Factsheet 12

Turner Syndrome and **Hypertension**

TURNER SYNDROME
TSSS
SUPPORT SOCIETY [UK]

The heart works by pumping blood around your body to deliver oxygen and nutrients to your organs. Your blood pressure is the force your heart uses to pump blood around your body through the arteries, which are your blood vessels. You need some pressure to keep your blood moving around your body. Your blood pressure naturally goes up and down, especially when moving or exercising. If your blood pressure is always high, even when you are resting, then you have developed hypertension or high blood pressure.

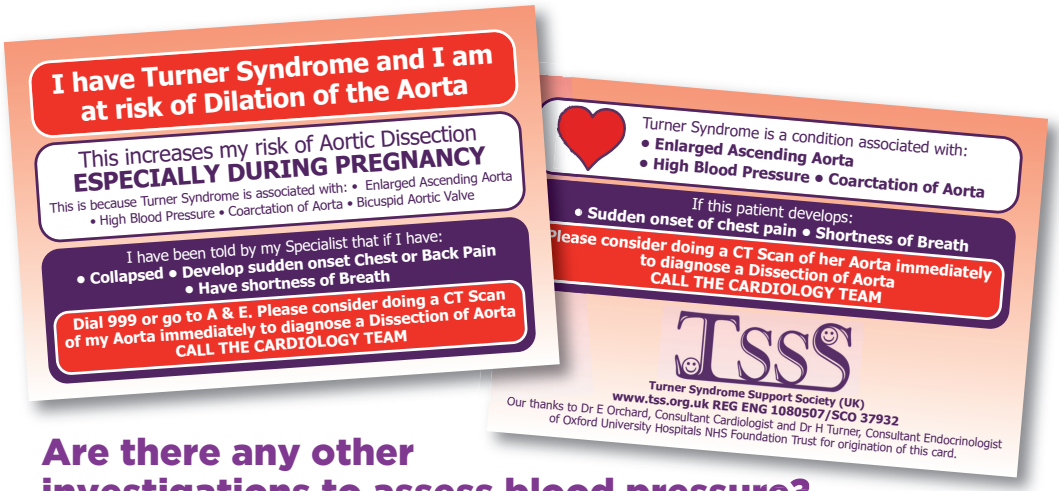
Your blood pressure is measured using a blood pressure cuff placed on your arm. When you have your blood pressure measured, your reading is written as two numbers. The first is when the pressure is at its highest (or systolic pressure), for example in adults 120mmHg and the second is when it is at its lowest (or diastolic pressure), for example 80mmHg. Your blood pressure in adults should be under 140/90 mmHg. In younger girls, centiles for BP are used.

Hypertension can be due to many factors including your diet, lifestyle or because you have a medical condition which increases the risk of having a high BP, for example coarctation of the aorta. Around 50% of women with TS do suffer from Hypertension. Drinking too much alcohol, eating too much salty food, smoking, being overweight and not doing enough exercise can all increase your BP.

What are the signs and symptoms of hypertension?

It is difficult to know if you have high blood pressure without measuring it, as many people do not experience any signs or symptoms of high BP. Often people present firstly to hospital or their doctor with a medical problem which has been caused by their high blood pressure. Therefore it is important for women with TS to have regular routine surveillance blood pressure monitoring.

High blood pressure can lead to heart and circulatory diseases like heart attack or stroke and can affect your kidneys. High blood pressure means that your heart has to work harder to pump blood around your body, so the pressure is always higher than it should be. If you have high blood pressure, your aorta, the main blood vessel coming out of the heart can enlarge and over time there is a risk of the aorta tearing.



Are there any other investigations to assess blood pressure?

Occasionally your medical team may require additional blood pressure recordings, especially if blood pressure medication has been commenced. A 24-hour blood pressure monitor maybe arranged. This is when you wear a blood pressure cuff and machine for the day and night.
The blood pressure recordings are then reviewed by your medical team to help provide an overview of your blood pressure to help guide treatments.

What are the treatments for hypertension?

You can improve your blood pressure by changing your diet, losing weight if overweight, and being more active. However you may require treatment, especially if you have coarctation of the aorta or dilatation of the aorta. Commonly used medications called ACE-Inhibitors, diuretics or water tablets or betablocker might be prescribed. Your medical team will advise you if blood pressure medications are appropriate for you. Once started on medications, you may need a blood test to check your kidney function.

We check blood pressure at each clinic review and compare this to a reference for healthy girls of the same age and height (there are centile charts for blood pressure like height for children).

We measure systolic blood pressure (bigger number) and diastolic pressure (lower number) using a blood pressure cuff (sphygmomanometer) and aim for both these numbers to be lower than the 95th centile.

Kacey was younger, we had a few different ideas to help her stay calm and distracted while having her B/P taken.

Bringing her favourite cuddly toy made a difference as he always had his B/P taken first. This way Kacey was able to see visually what to expect.

Sticker sheets helped, by the time Kacey had chosen one her B/P was almost finished.

Hospital play therapists also read story books and played videos on tablets/phones.

Sometimes we would do Kacey's B/P at home, where she was more relaxed and comfortable in her own surroundings." **Val**

We know that sometimes girls and women can be stressed when they come to clinic so if the blood pressure is higher than the 95th centile at consecutive clinic appointments we would first perform ambulatory blood pressure monitoring (measures your blood pressure at home over 24hours). High blood pressure is common in Turner Syndrome (in papers looking at this, they find it in 40% of women).

"You might see red patches or marks where the cuff was on your arm, this will go away in a couple of minutes.

Now I'm older and understand how important it is to have my B/P taken. I always sit up straight in my seat, keep still and don't speak. Think of something that makes me smile as I know in a few minutes my B/P will be done." **Kacey**

It is important that we both find high blood pressure and treat it as it is one of the few modifiable risk factors of cardiovascular problems in later life.

This factsheet was written by Dr E Orchard, Cardiologist & Dr H Turner, Endocrinologist, E Weingart, Cardiac Nurse Specialist, Oxford and Dr Avril Mason, Paediatric Endocrinologist, Royal Hospital for Children Glasgow

Ref: Clinical Practice Guidelines, European Journal of Endocrinology (2017) 177, G1–G70, **www.tss.org.uk**.

This factsheet was produced thanks to a grant from the Society of Endocrinology.

TURNER SYNDROME TSSS SUPPORT SOCIETY [UK]

Further information about Turner Syndrome can be obtained from: Arlene Smyth - Executive Officer
Turner Syndrome Support Society (TSSS)
12 Simpson Court • 11 South Avenue
Clydebank Business Park • Clydebank G81 2NR
Helpline **0300 111 7520**
Email **turner.syndrome@tss.org.uk**
Twitter: @**turnerSyndSoc**
Facebook: **www.facebook.com/TSSSUK**

Charity Reg No. 1080507
Scottish Charity No. SC037932

Spring 2021