



# PAEDIATRIC AND ADULT HEALTH CHECKLIST FOR THE MANAGEMENT OF TURNER SYNDROME

It is usually recommended that the overall care plan should be managed by a paediatric endocrinologist in a regional growth clinic. The endocrinologist will see the patient regularly to monitor their growth, puberty development and later transition to an adult service.

The endocrinologist should take on the additional role of supervising and coordinating other aspects of care.

Rather than be prescriptive in areas where there is debate over the detail of management, the following checklist is a recommendation that can then be audited.

This checklist will also ensure continuity of care between the clinical departments that manage Turner Syndrome.

Further copies can be obtained from: [www.tss.org.uk](http://www.tss.org.uk) and [www.ipSEN.co.uk](http://www.ipSEN.co.uk)

## PAEDIATRIC CHECKLIST

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

Postcode: \_\_\_\_\_

Date of birth: \_\_\_\_\_

NHS No:

DIAGNOSIS:	Date	How was it diagnosed?
Pre-natal		
Post-natal		

AT DIAGNOSIS:	Yes/No	Date
Karyotype: specify		
<ul style="list-style-type: none"> <li>• Y chromosome material checked by FISH</li> <li>• Gonadectomy performed if Y sequences</li> </ul>		
Genetic counselling referral		
Cardiology referral		
Pelvic/renal ultrasound		
Support group referral		

GROWTH:	Yes/No	Date
GH treatment started		
GH treatment stopped		
Oxandrolone treatment started		
Oxandrolone treatment stopped		

PUBERTY:	Yes/No	Date
Spontaneous puberty		
If spontaneous puberty has not occurred by 10 years check LH/FSH and consider pelvic ultrasound		
Puberty induced		
First period		
Hormone replacement therapy/OCP: specify		

EDUCATIONAL:	Yes/No	Comments
Mainstream school		
Additional support: specify		
Specific educational difficulties: specify		

GENERAL:	Frequency
Height	Each outpatient visit
Weight	Each outpatient visit
BMI	Each outpatient visit
Blood pressure	Each outpatient visit
Thyroid function	12-24 monthly
Thyroid antibodies	12-24 monthly
Coeliac antibodies	12-24 monthly
Glucose and HbA1c	Annual
Glucose tolerance test	As required
IGF-1	Annual
Insulin level	As required
Liver function	Prior to puberty induction and adult transfer
Bone age	Annual
Pelvic/renal ultrasound	At diagnosis and as required
Dietary advice	As required
Hearing	As required
Speech problems:	
<ul style="list-style-type: none"> <li>• Self assessment</li> <li>• Referral to speech and language therapist</li> </ul>	As required As required
Cardiology referral	At diagnosis and as required
Ophthalmology referral	As required
Podiatry referral	As required
ENT referral	As required
Dermatology referral	As required
Orthopaedic referral	As required
Orthodontic referral	As required
Clinical psychology referral	As required
Genetics referral	At diagnosis and as required
Support group referral	At diagnosis and as required

# ADULT CHECKLIST

TRANSITION TO ADULT CARE:	
Referral to adult endocrinologist with an interest in TS	
Referral to specialist TS clinic	
Referral to cardiology	
Referral to GP	
Referral to gynaecology	
General counselling	
Post-GH assessment of:	
• Final height	
• Weight	
• BMI	
• Blood pressure	
• Thyroid function	
• Thyroid antibodies	
• Glucose tolerance test	
• Insulin level (fasting)	
• Lipid levels	
• Liver function	
• Renal function	
• Bone densitometry	
• Pelvic ultrasound (include uterine size)	
• Abdominal ultrasound	
• Echocardiogram	

GENERAL:	Advised every visit:
Weight	✓
BMI	✓
Thyroid function	Annual
Renal function	Annual
Liver function	Annual
Lipid profile	Annual
Oral glucose tolerance test	5 yearly
Thyroid and coeliac autoantibodies	5 yearly
Quality of life	As required

## References

1. Bondy CA. *Jnl Clin Endocrinol and Metab.* 2007;92:10-25
2. Saenger P, Albertsson Wikland K, Conway GS et al. *Jnl Clin Endocrinol and Metab.* 2001;86:3061-3069

HRT:	Advised every visit:
Adequate dose?	✓
Optimal route?	✓

Cardiology:	Advised every visit:
Blood pressure	✓
Echocardiogram	3-5 yearly
MRI	Pre-pregnancy
Cardiology referral	As required

Audiology:	Advised every visit:
Hearing deficit awareness?	✓
Ongoing ENT problems	✓
Hearing aid	As required
Hearing test	5 yearly

Reproduction:	Advised every visit:
Fertility plans	✓
Sexual function	✓
Uterus ultrasound	Pre-pregnancy

Bones:	Advised every visit:
Fracture history	✓
Bone density	5 yearly

Social:	Advised every visit:
Work place history	✓
Relationships	✓
Mood history	✓
Clinical psychology referral	As required