Management of Stroke in Antiphospholipid (Hughes') Syndrome (APS)

A Guide For Patients

Introduction

Antiphospholipid Syndrome (APS) is an autoimmune disorder that increases the risk of blood clots, which can lead to serious complications such as stroke. This leaflet provides information on understanding and managing the risk and impact of stroke in APS patients.

Understanding Stroke in APS

A stroke occurs when blood flow to a part of the brain is interrupted or reduced, preventing brain tissue from getting oxygen and nutrients. This can result from blood clots, which are more likely in individuals with APS.

Identification of Stroke

Remember **FAST:**

This gives the person having a stroke the best chance of survival and recovery

FAST (Face, Arms, Speech, Time) is a test to identify if someone is having a stroke

Face weakness: Can the person smile? Has their mouth or eye drooped?

Arm weakness: Can the person raise both arms?

Speech problems: Can the person speak clearly and understand what you say?

Time to call 999: Don't delay, call 999 immediately if you see any of these signs.

Ambulance paramedics are trained to manage people who have had a stroke and will ensure the person receives initial emergency medical care and specialist treatment.

Symptoms of stroke

- Sudden numbness or weakness in the face, arm, or leg, especially on one side of the body.
- Sudden confusion, trouble speaking, or understanding speech.
- Sudden trouble seeing in one or both eyes.
- Sudden trouble walking, dizziness, loss of balance, or lack of coordination.
- Sudden severe headache with no known cause.

If you or someone else experiences these symptoms, seek immediate medical attention.

Risk Factors for Stroke

Hughes Syndrome (APS) related factors

- Persistent high levels of antiphospholipid antibodies.
- Double or triple positive antiphospholipid antibody profile
- Persistent low platelet count (thrombocytopenia)

Conventional Stroke risk factors

- History of previous stroke or transient ischemic attack (TIA).
- Hypertension (high blood pressure).
- Diabetes.
- Smoking.
- High cholesterol.
- Sedentary lifestyle
- Combined Oral Contraceptive use
- History or family history of blood clotting abnormalities (e.g. Factor V Leiden, Protein C deficiency, Protein S deficiency)

Prevention and Management Strategies

1. **Regular Monitoring**:
    - Regular follow-ups with your healthcare provider.
    - Blood tests to monitor antiphospholipid antibody levels and blood clotting status.
    - Monitoring and managing blood pressure, cholesterol, and blood sugar levels.
2. **Medications**:
    - **Anticoagulants**: Warfarin or heparin to reduce the risk of blood clots.
    - **Antiplatelet Agents**: Low-dose aspirin to prevent clot formation.
    - **Statins**: To manage cholesterol levels.
    - **Antihypertensives**: To control blood pressure.
3. **Lifestyle Modifications**:
    - **Healthy Diet**: Low in saturated fats and cholesterol, rich in fruits, vegetables, and whole grains.
    - **Regular Exercise**: At least 30 minutes of moderate-intensity exercise most days of the week.
    - **Weight Management**: Maintaining a healthy weight to reduce stroke risk.
    - **Smoking Cessation**: Avoid smoking and exposure to secondhand smoke.
    - **Limit Alcohol**: Drink in moderation if at all.

Post-Stroke Management

1. **Rehabilitation**:
    - **Physical Therapy**: To regain strength and coordination.

    - **Occupational Therapy**: To assist with daily activities and regain independence.
    - **Speech Therapy**: For those with speech or swallowing difficulties.
2. **Medications**:
    - Continue anticoagulant and antiplatelet therapy as prescribed.
    - Medications for managing risk factors like hypertension, diabetes, and high cholesterol.
3. **Regular Medical Care**:
    - Regular check-ups with a neurologist and your primary care provider.
    - Monitoring for any new or worsening symptoms.
4. **Support Systems**:
    - Joining a stroke support group.
    - Engaging with family and caregivers for emotional and practical support.

When to Seek Immediate Medical Attention

- Sudden onset of stroke symptoms (see above).
- Severe ("thunderclap") headache with no obvious cause.
- Sudden vision changes.
- Unexplained dizziness or loss of coordination.

Support and Resources

- **Support and Information**:
- The Stroke Association (www.stroke.org.uk)
- NHS website (www.nhs.uk)
- **Patient Education Materials**: Request more information from your healthcare provider.
- **Specialists**: Specialised care of stroke associated with Hughes Syndrome/APS should always involve a Neurologist or a specialist Stroke Physician, a Rheumatologist with experience of Hughes Syndrome/APS, and an Haematologist (blood doctor) to oversee anticoagulation.

Conclusion

Managing the risk and impact of stroke in APS involves a combination of medical treatments, lifestyle changes, and regular monitoring. By working closely with your healthcare team, you can effectively manage these risks and maintain a good quality of life.

Dr. Arvind Kaul on behalf of Hughes APS Trust 2024