

Living with Antiphospholipid Syndrome

- *Understanding Fatigue and Brain Fog*

Information for patients

This leaflet is for people living with antiphospholipid syndrome (APS) who experience fatigue. Fatigue is a common symptom of APS and can be very different from ordinary tiredness, affecting both your physical and mental energy and your day-to-day life.

This leaflet explains what fatigue can feel like, possible factors that may contribute to it, and practical strategies that may help you manage your energy and improve your quality of life.

Feeling exhausted? You're not alone

Although fatigue is not included in the formal classification criteria for APS, it is one of the symptoms most commonly reported by people living with the condition and can have a significant impact on quality of life. Although not everyone is affected, many people living with APS experience fatigue at some point.

Unlike normal tiredness, APS-related fatigue can be overwhelming, often does not improve with sleep or rest, and may significantly affect day-to-day life.

Many people find that fatigue fluctuates over time, with periods of feeling relatively well followed by days when it is much more noticeable.

What is fatigue?

Fatigue is more than simply feeling tired after a busy day.

It is characterised by a lack of physical and mental energy that can make even simple tasks feel difficult. People often describe:

- Extreme exhaustion that doesn't improve with sleep
- A feeling of heaviness or aching muscles
- Difficulty concentrating or "brain fog"
- Poor memory or difficulty finding words
- Reduced motivation or difficulty getting started with everyday tasks
- Feeling mentally drained and physically exhausted

Everyone experiences fatigue differently. Some people feel tired all the time, while others have good days and bad days. You may have days when you feel almost back to normal, followed by days when even simple activities feel exhausting. This pattern of fluctuating fatigue is a common experience for people living with APS.

Quote from a Person living with APS

"People often tell me I look well, but they don't see what it takes to get through the day. Living with APS fatigue isn't just about feeling tired, it's about constantly having to think about how to use the little energy I have."

Why does APS cause fatigue?

The exact cause isn't fully understood and is likely to be due to a combination of factors that vary from person to person.

Possible contributing factors include:

- Living with a long-term autoimmune condition
- Previous blood clots or organ damage
- Chronic pain
- Poor sleep
- Anxiety or low mood
- Reduced fitness following illness
- Side effects of medication

Researchers continue to investigate why fatigue is so common in people living with APS.

Could something else be causing my fatigue?

Yes. Fatigue can have many different causes and should not automatically be attributed to APS. If your fatigue is new, worsening, or having a significant impact on your daily life, speak to your GP or specialist team.

They may want to investigate other possible causes, many of which can be treated, before concluding that your fatigue is related to APS.

Iron deficiency is one of the commonest treatable causes of fatigue. It can occur with or without anaemia and is diagnosed using a blood test called ferritin, which measures your body's iron stores.

If iron deficiency is identified, your healthcare professional may recommend iron supplements. It can take several weeks or months for iron levels to recover, so it is important to continue treatment as advised. If one type of iron tablet causes stomach upset, speak to your GP or pharmacist, as an alternative preparation may be better tolerated.

What can I do to help manage fatigue?

Although there is no single treatment for APS related fatigue, many people find the following strategies helpful.

Keep well hydrated

Even mild dehydration can make fatigue worse. Try to drink plenty of fluids throughout the day, unless your healthcare team has advised you to limit your fluid intake.

Eat a healthy, balanced diet

Eating regular meals and a varied diet containing fruit, vegetables, wholegrains, and lean protein can help maintain your energy levels. If a vitamin or mineral deficiency is suspected, your healthcare professional may recommend blood tests or supplements where appropriate.

Keep active

Many people find that regular gentle exercise helps improve their energy levels and overall wellbeing. Choose activities you enjoy that are appropriate for your current level of fitness, such as walking, swimming or cycling. Start with small, achievable goals. Even a few minutes of gentle activity is a positive step. Build up gradually at a pace that feels right for you.

Pace yourself

One of the biggest challenges is the temptation to do too much on days when you feel well, only to experience severe fatigue afterwards.

Many people find pacing helpful:

- Listen to your body
- Break larger jobs into smaller tasks
- Alternate activity with planned rest
- Prioritise the tasks that matter most
- Maintain regular routines where possible
- If you're struggling with one task, take a break or switch to something less demanding

Learning to recognise your own limits may help prevent the “boom and bust” cycle, where doing too much on a good day can lead to increased fatigue and the need for a longer period of recovery.

Sleep well

Aim for a regular sleep routine and speak to your GP if you think poor sleep is contributing to your fatigue.

Brain fog

Many people with APS also experience “brain fog.”

This can include:

- Difficulty concentrating
- Forgetfulness
- Slower thinking
- Difficulty processing information
- Struggling to find the right words

Brain fog can be frustrating and may make everyday tasks feel more difficult. Like fatigue, it often fluctuates and may be more noticeable on days when you feel particularly tired.

Keeping lists, setting reminders and planning important tasks for times when you have more energy may help. If you are concerned about changes to your memory or concentration, speak to your healthcare team.

Work, family life and emotional wellbeing

Fatigue can affect many aspects of daily life, including work, family responsibilities, hobbies and social activities. Living with an invisible condition can sometimes be frustrating, particularly if other people don't understand how fatigue affects you.

Living with a long-term condition can also affect your emotional wellbeing. Feeling anxious, stressed or low in mood can make fatigue feel worse, just as fatigue can affect your mood. If you are struggling, please speak to your healthcare team. Support is available.

If fatigue is affecting your work, speak to your employer about whether any reasonable adjustments, such as flexible working hours or regular rest breaks, could be made to support you. If adjustments are not possible, discuss other ways to manage your workload or working pattern where appropriate.

Top tips for managing fatigue

- Pace yourself and take regular breaks.
- Keep well hydrated.
- Stay as active as you comfortably can.
- Aim for a regular sleep routine.
- Eat a healthy, balanced diet.
- Accept help when you need it.
- Speak to your healthcare team if your fatigue suddenly worsens or changes.

Remember

- Fatigue is an invisible symptom. Just because you look well doesn't mean you feel well.
- Although fatigue can be frustrating, many people find that learning to pace themselves, staying active within their own limits and recognising their personal triggers helps them manage their symptoms and improve their quality of life.
- Everyone's experience of APS is different, so don't be discouraged if it takes time to find the strategies that work best for you. If fatigue is affecting your daily life, you don't have to manage it alone. Speak to your healthcare team, who can help identify possible causes and discuss ways to support you.
- With the right support and self-management strategies, many people find they are able to better manage their fatigue and continue to live full and active lives.
- Be kind to yourself. Living with a long-term condition can be challenging, and it's important to recognise that looking after yourself is an essential part of managing APS.

Further information

Hughes APS Trust

- Managing Fatigue in Antiphospholipid Syndrome. Available at:
- www.hughesapstrust.org

APS Support UK

- APS and coping with fatigue. Available at:
- www.aps-support.org.uk

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© The Leeds Teaching Hospitals NHS Trust • 1st Edition Version 1
Developed by: Louise O'Prey - Antiphospholipid CNS
Produced by: Medical Illustration Services • MID code: 20260828_002/MH

LN006267
Publication date
10/2026
Review date
10/2029