

RECOMMENDED SPECIALIST CARE FOR ADULTS WITH TURNER SYNDROME

The Turner Syndrome Support Society [TSSS] has put together this information for the benefit of women with Turner Syndrome [TS], their GPs and other health professionals involved in their care. Not all may be aware that there are specialist TS clinics available to them [see over], or of the required specific specialist care.

“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.

The health care profession has been slow to realise the range of problems that women with TS may face particularly the risk of cardiovascular complications and the long-term consequences of oestrogen deficiency. Oestrogen replacement is important from an early age for gynaecological health and prevention of osteoporosis [1]. Some women with TS are in fact susceptible to a number of specific medical problems as well as cardiovascular disease. These can include osteoporosis, thyroid, gastrointestinal and kidney disorders, hearing problems and diabetes.

Quality of life in women with TS may be improved with access to better care as adults. Most women with TS require **long-term follow-up**, and early treatment for any possible problems will ensure they have the best possible quality of life, and that their life expectancy is as good as for women without TS. In many cases, relatively simple preventative measures will address these issues.” [ii]

PREVENTION IS BETTER THAN CURE

Health Checks for an adult with TS

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 to calculate body mass index (BMI); blood pressure; cardiovascular assessment etc. and almost certainly thyroid function, lipid analysis, blood glucose, 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.

“Women with TS considering an assisted pregnancy [IVF] should have a full cardiological assessment before becoming pregnant. Because hypertension is more common in women with TS this should be monitored and actively treated. The minority of women with TS who are able to consider natural pregnancy should also have a full cardiological assessment before becoming pregnant and should have access to genetic counselling because of a number of possible problems. Ideally women with TS should be cared for in a specialist obstetric centre.” [iii]

Other possible issues to be considered

Genetic counselling - all women with TS should be offered genetic counselling - only their parents may have had the benefit of genetic counselling in the past.

Psychotherapy – some women with TS benefit from sessions with a psychotherapist/psychologist for help with problems of self-esteem.

Inflammatory bowel disease [IBD] & Coeliac disease – it would 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.

Feet – is an area which sadly is ignored in TS. Girls and women with TS are particularly at risk from in growing toenails as they often have increased transverse curvature of the nails. Referral to a podiatrist is recommended to prevent infection.

Lymphoedema [swelling of one or more limbs caused by failure of the lymphatic vessels to drain fluid from the tissue spaces] – is another area where women with TS do not currently receive appropriate treatment. Referral to a lymphoedema nurse specialist may be beneficial

Recommended further reading & Refs. [i, ii & iii] "Turner syndrome – lifelong guidance & support" available from the TSSS 12 Simpson Court, 11 South Ave, Clydebank Business Park, Clydebank, G812NR

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Adult TS Clinics 06/2017

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