# Health tips for the over 40s and beyond!

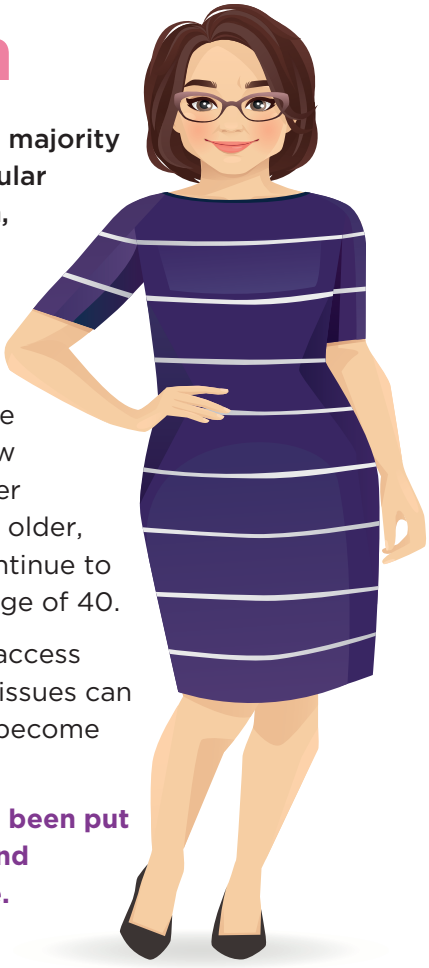
TURNER SYNDROME
TSSS
SUPPORT SOCIETY [UK]

*Our lovely women at our Annual Conference 2019*

# Contents

# Health tips for women with TS who are over 40 and beyond!

## 1 Introduction



**It is important to emphasize that the vast majority of women with TS, who are receiving regular health checks and the correct medication, lead long, happy and healthy lives.**

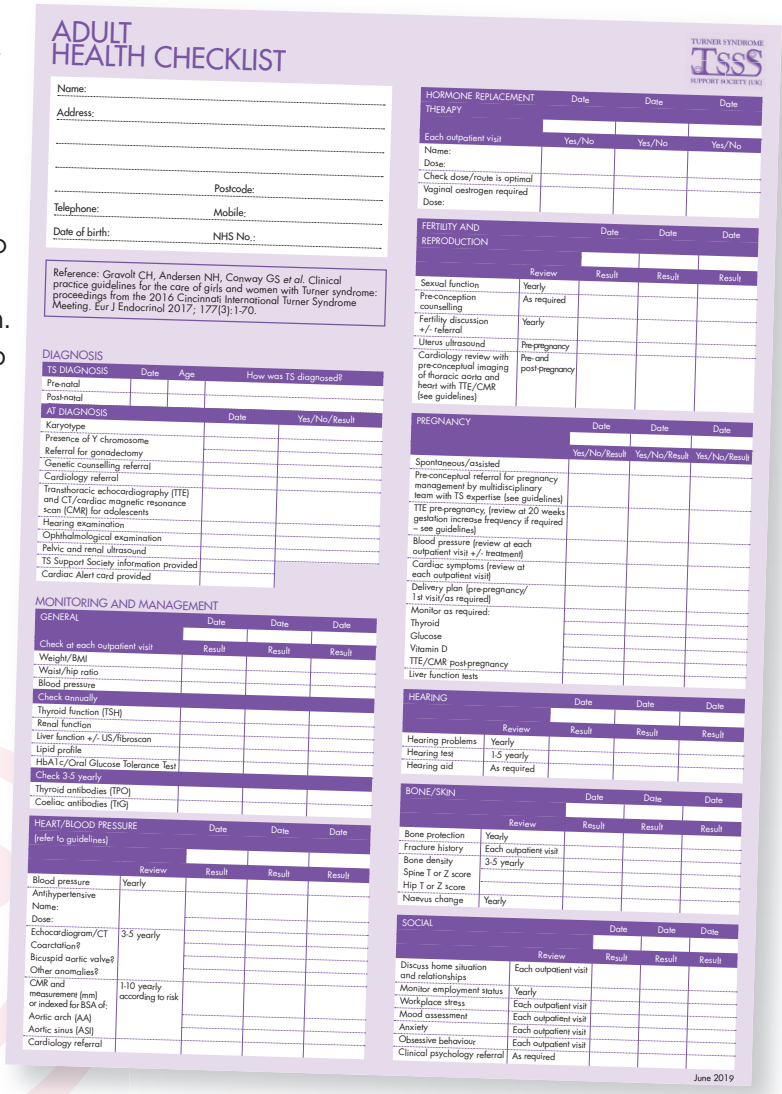
This is becoming more and more apparent by the increasing numbers of women over 40 with TS within the society's membership. So much so that the TSSS felt it would be helpful to share a few suggestions on staying healthy and to offer guidance on what women with TS getting older, should be looking out for, so that they continue to stay happy and healthy way beyond the age of 40.

