EXERCISING WITH EDS

Many people with Ehlers-Danlos Syndrome (EDS), and similar conditions like generalized hypermobility spectrum disorder (G-HSD) have questions about safe exercises that can help prevent injuries.[1] If you have EDS or G-HSD, the good news is that most exercises can be safe if you do them carefully. It's important to remember that how you feel can change from day to day, so you should listen to your body and change your routine if needed. If you're not sure how to exercise safely or how to adjust your activities for each day, you can talk to movement specialists like physiotherapists or kinesiologists. They are there to help you find the right exercises that support your health and well-being!

In this handout, we will discuss various exercise principles with considerations for people with EDS or G-HSD.

Aerobic Exercise

What is aerobic exercise?

Aerobic exercise, also known as cardio, is a fun way to get your heart and lungs working better. When you do aerobic exercise, your heart pumps faster, and your lungs help deliver oxygen to your muscles. This can make you feel stronger and more energetic. Some benefits of aerobic exercise include building stronger bones, improving your muscle strength, improving your mental function and giving you the stamina to feel less tired and out of breath when doing everyday activities, like climbing stairs or performing daily chores.[2,3]

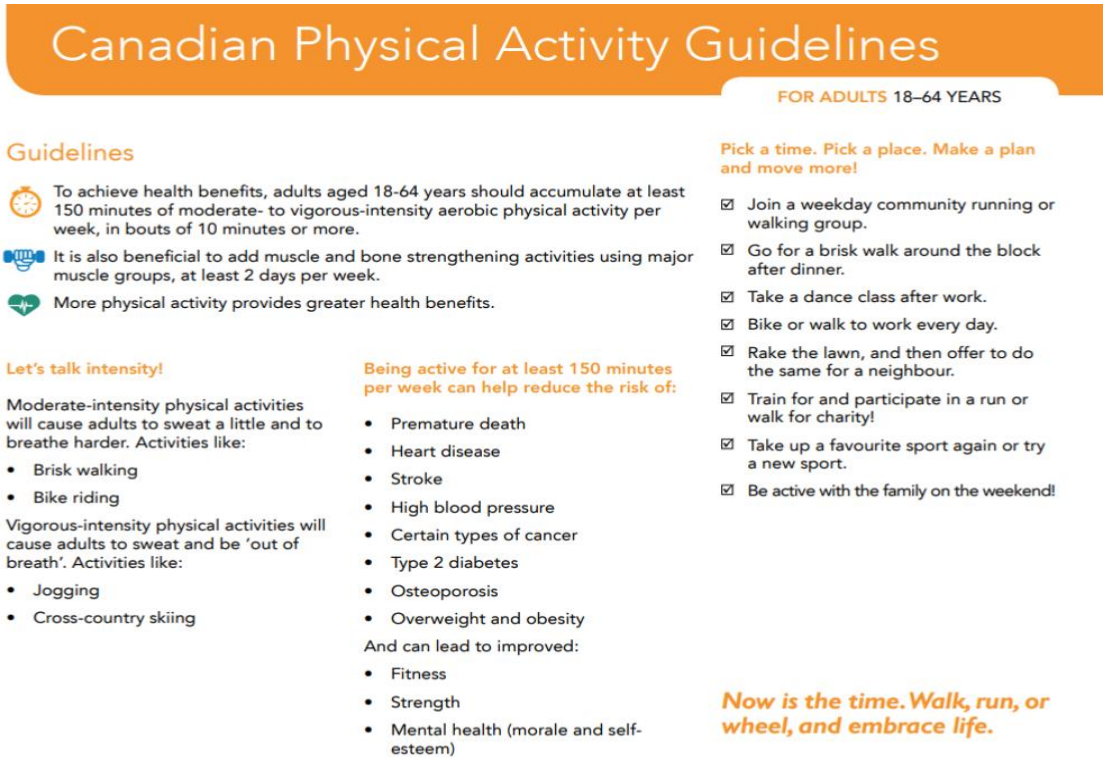
What types of aerobic exercise are safe?

For patients with EDS, aerobic exercise is generally safe and beneficial. It's often recommended to focus on low-impact activities like swimming, walking, cycling, or water aerobics.[1,4] The best type of cardio for you will depend on what you can do consistently and comfortably. For instance, if walking causes pain in your knees or feet, using a stationary bike or swimming might be more suitable. These options can reduce stress on your joints, making exercise less painful and allowing you to participate more frequently and for longer periods.

