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Fatigue and musculoskeletal symptoms are shared features of many rheumatic and musculoskeletal diseases (RMDs) that often impact on physical activity and work participation. Physical activity is particularly important in the management and quality of life of people with RMDs. Participation in regular exercise can facilitate positive adaptations\(^1\), but people with RMDs tend to be less physically active than the general population.\(^{2,3}\)

Two hundred and sixty-eight individuals with antiphospholipid syndrome (APS) participated in a cross-sectional online survey (85% female, mean age 47±11 years, 59% primary APS) on physical activity and exercise. It was found that 82% of participants wanted to increase the amount of physical activity and exercise that they do and 71% of participants were either motivated or very motivated to participate in physical activity and exercise. However, a range of barriers to increasing levels of physical activity and exercise were expressed as summarised in Table 1.

<table>
<thead>
<tr>
<th>Energy Levels</th>
<th>Exhaustion, tiredness, no energy after work, ADLs draining, ‘payback’, fatigue, mentally and physically exhausted, stressful job</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptoms</td>
<td>Pain, aching, flare, muscle spasms, headaches, migraines, stiffness</td>
</tr>
<tr>
<td>Strength, balance &amp; mobility</td>
<td>Bad falls, jelly legs, legs dead weight, balance, dizziness, giddiness, loss of control, mobility, light headed, lack of strength</td>
</tr>
<tr>
<td>Fitness</td>
<td>Level of fitness poor, lack of stamina/endurance, overweight, deconditioned</td>
</tr>
<tr>
<td>Psychological</td>
<td>Anxiety, depression, worry about side effects, stressful, scary, uncertain what can do, not sure if safe, no willpower, no motivation, no confidence, laziness, worry about negative effect on work</td>
</tr>
<tr>
<td>Environment</td>
<td>Resources, membership cost, travel costs</td>
</tr>
<tr>
<td>Time</td>
<td>Lack of time, work, carer, dependents, family demands, life too hectic, busy life, have to balance activities, do enough already</td>
</tr>
</tbody>
</table>

From a patient perspective, managing home and work priorities to get things done without compromising health is a tricky task! Self-management is an important skill for anyone with an RMD, but it is a challenging skill to learn as RMDs are often unpredictable and the art of listening to your body takes time and experience. Having the flexibility to adjust the cumulative load and stressors placed on your body and mind in response to your current health status is crucial. Exercise interventions need to be personalised and, importantly, be flexible so that they can be easily adjusted to reflect the health uncertainties and disruptions associated with many RMDs. These adjustments can be made to a variety of parameters including scheduling, type of exercise, volume, frequency, intensity or duration all of which need guidance for the patient. Flexibility can also be incorporated into work participation through changes to work tasks, location, start/finish times, breaks and working from home. In many countries, it is now a legal right to request flexible working and employers have legal
obligations to provide reasonable adjustments for individuals with health conditions such as RMDs.

In our APS study, two-thirds of people said that they had not been given any advice regarding participation in physical activity and exercise and of those who had received advice only 30% thought they had received adequate advice. The latest BMJ Best Practice for APS recommends in patient instructions “exercise regularly”. However, evidence from our study suggests that people are uncertain as what physical activity they can or should do and the specifics of exercise in terms of type, frequency, duration or intensity. People wanting to exercise looked for guidance from health care professionals as well as online, but found a lack of information regarding the types of exercise they should be doing and how to determine if they were doing too much or too strenuous exercise.

References