HUGHES APS TRUST

Managing Fatigue in Antiphospholipid (Hughes') Syndrome (APS)

A guide for patients

Introduction

Welcome to your patient information leaflet on managing fatigue associated with Antiphospholipid Syndrome (APS). This guide provides essential information to help you understand and cope with fatigue, a common symptom of APS.

What is Antiphospholipid Syndrome (APS)?

APS is an autoimmune disorder where the immune system mistakenly attacks normal proteins in the blood, leading to increased risk of blood clots. Common symptoms include recurrent miscarriages, strokes, and deep vein thrombosis (DVT). Fatigue is also a significant and often debilitating symptom for many APS patients.

Understanding Fatigue in APS

Fatigue in APS can be overwhelming and persistent, affecting your daily activities and quality of life. It is not just normal tiredness; it can be severe and may not improve with rest. This type of fatigue is often referred to as "chronic fatigue."

Causes of Fatigue in APS

The exact cause of fatigue in APS is not fully understood, but it may be related to:

- Inflammation and immune system activity
- Effects of blood clots and impaired blood flow
- Anemia (low red blood cell count)
- Medications used to treat APS
- Associated conditions such as lupus or other autoimmune disorders

Managing Fatigue: Strategies and Tips

1. **Medical Management**
    - **Regular Check-ups:** Regular visits to your healthcare provider to monitor your condition and adjust treatments as necessary.
    - **Medication Review:** Ensure your medications are optimized. Sometimes, side effects of medications can contribute to fatigue.
    - **Treat Underlying Conditions:** Manage any co-existing conditions such as anemia, depression, or thyroid disorders that can worsen fatigue.
2. **Lifestyle Modifications**
    - **Balanced Diet:** Eat a nutritious diet rich in fruits, vegetables, lean proteins, and whole grains. Avoid excessive caffeine and sugar.
    - **Hydration:** Drink plenty of water to stay hydrated, which can help improve energy levels.
    - **Exercise:** Engage in regular, gentle exercise such as walking, swimming, or yoga. Exercise can help improve stamina and reduce fatigue over time.
    - **Sleep Hygiene:** Maintain a regular sleep schedule. Create a restful environment, limit screen time before bed, and ensure adequate sleep each night.

    - **Stress Management:** Practice relaxation techniques such as deep breathing, meditation, or mindfulness to manage stress, which can exacerbate fatigue.
3. **Energy Conservation Techniques**
    - **Pacing:** Balance periods of activity with rest. Avoid overexertion by spreading tasks throughout the day.
    - **Prioritization:** Focus on essential tasks and delegate or postpone non-essential activities.
    - **Adaptive Tools:** Use tools and devices to reduce physical strain, such as ergonomic furniture or assistive devices.
4. **Support Systems**
    - **Counseling:** Consider speaking with a therapist or counselor to help cope with the emotional impact of chronic fatigue.
    - **Support Groups:** Join support groups for APS patients to share experiences and coping strategies.
    - **Communication:** Keep open communication with family, friends, and employers about your condition and its impact on your daily life.

When to Seek Help

Contact your healthcare provider if:

- Your fatigue significantly worsens or does not improve with self-care measures.
- You experience new or worsening symptoms, such as severe pain, shortness of breath, or swelling.
- You have concerns about your medications or side effects.

Conclusion

Managing fatigue in APS requires a comprehensive approach that includes medical management, lifestyle changes, and supportive measures. By following these strategies, you can improve your energy levels and enhance your quality of life. Always work closely with your healthcare team to tailor a plan that best meets your individual needs.

Further Information

For more information, please contact your healthcare provider or visit reputable websites:

- Lupus UK: https://lupusuk.org.uk/what-is-lupus
- NHS England: A self help guide to fatigue management https://www.england.nhs.uk/

Remember, you are not alone in this journey, and support is available to help you manage your fatigue and live well with APS.

Dr. Arvind Kaul on behalf of Hughes APS Trust 2024

This leaflet is provided for educational purposes and must not replace professional medical advice. Always consult your healthcare provider for personalised recommendations and treatments.