On the positive side, women with TS can access such good health care and regularly, that issues can be flagged up before any real symptoms become apparent.

**The TSSS must stress that this leaflet has been put together by the women for the women and should not be held up as a medical guide.**

The TSSS health checklist, recently updated to reflect the Clinical Care Guidelines, is an excellent template of what health checks you should be having and when. This should be discussed with your consultant and should be used as a point of reference. How this is presented to your consultant/GP is key in getting them on board and working together. Having time with health care professionals is ideal so that the checklist is gone through completely and thoroughly.

If you feel your health professional is not taking you seriously, do not be afraid to ask for a second opinion. Keeping on top of the health checks/being monitored is key for your long-term health.



# ADULT HEALTH CHECKLIST

TURNER SYNDROME TSSS SUPPORT SOCIETY (UK)

Name:

Address:

Postcode:

Telephone: Mobile:

Date of birth: NHS No.:

Reference: 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. 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 | Result | Result | Result |
| 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 (TG) | | | |

| HEART/BLOOD PRESSURE (refer to guidelines) | Review | Date Result | Date Result | Date Result |
|---|---|---|---|---|
| Blood pressure | Yearly | | | |
| Antihypertensive Name: Dose: | | | | |
| Echocardiogram/CT Coarctation? Bicuspid aortic valve? Other anomalies? | 3-5 yearly | | | |
| CMR and measurement (mm) or indexed for BSA of: Aortic arch (AA) Aortic sinus (ASI) | 1-10 yearly according to risk | | | |
| 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 | Review | Date Result | Date Result | Date 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 Yes/No/Result | Date Yes/No/Result | Date 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 | Review | Date Result | Date Result | Date Result |
|---|---|---|---|---|
| Hearing problems | Yearly | | | |
| Hearing test | 1-5 yearly | | | |
| Hearing aid | As required | | | |

| BONE/SKIN | Review | Date Result | Date Result | Date 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 | Review | Date Result | Date Result | Date 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 | | | |

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# 2 HRT

**It is important to discuss with your TS specialist consultant when is the right time for you to come off HRT, taking into account, bone density, age, general health etc. and using the results from all the health checks you've been having over the years. This will guide you to making the right decision for you.**

Also, it is important to remember that a woman without TS will go through the menopause in her early 50s but would then, possibly, go on to use HRT to help her through the menopause. This can take anything up to 5 years so you could, potentially, be looking at taking HRT into your early 60s with the agreement of your specialist. It is important that you come off oestrogen gradually rather than just stopping suddenly and completely.

It is important to remember that women with TS are taking HRT for oestrogen deficiency, which are different reasons to the women without TS. Therefore the negative press that surrounds HRT, which can be very confusing and misleading, in a lot of ways does not relate to women with TS.

Women without TS are taking HRT to top up their oestrogen and replace what they have already been naturally producing for several years rather than women with TS who lack oestrogen. This can mean that women with TS may have extreme difficulties when it comes to the menopause.

Not taking HRT could have its own knock-on effects which need to be taken into consideration.

As we grow older, sexual relationships continue to be an important way to promote, maintain intimacy and demonstrate affection. We may feel more confident and comfortable in our bodies, which leads to better sex. However, our bodies might need a little help as we age; the vulva and vagina may become dry (particularly if we have ceased, or have not taken, HRT) and we may need appropriate medication, such as hormone-based creams or water-or-oil-based lubricants that hydrate the delicate tissue. We may also experience loss of libido (sex drive) due to fatigue or preoccupation with other issues. Talking to your GP and/or a Sex Counsellor can help. Your GP needs to know if you experience pain during sex as there can be many reasons for this and it is important to establish a diagnosis. You will be called for cervical smear tests less often than previously and it is important that you attend.

# 3 Medical Checks

## 3.1 Hearing

**Girls/women with TS tend to have hearing issues and women with TS tend to lose their hearing earlier than the general population. Regular hearing checks should be taken and hearing aids sourced if needed.**

Women with TS tend to report that they need the subtitles on the TV to help them understand the dialogue completely.