Some patients with EDS may experience a condition called Postural Orthostatic Tachycardia Syndrome (POTS). Symptoms of POTS can include dizziness, light-headedness, fatigue, and heart palpitations, especially when standing up quickly. This can make cardio exercises performed in an upright position difficult to maintain for longer periods of time.[5]

How much should I do?

The Canadian Physical Activity Guidelines **(Figure 1)** say that adults should try to get at least 150 minutes of moderate to vigorous aerobic exercise each week.[6] To achieve this, try to be active for about 30 minutes a day, five days a week. If that sounds like too much, you can break it down into smaller chunks of time, like small bouts of 10 minutes of exercise three time per day on most days of the week.[7]



Canadian Physical Activity Guidelines

FOR ADULTS 18–64 YEARS

Guidelines

To achieve health benefits, adults aged 18-64 years should accumulate at least 150 minutes of moderate- to vigorous-intensity aerobic physical activity per week, in bouts of 10 minutes or more.

It is also beneficial to add muscle and bone strengthening activities using major muscle groups, at least 2 days per week.

More physical activity provides greater health benefits.

Let's talk intensity!

Moderate-intensity physical activities will cause adults to sweat a little and to breathe harder. Activities like:

- Brisk walking
- Bike riding

Vigorous-intensity physical activities will cause adults to sweat and be 'out of breath'. Activities like:

- Jogging
- Cross-country skiing

Being active for at least 150 minutes per week can help reduce the risk of:

- Premature death
- Heart disease
- Stroke
- High blood pressure
- Certain types of cancer
- Type 2 diabetes
- Osteoporosis
- Overweight and obesity

And can lead to improved:

- Fitness
- Strength
- Mental health (morale and self-esteem)

Pick a time. Pick a place. Make a plan and move more!

- ☑ Join a weekday community running or walking group.
- ☑ Go for a brisk walk around the block after dinner.
- ☑ Take a dance class after work.
- ☑ Bike or walk to work every day.
- ☑ Rake the lawn, and then offer to do the same for a neighbour.
- ☑ Train for and participate in a run or walk for charity!
- ☑ Take up a favourite sport again or try a new sport.
- ☑ Be active with the family on the weekend!

Now is the time. Walk, run, or wheel, and embrace life.

**Figure 1*

If doing moderate or vigorous activities feels too hard right now, it's okay to start with lighter exercises. You can gradually do more as you feel ready. The important thing is to find activities you enjoy and to keep moving at your own pace!

Resistance Exercise

What is resistance exercise?

Resistance exercise is an excellent way to strengthen your muscles and provide support for your ligaments, tendons and bones. By working against an external force, like weights or resistance bands, you can improve your overall strength.[8] This added strength not only helps lower the risk of injuries but also gives extra support to your joints, making daily activities – like climbing stairs or lifting groceries – easier and safer.[9,10]

What types of resistance exercises are safe?

For patients with EDS, resistance exercise is generally safe and beneficial. It's important to perform resistance exercises that are right for you, and your current abilities. You might start with bodyweight exercises, which are a great way to build strength without added stress. As you become more comfortable, you can gradually progress to using resistance bands and then weights (like dumbbells or barbells).

When performing resistance exercises with joint instability and hypermobility it is important to perform exercises with the correct posture, and technique. Proper posture ensures that your body is aligned correctly, reducing unnecessary strain on your joints and muscles. This alignment helps distribute stress evenly throughout the body, can prevent overuse injuries and help you to feel more stable. Additionally, it is important to perform your exercises with controlled movements and avoid hyperextension. See **Figure 2** for some examples of traditional resistance exercises and how to modify them for G-HSD/EDS.

Wearing joint braces such as knee or wrist braces may provide additional stability and support to vulnerable joints and prevent hyperextension while you are performing resistance training, especially when lifting heavier weights.[11] This will allow you to perform exercises safely and with confidence. In addition to traditional resistance training, activities like Pilates can be helpful. Pilates focuses on building core strength, improving body awareness, and enhancing proprioception (your body's ability to sense its position in space).[10]

How much should you do?

Every patient with EDS is unique, so how often you do resistance exercises should depend on your own comfort and tolerance. The best resistance exercises are those you can gradually add to your daily routine. Start with a few repetitions and sets that feel comfortable without causing joint flare-ups.

