

Healthy Living with Turner Syndrome



TURNER SYNDROME

TSSS

SUPPORT SOCIETY [UK]

Maintaining a healthy weight and eating a balanced diet are important for health and overall wellbeing for everyone. Research shows that an unhealthy diet, low levels of physical activity and increased BMI (Body Mass Index – how heavy we are compared to how tall we are) and other metabolic complications, eg diabetes mellitus, increase our risk of developing cardiovascular (heart and blood vessel) disease. Women with Turner Syndrome (TS) are more likely to develop a problem with their heart and blood vessels compared with women without TS, so a healthy lifestyle is especially important for girls and ladies with TS.

Acquired Cardiovascular Disease

(heart and blood vessel disease that develops during your lifetime)

Girls and ladies with TS should have regular heart check-ups (See **Factsheet 13: Heart Health in Turner Syndrome**).

Coronary artery disease occurs when fatty material collects in the blood vessels that supply blood to the heart (your coronary arteries). The coronary arteries become narrow, and they cannot carry as much blood to the heart. This means that the heart receives less oxygen, causing symptoms such as chest pain (angina) and breathlessness. A piece of fatty material may break off and cause a blood clot to form and block the coronary artery, cutting off the blood and oxygen supply to the heart. This is known as a heart attack.

There are many risk factors that make it more likely that people will develop coronary artery disease. These include high blood pressure, high cholesterol, being diabetic, your ethnicity, and a family history of heart attacks. There are ways to reduce your risk of coronary heart disease by living a healthy lifestyle, for example, doing plenty of exercise, having a healthy and nutritious diet and refraining from smoking. In this fact sheet we have provided tips to help you lead a healthy lifestyle. We hope you find these useful.

Weight Management

Some girls and ladies with TS struggle to maintain a healthy weight. Our weight increases if we eat food that contains more energy (calories) than the amount of energy we use up during the day.

We recognise that girls and ladies with TS often find it even more difficult to keep a healthy weight than their sisters and friends. This can be extremely frustrating!

We have given some tips on how to lead a healthy lifestyle below, and we hope these are useful. However, losing weight can be difficult, and extra support from healthcare professionals can be helpful if you are finding it hard to make progress.

Physical Activity

What are the benefits of exercise?

Increased fitness level

Improves how well your lungs work, increasing stamina and reducing breathlessness.

Decreased chance of illness

Boosts your immune system so you are less likely to get coughs, colds and other illnesses.

Increased confidence and self-esteem

Helps you to achieve goals and feel more confident about what you can achieve.

Contributes to maintaining a healthy weight

Helps you to have a healthy appetite and burn energy, helping you to reach or maintain a healthy weight.

Makes you feel good and reduces stress and anxiety

Reduces levels of stress hormones and increases “feel-good chemicals” (endorphins) in the brain. This can help to reduce stress and improve your mood, helping to improve your overall mental and physical wellbeing.

Improves bone health

Regular weight-bearing exercise, such as jogging, can help to increase your bone strength (if you have a dilated aorta check with your doctor first). This is important because the risk of developing osteoporosis (weak bones) is higher in women with TS. Remember, your hormone replacement therapy (HRT), is also important in protecting the health of your bones.

Improves balance, co-ordination and flexibility

Exercise, especially exercise that includes coordination of your movements such as dancing, can help develop and improve your spatial abilities. Coordination and spatial awareness difficulties (see **Factsheet 5: Spatial awareness**) are common in TS. Remember to exercise in a safe environment to reduce the risk of injury.

Improves sleep

Promotes relaxation, improving the amount and quality of your sleep.

Increases social skills

Taking part in team sports or group exercise is a great way to make new friends. You'll develop greater empathy and improve your social skills at the same time. Physical activity also improves your confidence, which helps in social situations.

Improves concentration and learning

Relieving stress by exercising can help with concentration on important work and when learning new skills.



Frequently asked questions:

How much exercise should I be doing?