This tends to start to become more of an issue in the early 30s when hearing aids need to be sourced via a referral by your GP to an audiology clinic. This could greatly improve your hearing and, in doing so, improve your general wellbeing as you would be able to hear complete conversations and engage more. Any sense of isolation and loneliness you may have been feeling will diminish considerably. The earlier this issue is dealt with the better your wellbeing will be long-term.

Women wearing hearing aids tend to pick up more ear infections as a result so keeping hearing aids clean and in good repair is very important alongside regular check-ups.

Age UK/RNID has excellent advice/help/equipment to support people who are hard of hearing. These include hearing aid compatible headphones which could be useful in the workplace, telephones to be used in the home etc.  There also can be funding available to obtain none NHS hearing aids. If you are struggling with your hearing, a referral to a hearing therapist may be appropriate and helpful in making psycho-emotional adjustments for your restricted hearing.

## 3.2 Eyesight

**As with hearing, this tends to deteriorate sooner in women with TS than the general population.**

You need to see your optician on a regular basis to make sure your eyes are kept in tip top condition.

Women with TS need to be aware that glaucoma/cataracts can be more common in women with TS and must not be afraid to request pressure checks and retinal photography as part of their routine visits to Opticians. This is especially important if you have diabetes.

## 3.3 Thyroid

**Underactive thyroid can be a result of autoimmune disease, common in TS, which can also affect other parts of the body, such as joints, leading to rheumatoid arthritis. It can also mean that you are prone to infection/tiredness/picking up colds being generally unwell and unable to shrug off bugs.**

This too can become more of an issue as you get older so needs to be checked out on a regular basis with Thyroid function tests and then, if necessary, medication can be prescribed. This test will need to be repeated on an annual basis.

This issue can creep up on you without you knowing and showing no symptoms, so it is important that it is regularly checked.

You need to ensure that you take your tablets at the best time of day meaning you get the optimum effect from your medication.

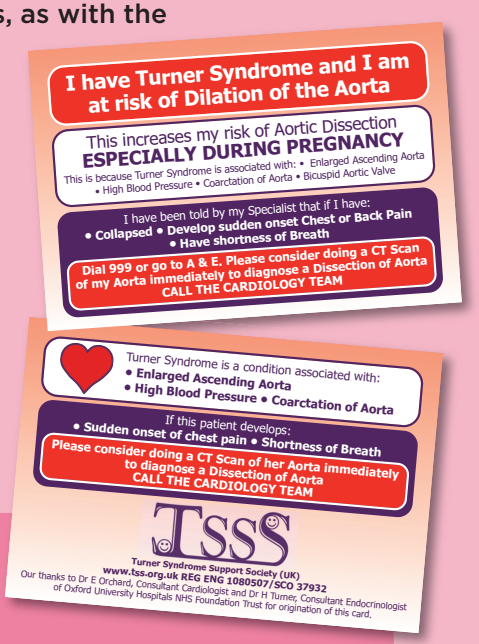
## 3.4 Heart

**The heart needs monitoring every 3/5 years to check for any abnormalities. This is even more important the older you get as there is a greater risk of heart problems, as with the general population.**

MRI/Echocardiographs/ECGs will give good indications of what is happening with your heart.

All monitor slightly different things so, ideally, all three need doing regularly. The MRI gives a more detailed report and can pick up things that the others could miss.

**It is worth mentioning that the cardiac checks are needed even if you have had no problems earlier in life.**




***Please carry a Cardiac Alert Card (available by sending a SAE to the TSSS office) on your person or have a Medi Alert bracelet.***

## 3.5 Liver Function

**This can be an issue and needs regular checks to monitor and a change of delivery of medication may be required i.e., instead of taking HRT orally (which goes directly to the liver to then be dispersed), it may be worth considering one of the other options such as a patch or gel which goes directly into the blood stream, by-passing the liver, so taking any pressure off the liver limiting the damage there may be.**

It's also been suggested that increased liver enzymes are a direct result of increased BMI so keeping control of your weight is also worth doing from this point of view.

The liver function test can be interpreted differently by a GP, who perhaps does not have a knowledge of TS, than a consultant who is able to take your TS into consideration when reading your results. This is another reason why it is important to be seen by a health professional with a knowledge of TS.

