

PAEDIATRIC AND ADULT HEALTH CHECKLIST

FOR THE MANAGEMENT OF TURNER SYNDROME

The overall care plan for girls with Turner syndrome (TS) should be managed by a paediatric endocrinologist and their team in a specialist centre. The paediatric endocrinologist will see the individual regularly to monitor all aspects of their condition including growth and pubertal development. The paediatric endocrinologist will manage a planned, coordinated and staged transition process for the girl in later adolescence to an adult service (either endocrinology or gynaecology, or ideally both) with an expertise in providing care for women with TS. Ideally the transition process will take place in a dedicated joint paediatric/adult clinic.

The adult service at a TS specialist clinic should supervise and coordinate all aspects of comorbidity management.

This TS Health Checklist will ensure continuity and consistency of care between paediatric and adult services that are involved in the management of girls and women with TS.

Further copies of the TS Health Checklist can be obtained from:

www.tss.org.uk or email turner.syndrome@tss.org.uk

For reference and further information:

- Gravholt CH, Andersen NH, Conway GS *et al.* Clinical practice guidelines for the care of girls and women with Turner syndrome: proceedings from the 2016 Cincinnati International Turner Syndrome Meeting. *European Journal of Endocrinology* 2017;177:1-70.
- TS Support Society information should be provided to all girls and women with TS, as well as their families, at diagnosis and throughout their care.
- Cardiac Alert cards are available for girls and women with TS that alert paramedics, doctors, nurses and all healthcare professionals about the possible heart complications associated with TS.

PAEDIATRIC HEALTH CHECKLIST

Name: _____

Address: _____

Postcode: _____

Telephone: _____ Mobile: _____

Date of birth: _____ NHS No.: _____

Reference: Gravolt CH, Andersen NH, Conway GS *et al.* Clinical practice guidelines for the care of girls and women with Turner syndrome: proceedings from the 2016 Cincinnati International Turner Syndrome Meeting. *Eur J Endocrinol* 2017; 177(3):1-70.

DIAGNOSIS

TS DIAGNOSIS	Date	Age	How was TS diagnosed?
Pre-natal			
Post-natal			
AT DIAGNOSIS	Date	Yes/No/Result	
Karyotype			
Presence of Y chromosome			
Referral for gonadectomy			
Genetic counselling referral			
Cardiology referral			
Transthoracic echocardiography (TTE) and CT/cardiac magnetic resonance scan (CMR) for adolescents			
Hearing examination			
Ophthalmological examination			
Speech and language assessment			
Referral			
Pelvic and renal ultrasound			
TS Support Society information provided			
Cardiac Alert card provided			

MONITORING AND MANAGEMENT

GENERAL	Date	Date	Date
Check at each outpatient visit	Result	Result	Result
Height			
Weight/Body Mass Index			
Waist/hip ratio			
Blood pressure			
Check annually			
Thyroid function			
Glucose and HbA1c			
Bone age			
IGF-1			
Liver function tests from age 10 years			
Check 2-3 yearly			
Thyroid antibodies (TPO)			
Vitamin D			
Coeliac antibodies (tTG)			
As required			
Dietary and exercise advice	Clinical psychology referral	Dermatology referral	
Hearing and ENT referral (yearly if concern)	Ophthalmology referral	Dental/orthodontic referral	
Orthopaedic referral	Podiatry referral	Lymphoedema referral	
GROWTH	Date	Date	Date
	Yes/No	Yes/No	Yes/No
Growth hormone treatment			
Name:			
Dose:			
IGF-1 measurement			
Check for scoliosis annually			
Growth hormone stopped			
Oxandrolone started			
Oxandrolone stopped			

PUBERTY	Date	Date	Date
	Yes/No	Yes/No	Yes/No
Spontaneous pubertal development			
Age:			
Breast development stage			
Spontaneous menarche			
Age:			
Puberty induced			
First period			
Low-dose oestrogen replacement			
Name:			
Dose:			
Breakthrough bleeding			
Progesterone			
Name:			
Dose:			
Counselling on role of oestrogen and bone health			
Sexual function, fertility/ cryopreservation discussion			

ACADEMIC/SOCIAL	Date	Date	Date
	Yes/No	Yes/No	Yes/No
Mainstream school			
Additional support required			
Neuropsychological assessment at key transitional stages			
HEEADSSS questionnaire:			
Home			
Education/employment			
Eating			
Activities			
Drugs			
Sexuality and			
Suicide/depression			
Safety			
Specific difficulties			