Higher levels of weekly physical activity are recommended for individuals who are at an increased risk of developing cardiovascular disease. Ladies with TS fall into this category, you must seek the advice of your specialist, especially if your heart is being monitored.

National guidelines recommend that adult women in this category should do:

- at least 150 minutes of moderate intensity aerobic activity every week or
- 60 minutes of vigorous intensity aerobic activity or a mix of moderate and vigorous aerobic activity, three times a week

Intensity of aerobic physical activity	Examples
Light	Normal walking, general housework, bowling, stretching
Moderate	Brisk walking, gentle cycling, swimming, low impact dance, swimming
Vigorous	Jogging, skipping, fast cycling, high impact aerobics, playing competitive sports, heavy housework (e.g., moving furniture)

The guidance for ALL children and young people is as follows:

Age group	Recommended physical activity
Infants <1 year	Mobile: interactive floor-based activity, e.g. crawling Not Mobile: at least 30 minutes of tummy time each day
1 – 5 years	Minimum of 180 minutes of variety of physical activity including indoor/outdoor play each day These 180 minutes should include 60 minutes of moderate – vigorous intensity activity
5 – 18 years	Moderate – vigorous intensity for average of 60 minutes per day across the week Variety of types & intensities to develop movement skills, muscular fitness, and bone strength Minimise sedentary behaviours

How can I start being more active?

Walking is an excellent way to keep physically active. It is free and easy to build up. Walking with friends and family can be a nice way to catch-up, whilst probably forgetting that you are being active!

Group exercise such as dance, yoga and Zumba classes are fun and can help to keep you motivated to keep going when you might feel like giving up. They have the additional benefits of meeting new like-minded people.

It is important to remember that physical activity tends to become easier with time. This promotes a rewarding cycle in which you can increase physical activity levels as the activity becomes easier to do.

What if I'm worried about exercising in front of people?

It is normal to feel self-conscious when exercising, especially at the start. Free exercise videos online, which can be completed in the comfort of your home, can help to increase your confidence. It's important to remember that when exercising in a group environment, the people around you are focusing on their own exercise, and probably not thinking about what you are doing!

What if I'm worried about exercising because of my heart?

Always talk to your doctor if you are worried about this. Overall, international guidelines for girls and women with TS recognise the benefits of safe levels of exercise on improving heart health and reducing risk of heart disease.

A free cardiac alert card can be posted to you by the TSSS. It might help you to feel safe if you keep this on yourself when exercising.

Our exercise checklist:

60 minutes!

Aim for an average of at least 60 minutes of moderate or vigorous intensity physical activity at least 3 times a week. It doesn't matter how 'intense' the exercise is – if your heart rate is increased and you're out of breath – great!

Switch it up!

You should aim to do 2 types of physical activity each week: aerobic exercise and exercise to strengthen your muscles and bones.

Variety

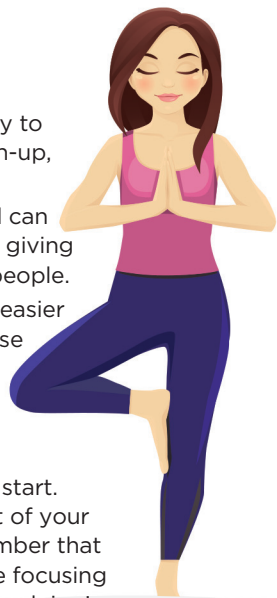
Try a variety of types and intensities to develop movement skills, muscles and bones.

Spread it out!

Break up long periods of not moving with some activity.

Do what you enjoy

Most importantly – find something you enjoy as you will want to exercise and move more, don't force yourself to run if you don't enjoy it – there's lots of other aerobic activities you can try instead!



Dietary Advice

Why is a Healthy Diet important?

Foods and fluid contain essential nutrients which can help prevent infections, reduce inflammation, keep your heart and lungs healthy and keep you feeling as fit and strong as possible!