## 3.6 Diabetes

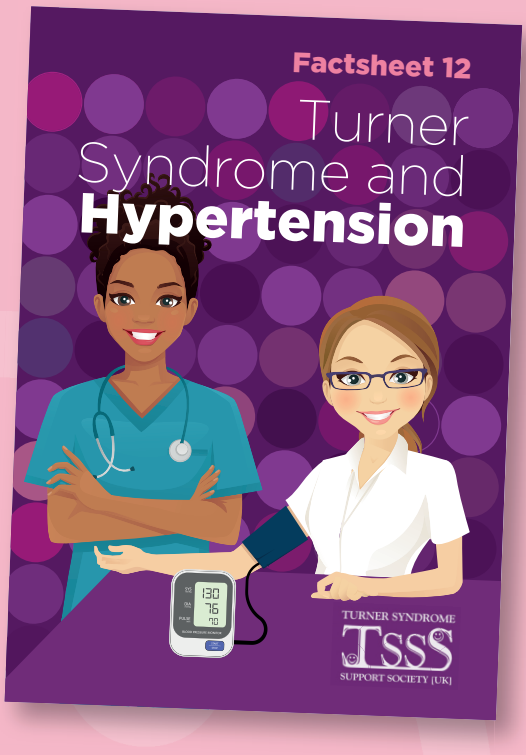
**This, like hearing, tends to become an issue in the early 30s and as time goes on could become more and more of an issue if not controlled. It has been shown to be related to being overweight (which when you have restricted height is going to be more of an issue).**

Treatment options include dietary modifications, tablets alongside the dietary modifications and then looking at insulin injections. Regular blood tests need to be done to check your average blood sugar levels so, if there are any changes, adjustments can be made. These are generally done by a practice nurse from your GP's surgery who can advise on any changes that may be needed. You can also obtain, via your surgery, a blood monitoring device which will help you on a day-to-day basis to keep your blood sugar levels in check enabling you to make any changes to your diet you may need.

## 3.7 Managing blood pressure/cholesterol

**Women with TS often have high blood pressure.**

This needs regular monitoring and if necessary, controlling with medication avoiding any knock-on health issues i.e., pressure on heart, risk of stroke.




You can buy a blood pressure monitor to use at home. This will enable you to keep an eye on your blood pressure in-between appointments. (See BP in TS Factsheet on **http://tss.org.uk/information**)

It is important to be aware of high cholesterol, this can often improve with changes in your diet or treatment with statins if required.

## 3.8 Bone Density

**The older you are, the more at risk you are of osteoporosis so you need regular bone density scans, especially when looking to come off HRT, every 3-5 years, depending on the level of risk.**

You need to ensure that your bones remain healthy. Weight-bearing exercise, such as walking or dancing, can help and having plenty of calcium in your diet. It is also worth taking Vitamin D.

## 3.9 Kidneys

**Some women with TS have issues with the kidneys, for example this can be just having one kidney, duplex kidney, or a horse-shoe kidney.**

The kidney function requires regular monitoring to ensure that there are no changes.

# 4 Diet & Exercise

**As with the general population weight can increase as you get older. This influences your overall health and wellbeing and can increase the risk of diabetes, heart problems and stroke.**

As well as affecting your general feeling of wellbeing and so having a psychological effect on your day-to-day life. Portion control is obviously a simple thing to do but, especially when eating out, this can be easier said than done! Looking into the type of diet that works for you can be worthwhile. Many ladies have lost weight through slimming clubs. The NHS has some great healthy eating and weight loss support available online. Alternative therapies such as Hypnosis are easily available to stave cravings and may be a great help as an aid to weight control.

Exercise is important and finding something that you enjoy is ideal. Using gym equipment can be particularly challenging when you are short in stature! However there are other options such as taking a brisk walk, using the stairs rather than taking the lift, or following an exercise DVD. Joining a local dance or yoga class could be good socially too.

# 5 Fatigue

**Women with TS have reported tiredness, lack of energy becomes much more of a problem the older they get. You need to look at strategies that help you cope such as being organized and doing tasks in "bite sized chunks", being able to pace yourself and to know your limits and to try and live within those limits (and not beating yourself up about those limits or not being able to do as much as others - without copping out of doing what you are able to do!).**

A lack of energy and feeling tired can be down to several underlying issues such as increased BMI, lack of iron, low vitamin D, thyroid problems etc.

Consider what you need to have around the house to make things easier i.e.: stools, handrails etc.

Look to plan to do most tasks when you are at your most energetic. Time management can help here in planning your day.

Women with TS need understanding from those around them: family/partners/friends/work colleagues. More awareness is needed of the stress caused by doing unsuitable jobs. Goal posts being changed can also be stressful and have a detrimental effect on energy levels.

