

DofE Survival Tips (For hEDS and Hypermobility Syndromes)



- **Adaptations of the 20 Conditions**

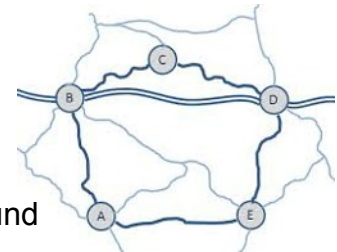
If your hypermobility limits your everyday life significantly then the chances are that you'll find a 4 day expedition challenging. Talk to your supervisor about your concerns and see if there are any ways that it can be made more feasible.



I asked my physiotherapist for her opinions on how far I could push myself without damage and went from there. Rich Adventures were advertising an expedition for a limited mobility group, and had a good understanding of my limitations. They were able to carry my stuff from campsite to campsite so I only had to carry a daypack. My physio had been strict about not carrying heavy loads, so this really helped. We also covered shorter distances with more aimwork.

- **Know Your Limitations and Find Compromises**

Being aware of what you find most difficult/dangerous is essential, your practice should really help with giving you an idea of distances and types of terrain that are easier or harder and you can work around that with your team planning.



For me, I find rubble really difficult to walk on (due to risks of turning/dislocating my ankles) so we tried to avoid it and allowed extra time for it, calculating our route cards as 2k/hour rather than 3- 4k/hour. Furthermore, I can only usually walk 3k a day without pain, so the average 20k a day was unthinkable. Instead we did 5.5 - 9k a day, which was very challenging but not impossible.

- **Frequent Breaks and Excellent Map Reading**



Frequent breaks are essential to assess your body's needs and adjust accordingly. Map reading skills are even more important if you have a chronic pain condition, there's nothing more gutting than going the wrong way only to have to turn back on yourself, especially when already in pain!

- **Warm Clothes in Layers**

Having layers is really important for anyone on DofE, even more so if you have a hypermobility syndrome and/or autonomic dysfunction.

For me, getting cold means my muscles seize up leaving me stiff, in pain and struggling to move. On the other hand if I get too warm POTS and heat intolerance tend to kick in and I can get dizzy and nauseous and come up in rashes. Having layers and frequent breaks allowed me to easily monitor my temperature and adjust accordingly.

