

ADULT CARE RECOMMENDATIONS

SCREEN AND ASSESSMENT FOR TURNER SYNDROME

BY THE ENDOCRINE SOCIETY

ENDOCRINETRANSITIONS.ORG

You are now independently in charge of your healthcare and are able to make your own healthcare decisions. This is an exciting time for you, but also can be overwhelming. These recommendations will help you ease into your new role. Remember you are the most important part of your medical team. Know your facts and advocate for yourself.

CARE RECOMMENDATIONS

Below is a list of recommendations for care of adults with Turner Syndrome. Your physicians should be familiar with these recommendations, but if not, you should feel comfortable making them aware of the recommendations. In addition, be sure to ask if the recommendations have ever been updated.

WHO IS RESPONSIBLE FOR WHAT?

In order to avoid confusion you and your care team should be clear on who is responsible for managing different aspects of your care. The goal is to minimize missed recommendations without duplicating the recommendations. You can use this sheet to be sure each component is delegated to a certain physician.

REMINDER

Though not in the following chart, we want to highlight one set of physical findings that are more prevalent in adults with Turner syndrome of which you and your doctors should be aware. Chest pain and shortness of breath can signify something called aortic dissection. Unfortunately this can be dangerous and even fatal. If you experience chest pain or shortness of breath it is important for you to seek immediate medical care.

WHO MAKES UP YOUR HEALTHCARE TEAM?

Finally, we want to address the composition of your adult care team. As an adult, different physicians have expertise in different areas. Each person with Turner syndrome may have different types of physicians on their care team, depending on their needs. The types of physicians with expertise in Turner syndrome in your area may also drive the type of doctors on your team. Some people will see only a primary care physician and a reproductive endocrinologist. Some will see a primary care physician, adult endocrinologist and gynecologist. Depending on your health issues you may be seeing other specialists as well. You may want to speak with your current doctors to get their input on which types of physicians should make up your team and which adult specialists have an expertise in Turner syndrome.

ABC'S OF STAYING HEALTHY WITH TURNER SYNDROME

- A) Be active and eat healthy
- B) Keep your blood pressure normal
- C) Take estrogen as prescribed

SCREENING RECOMMENDATIONS	RESPONSIBLE PROVIDER				
	Primary Care	Adult Endocrine	Gynecologist or Reproductive Endocrinologist	Cardiologist	Other
Laboratory Studies (Annually)					
CBC					
BUN/Creatinine					
HgbA1c, fasting glucose					
Lipid profile					
Liver enzymes (ALT, AST, GGT, alk phos)					
Free T4, TSH					
Transglutaminase antibody					

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	Primary Care	Adult Endocrine	Gynecologist or Reproductive Endocrinologist	Cardiologist	Other
Laboratory Studies (Annually)					
If HLA DQ2 or 8 absent, can likely skip					
Vitamin D					
OGTT if indicated					
Urinalysis					
Screen for Cardiovascular Risk Factors					
Blood Pressure					
Baseline EKG, then as indicated					
Baseline cardiac MRI/MRA, if not completed previously					
Surveillance imaging of Aorta Cardiac MRI/MRA vs Echocardiogram Every 5-10 years Referral to cardiology if abnormal					
Audiology Evaluation: Every 1-5 years, adjust for individual needs					
Screen for Bone Health: Baseline DEXA(adjusted for size) If normal-repeat at 40-50 yrs old					
Reproductive Health:					
Routine gynecologic care and pap smear					
Management of estrogen/progestin therapy					
Discuss and assist with reproduction options					
Psychosocial Issues: Annual evaluation as indicated					
Obesity risk assessment: BMI goal < 25 kg/m ² ; waist/hip <0.8					
Other: Referral and management of consultants					