don’t try to read people’s minds and remind yourself that no-one will be as hard on you as you are on yourself. Give people a chance to surprise you – in a nice way!
- 9** If you are struggling to think positively about yourself then don’t suffer in silence. Talk to others in a similar situation with a commitment to opening yourself up to seeing things differently. Keep a diary of more helpful ways of thinking and read it back to yourself regularly. Challenge your negative thoughts to see if they are true.
- 10** Remember: no one can chip away your self-esteem without your permission.

Summary

All women – regardless of their genetic make-up – are exposed to narrow and restrictive ideas about what it takes to be a woman. TS can offer women an interesting opportunity to reflect on the many different ways there are to be a woman and to think creatively about what kind of woman they want to be. For modern women developing a positive self-image means questioning the unrealistic and impossible benchmarks that society puts forwards.

This means questioning the whole notion that there is such a thing as a ‘real woman’. Women with TS may be particularly prone to negative self-judgement and devaluation. Learning how to deal effectively with this is an important part of living with TS. As with any other skill, learning to value yourself requires practice, and sometimes support. Whilst most women with TS manage perfectly well without specialist support, acknowledging and seeking support when needed is an important step in the lifelong journey to Living Well With TS.