It is also important to pay attention to your recovery time after exercising. If any soreness or pain returns to your normal baseline within 2 hours, that means the effort level was just right for you. Aim to perform these exercises at a mild to moderate intensity level, which will help you build strength safely. [8]

Remember, the key is to listen to your body and choose exercises that feel right for you. Finding enjoyable ways to stay active will help you build strength and confidence while supporting your overall well-being!

Examples of Resistance Exercise Modifications

Exercise	**Potential Risk**	**EDS Adaptation Suggestions**
Squats	Knee instability, joint pain	Use a stability ball placed between knees or perform wall squats. Use support if balance is an issue
Push-Ups	Wrist pain, shoulder instability	Perform on knees or against a wall Place a thin towel or rolled thin mat under wrists to pad the wrists

Rows	Shoulder and elbow strain	Use resistance bands, maintain neutral wrist, keep shoulder joint aligned throughout the movement (joint is positioned in the socket)
Lunges	Knee instability, balance issues	Perform stationary lunges, use support, modify the depth of the lunge as tolerated
Bicep Curls	Elbow hyperextension, Shoulder shifting forward or instability	Use lighter weights, avoid full extension, keep shoulder joint aligned throughout the movement (joint is positioned in the socket)
Triceps Extensions	Elbow strain, shoulder instability	Use resistance bands, keep elbows close, keep shoulder joint aligned throughout the movement (joint is positioned in the socket)

**Figure 2*

Proprioception

What is proprioception?

In patients with G-HSD/HSD, it is common to have poor body awareness/proprioception.[12,13] This may commonly be described as clumsiness or poor coordination. Proprioception is the body's ability to sense where our limbs are and how they move in relation to space. This means we can know the position of our arms and legs without even looking! When proprioception is impaired, it can be more challenging to stabilize joints which may result in increased stress on your joints, muscle spasm and injury. Improving proprioception is important for joint stability and allowing your body to understand where your joints and muscles are so you can control them better.

What exercises can improve your proprioception?

- Mind-body movements: Performing mind-body types of exercises such as Tai Chi, Pilates, yoga and qi gong focus on slow, controlled movements that can enhance your body awareness and help you feel more balanced. [9]

- Balance Exercises: Performing balance exercises that are challenging, but that you can perform while still in control may be helpful for improving your joint proprioception and body awareness. Examples of balance exercises may include standing on the floor with your feet together, or standing on one leg. You may progress your exercises to involving an unstable surface such as foam, or performing the task with your eyes closed for an added challenge. If you feel unsteady during any of your exercises, you can hold onto a wall or chair for extra support. Remember, it is important to perform these exercises cautiously and with supports if needed to prevent injury![13]

- Using External Feedback or Visual Input:

1. *Mirrors* – using visual feedback from a mirror can help you with understanding where your body is in space. This can be helpful when working on proper posture such as preventing knee hyperextension.

2. *Resistance Bands/Exercise Balls* - Incorporating resistance bands or exercise balls into your routine can give you better feedback on which muscles you're using. For example, placing an exercise ball between your knees can help with providing more stability to your pelvis or adding a resistance band around your thighs during squats may help you to feel your glutes activate better.[13]

3. *Clothing/Taping* – Using compression clothing or sleeves may help with increased proprioception on specific joint areas. However, make sure that the clothing is not too tight that it impacts your circulation. Additionally, using tape over muscles and joints may help with additional feedback and body awareness. [14, 15]

A Note on Stretching

Many people with hypermobility experience increased tightness in some muscle groups, and often wonder if stretching is safe. Even though your joints are hypermobile, this tightness in your muscles can be your body's way of trying to stabilize your joints These tight muscles pulling on lax joints can create imbalances compared to individuals with normal joint flexibility[16] For example, if you tend to stand with your knees hyperextended, your hamstrings may be tight as they are trying to stabilize your knee.

Our bodies stretch more easily in areas that are already loose. So, stretching might be more helpful after your muscles get stronger and your joints are more stable. When you do static stretching (holding a stretch), don't stretch as far as you can because it can make your joints unstable. Instead, try a dynamic warmup before exercising. This means doing gentle, active movements to get your heart rate up and blood flowing. It helps your muscles get ready for exercise and lets you move your joints safely without risking injury. [17]

Things to consider before exercising

Start Slowly and Progress Gradually

Begin with low-intensity workouts and gradually increase the intensity to avoid putting too much strain on your joints. You might find it helpful to start with exercises while lying down before moving to sitting or standing exercises. Only progress if you're not experiencing any joint pain and the exercise intensity is mild to moderate.