A lack of iron could be a cause here, so anemia levels need checking and adjusting with medication if necessary.

Sleep apnoea might be a possible cause of fatigue and is well worth getting it ruled out or treated, as necessary.

Your doctor can ask a series of 10 questions and depending on the answers can indicate if sleep apnoea is suspected and refer onto a sleep clinic if necessary. Weight control is a big factor here.

Generally, the message is that, as with any woman, things get harder as you get older and your health deteriorates. This is just part and parcel of aging; however, it is being able to offer tips and advice on how to cope with this. It is as much to do with a positive mind set as well as a state of body. The two go hand in hand.

## Symptoms of sleep apnoea mainly happen while you sleep

**They include:**

- breathing stopping and starting
- making gasping, snorting or choking noises
- waking up a lot
- loud snoring

**During the day, you may also:**

- feel very tired
- find it hard to concentrate
- have mood swings
- have a headache when you wake up

*Ref: NHS website*

**Having regular checks and keeping on top of any health issues is key, so that you do not get to the stage where you have a complete breakdown because things have been left untreated and gone too far.**

This in turn has a direct impact on your mental wellbeing enabling women with TS to continue to live a full, healthy and active life.

Good advice is needed on exercise to help prevent/control any problems generally on health and aids mental wellbeing. There are many things out there – apps, support groups, classes, social media etc. that can help.

Prevention is key to staying healthy. Be proactive.

Taking someone along with you for support to medical check-ups is a good idea to make sure that the right questions are being asked and all information given is taken on board. Before any appointment think about what you want to get from the consultation. Have some questions/notes prepared so you come away having all your questions/concerns addressed.

# 6 Mental Health

**It is important that we maintain the health of our minds in conjunction with the health of our bodies as we grow older. Physical exercise and a presence 'in nature' (walking in the woods or by the sea, cycling along country lanes, whatever is your preference), learning new skills, and regularly and frequently doing things for others can all help to keep your mood buoyant.**

Maintaining relationships is very important (phone calls, meet-ups, letters, and direct electronic communication). Exchanging information with others about your lives can be reassuring and inspiring. Taking care with personal hygiene and your personal appearance can boost confidence and give a sense of well-being. An appropriate amount of healing and refreshing sleep is very important, and significantly contributes to our problem-solving abilities.

Managing our emotions is key to maintaining a calm and productive approach to any problem and giving a sense of being in control. If you often feel 'out of control', look at negative stress-triggers in your life, and consider counselling to help you explore your emotions. When we feel overwhelmed, distraction and diversion can help, such as watching a favourite television programme, reading a book, getting a facial or a haircut.

# 7 Childlessness and Infertility

**As we move further away in time from the 'childbearing years', we may feel sad, or even bereft, if we face an old-age without children or grandchildren.**

These are very natural and appropriate feelings. It is important to nurture and maintain our relationships with the young people, family and friends in our lives, many of us are much loved god mothers and aunties. Remember that we all leave a legacy in our own right, regardless of whether or not we are childless.


*Hayley & Kacey*

# Useful links and References

**https://www.ageuk.org.uk/** Age UK

**https://thebms.org.uk** British Menopause Society

**https://rnid.org.uk** Royal National Institute for the Deaf

**https://www.rnib.org.uk** Royal National Institute for the Blind

**https://www.btf-thyroid.org/** British Thyroid Foundation

**https://www.bhf.org.uk** British Heart Foundation

**https://www.curainsurance.co.uk/health-conditions/turner-syndrome/**

**https://www.diabetes.org.uk** Diabetes UK

**https://www.nhs.uk/common-health-questions/lifestyle/what-is-blood-pressure/**

**https://www.nhs.uk/live-well/healthy-weight/start-the-nhs-weight-loss-plan/**

**https://www.mind.org.uk** Mental Health Charity

**https://theros.org.uk/** Royal Osteoporosis Society

**https://tss.org.uk/information** Turner Syndrome Support Society [UK]

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.

Reference: TSSS[UK] publications

If you have any further comments or tips to be added to the leaflet, please do not hesitate to send Arlene an e-mail at **turner.syndrome@tss.org.uk**

**A wide range of information is available from the TSSS website https://tss.org.uk**



TURNER SYNDROME
TSSS
SUPPORT SOCIETY [UK]

**Turner Syndrome Support Society (TSSS)**
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Website: **https://www.tss.org.uk**

Charity Reg No. 1080507 • Scottish Charity No. SC037932