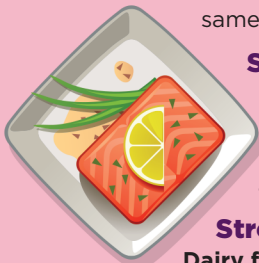
Support your immune system

Fruit and vegetables have vitamins and minerals that support your immune system. This can help you fight-off infections. You should aim to eat 5 portions of a variety of fruit and vegetables a day. They should make up a bit less than half of your overall diet.



Gives you energy

Starchy carbohydrates, such as potatoes, bread, rice, pasta and breakfast cereals, give your body energy for breathing, exercising and everyday tasks. Choosing high fibre wholegrain varieties will make you feel fuller for longer, help protect your heart and keep your bowels moving. Carbohydrates should make up the same amount of your overall diet as fruit and vegetables.



Strong muscles

Protein, such as lean meats and fish, helps keep your muscles strong. This includes chest muscles which help your ribs expand as you breathe. Protein is also important for your immune system and should make up about 10% of your overall diet.

Strong bones

Dairy foods (milk) and their alternatives (soya drinks) are a good source of protein, vitamins, and minerals. This includes calcium and vitamin D which helps keep bones strong and healthy. Lower fat and lower sugar options are better for your health. As with protein, they should make up about 10% of your overall diet.



Fighting infections

Oils contain a range of vitamins, such as vitamin A and E, which are important for fighting infections. Vegetable oils are often lower in saturated fat and a better choice. Oils and spreads should be consumed in small quantities.

How do I know if I'm eating well?

The amount of energy each person needs is different, it depends on height, activity levels, rate of growth and lots of other factors. The energy we need each day for our body to function is called the Basal Metabolic Rate. We measure this energy in calories.

Any nutritious food changes you make, however small, can make your intake healthier. It is important to create a healthy relationship with food. Focus on enjoyment, healthy eating should not be a chore! Eating a varied and balanced diet provides the body with optimal nutrition and can help you to maintain a healthy weight.

Sleep

Did you know?

About 1/3 of our lives are spent sleeping.

Why is sleep important?

Sleep is essential - it should be considered as important as eating, drinking and breathing. It is a time where the mind and body can rest and recover from the stresses and strains of the day. Research has shown that without adequate sleep the brain cannot function properly, resulting in concentration and memory problems. Sleep has a large impact on our wellbeing.

Research has demonstrated sleep and health to be **linked**. This is true of both physical and mental health. For example, depression and anxiety have been associated with poor sleep.

What is good sleep hygiene?

Good sleep hygiene includes a bedroom environment and daily routine which promotes consistent, uninterrupted sleep. Limiting caffeine, nicotine, alcohol and bright light before bed can help you to sleep better.

Our top tips: :

Be consistent: Aim to go to bed and wake up at the same time each day. This includes weekends!

Calm environment: Try and make your bedroom a relaxing space that is quiet and dark. Room temperature is also super important so make sure it is comfortable for you. Studies suggest that bedroom temperature of around 65°F (18°C) promotes the best night's sleep.

Unplug before bed: Aim to use screens (mobile phone, laptop, TV) as little as possible for at least one hour before bed. The screen light from devices can disrupt our natural body clock and staying alert on games, phones or watching videos will keep your mind active, keeping you awake.

Avoid eating too close to bed time: This may help with sleep and weight management too.

Limit caffeine and stimulants: Try and limit your caffeine intake at least 6 hours before bed. This includes food and drinks that contain caffeine such as chocolate, coffee, non-herbal teas and fizzy drinks.

Get regular exercise: Research shows that a regular exercise routine can help improve the quality of your sleep. Try to keep being physically active during the daytime to help you fall asleep more easily at night-time. Ideally try to exercise at least 3 hours before your bedtime.

Some good websites:

<https://www.nhs.uk/live-well/eat-well/>

<https://www.nhs.uk/better-health/lose-weight/>

National Osteoporosis Society

<https://theros.org.uk/>

Other useful websites are available on the weblinks tab:

<https://tss.org.uk/links/useful-websites>



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SUPPORT SOCIETY [UK]

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