How Much and How Hard?

The **FITT principle** can be a useful tool for you and your healthcare provider when planning your exercise routine. This tool can be modified to your specific abilities. Here is an example of how to use the tool to help with prescription for resistance training:

- **Frequency**: How often you exercise. This could be 2-4x/week
- **Intensity**: How hard you exercise. This could be measured by your heart rate, the amount of weight you lift, or how hard you feel you're working. We would want to make sure our effort level is at anywhere from light-moderate or moderate-hard based on your tolerance.
- **Time**: How long you exercise. This could be the duration of each workout session, like 15-20 mins.
- **Type**: The kind of exercise you do. This could include activities like light weights, Pilates or bodyweight exercises.

Rating of Perceived Exertion (RPE) Scale

The RPE scale is a helpful guide to determine how hard you're working during exercise. For patients with EDS/G-HSD, aiming for an RPE of 1-6 is generally safe and can help prevent further injuries or flare-ups. [6]

Rating of Perceived Exertion (RPE) Scale	
10	Extremely Hard
9	Extremely Hard
8	Extremely Hard
7	Extremely Hard
6	Hard
5	Hard
4	Somewhat hard
3	Moderate
2	Easy
1	Easy
0	Easy

Focus on Stability and Form

- Maintain Proper Posture**:** Maintaining proper posture is essential for minimizing the risk of injury during exercises and daily activities. To ensure your body is in good alignment, think about stacking 5 blocks on top of each other, keeping your head, shoulders, hips, knees and feet in a straight line. This alignment not only enhances your performance, but also promotes overall well-being.

Listen to Your Body

- Be Attentive: Always pay attention to any signs of pain or discomfort. If you experience these, it's important to modify or stop the exercise as needed.
- Pace Yourself: Monitor your heart rate and effort level. Consider spreading your exercises over different days to manage fatigue effectively. Aim to exercise when you feel most energetic to help prevent flare-ups.

Monitor Symptoms of Fatigue or Dysautonomia

- Stay Alert**:** Increased fatigue or symptoms of dysautonomia, such as dizziness, light-headedness, nausea, or heart palpitations, can occur. It's essential to monitor for these symptoms before exercising to avoid joint injuries or worsening flare-ups.

Safely Progressing and Regressing Your Exercises

Tips for Progression:

- Increase duration before intensity: For aerobic exercise, try to gradually increase the time of the activity by a small amount before increasing your effort level. For resistance exercises, begin by increasing the number of repetitions within a set. Once you feel comfortable, gradually add more sets to build your endurance before trying a new version of the exercise or increasing the weight Once you are comfortable with longer bouts of exercise, try increasing the intensity.
- Monitor Your RPE: If your Rate of Perceived Exertion (RPE) is consistently below 3/10 and any increase in baseline pain subsides within 2 hours after stopping, it may be a good time to increase the intensity of your workouts.
- Adjust Difficulty: Once you feel like you can increase the intensity, try incorporating a resistance band or light weights. Additionally, progressing the exercise from sitting to standing can also increase the exercise's difficulty.

Tips for Regression:

- Consult Your Practitioner: If you find the current exercises too challenging, don't hesitate to ask your healthcare practitioner for modified versions.
- Watch Your RPE: If your RPE exceeds 6/10 or if pain persists for more than 2 hours after stopping, it's wise to regress to a less strenuous version of your program.
- Listen to Your Body: After a flare-up, consider reducing the difficulty of your current routine by reducing the sets and repetitions. Once you feel you are able to manage this new routine, you can gradually progress your routine's difficulty level again.

Special Considerations for Exercise

- **Consult a Professional:** Always check with a healthcare professional if you have any concerns about starting or modifying your exercise routine.
- **For POTS Patients:** Patients diagnosed with POTS may not be suitable for all aerobic or resistance exercises due to symptoms like dizziness, light-headedness, fatigue and increased heart palpitations. Therefore, modifications to how you exercise may be necessary.
- **For vascular EDS Patients:** If you have vascular EDS (vEDS), it's crucial to adhere to specific exercise restrictions to avoid risks. This includes steering clear of contact sports, heavy lifting, and activities that involve jarring or sudden impacts.

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