TRANSITION ACTIONS

TRANSITION TO ADULT CARE	Date	Date	Date		
	Yes/No	Yes/No	Yes/No		
Referral to adult endocrinologist/ gynaecologist with an interest in TS					
Specialist TS clinic referral					
Cardiology referral					
Gynaecology referral					
Fertility counselling					
Genetics referral					
Psychological support					
Post-growth hormone/pubertal induction assessment	Result	Date	Result	Date	
Final height			Liver function		
Weight/BMI			Renal function		
Blood pressure			Vitamin D +/- bone density		
Thyroid function			Pelvic ultrasound (include uterine size)		
Thyroid antibodies (TPO)			Renal ultrasound		
Glucose/HbA1c			Echocardiogram/CMR		
			Bicuspid aortic valve		
			Aortic diameters		

ADULT HEALTH CHECKLIST

Name: _____
 Address: _____

 Postcode: _____
 Telephone: _____ Mobile: _____
 Date of birth: _____ NHS No.: _____

Reference: Gravolt CH, Andersen NH, Conway GS *et al.* Clinical practice guidelines for the care of girls and women with Turner syndrome: proceedings from the 2016 Cincinnati International Turner Syndrome Meeting. Eur J Endocrinol 2017; 177(3):1-70.

DIAGNOSIS

TS DIAGNOSIS	Date	Age	How was TS diagnosed?
Pre-natal			
Post-natal			
AT DIAGNOSIS	Date	Yes/No/Result	
Karyotype			
Presence of Y chromosome			
Referral for gonadectomy			
Genetic counselling referral			
Cardiology referral			
Transthoracic echocardiography (TTE) and CT/cardiac magnetic resonance scan (CMR) for adolescents			
Hearing examination			
Ophthalmological examination			
Pelvic and renal ultrasound			
TS Support Society information provided			
Cardiac Alert card provided			

MONITORING AND MANAGEMENT

GENERAL	Date	Date	Date
Check at each outpatient visit			
Weight/BMI			
Waist/hip ratio			
Blood pressure			
Check annually			
Thyroid function (TSH)			
Renal function			
Liver function +/- US/fibroscan			
Lipid profile			
HbA1c/Oral Glucose Tolerance Test			
Check 3-5 yearly			
Thyroid antibodies (TPO)			
Coeliac antibodies (tTG)			
HEART/BLOOD PRESSURE (refer to guidelines)	Date	Date	Date
	Review	Result	Result
Blood pressure	Yearly		
Antihypertensive Name:			
Dose:			
Echocardiogram/CT Coarctation?	3-5 yearly		
Bicuspid aortic valve?			
Other anomalies?			
CMR and measurement (mm) or indexed for BSA of:	1-10 yearly according to risk		
Aortic arch (AA)			
Aortic sinus (ASI)			
Cardiology referral			

HORMONE REPLACEMENT THERAPY	Date	Date	Date
Each outpatient visit	Yes/No	Yes/No	Yes/No
Name:			
Dose:			
Check dose/route is optimal			
Vaginal oestrogen required			
Dose:			

FERTILITY AND REPRODUCTION	Date	Date	Date
	Review	Result	Result
Sexual function	Yearly		
Pre-conception counselling	As required		
Fertility discussion +/- referral	Yearly		
Uterus ultrasound	Pre-pregnancy		
Cardiology review with pre-conceptual imaging of thoracic aorta and heart with TTE/CMR (see guidelines)	Pre- and post-pregnancy		

PREGNANCY	Date	Date	Date
	Yes/No/Result	Yes/No/Result	Yes/No/Result
Spontaneous/assisted			
Pre-conceptual referral for pregnancy management by multidisciplinary team with TS expertise (see guidelines)			
TTE pre-pregnancy, (review at 20 weeks gestation increase frequency if required - see guidelines)			
Blood pressure (review at each outpatient visit +/- treatment)			
Cardiac symptoms (review at each outpatient visit)			
Delivery plan (pre-pregnancy/ 1st visit/as required)			
Monitor as required:			
Thyroid			
Glucose			
Vitamin D			
TTE/CMR post-pregnancy			
Liver function tests			

HEARING	Date	Date	Date
	Review	Result	Result
Hearing problems	Yearly		
Hearing test	1-5 yearly		
Hearing aid	As required		

BONE/SKIN	Date	Date	Date
	Review	Result	Result
Bone protection	Yearly		
Fracture history	Each outpatient visit		
Bone density	3-5 yearly		
Spine T or Z score			
Hip T or Z score			
Naevus change	Yearly		

SOCIAL	Date	Date	Date
	Review	Result	Result
Discuss home situation and relationships	Each outpatient visit		
Monitor employment status	Yearly		
Workplace stress	Each outpatient visit		
Mood assessment	Each outpatient visit		
Anxiety	Each outpatient visit		
Obsessive behaviour	Each outpatient visit		
Clinical psychology referral	As required		