

My Duke of Edinburgh Expedition Experience

(with Chronic Fatigue)

From a young age I have always wanted to complete my Duke of Edinburgh awards; inspired by the fact my mum and uncle completed theirs and my love for a good challenge! I completed my Bronze and Silver awards whilst at school, but when I started to experience chronic fatigue in sixth form, I thought it would be difficult for me to complete the expedition section of my Gold award.

I still wanted to complete my award and here I am (the surprisingly smiley girl on the right) now having successfully completed my Gold qualifier in the Peak District!

I did it alongside my sister (on the left) and an awesome team of others who also have health conditions/ reduced mobility.

These are my experiences of going on expedition with chronic fatigue. If like me you've decided to go for your DofE but have health conditions too, I hope that this blog shows you that completing your expedition is certainly achievable and that you might even enjoy it too!

It's important to remember that this is my personal experience and that people with the same illness don't always experience the same symptoms. Take away the things that are useful for you and spend time finding what works for you.



What it's like to have chronic fatigue...

Chronic fatigue is exhaustion that goes on for a long time, that can be overwhelming and isn't relieved by sleep. There are many symptoms of chronic fatigue and not everyone with the condition has the same set of symptoms. I have had chronic fatigue with varying degrees of severity over the last 9 years and I experience the following:

- Unrefreshing sleep
- 'Brain Fog' and cognitive dysfunction
- Sensory overload (to noise and light)
- Poor short-term memory
- Irritability
- Sore muscles/joints
- Poor concentration
- Dizziness
- Nausea
- Prolonged symptoms after exercise

I also have Irlen syndrome (known as Visual Stress) which means that I cannot process visual information normally. I experience a lot of 'glare' from the environment which is worst on cloudy days and it can make my fatigue worse.

These symptoms can make everyday activities a challenge and I can't always lead life the way others do. In particular, my symptoms are exacerbated by exercise and the effects can last for several days.

My previous DofE experiences...

I completed my Bronze and Silver awards while at school, before my issues with chronic fatigue started. I did my Bronze expedition alongside classmates which was certainly a bonding experience! When it came to my Silver expedition there were not many of us still doing the awards, so I did it as part of an 'open' group. This meant that I was in a team with a few of my school friends and we joined with some other Silver DofE participants from local schools in Kent. At first it was quite scary getting to know new people, but in the end we had a lot of fun together.

While the expeditions were challenging and tiring in their own right, I enjoyed the experience and they were totally achievable as I was in relatively good health at the time. The only real problem I had was with my rucksack. I found it really difficult to keep the weight of my rucksack down (you are only allowed to carry a maximum of a quarter of your body weight) and I am a particularly 'bony' person so found that the straps would give me horribly painful bruises.

I embarked on my Gold award straight after completing Silver but my life soon got very hectic with A-levels and I didn't have the time to fit in the expedition (I did manage the Volunteering section while still at school). Once at university I completed my Skills section having a thoroughly good time learning how to be a coxswain of the rowing team, but my fatigue was at its worst and I couldn't see myself coping well with the expedition element. This was 2013 and 5 years later I realised I was rapidly approaching my 25th birthday with not much time left to complete my award.

By this point my little sister had caught me up and was looking at doing her Gold expedition soon; we decided to do this one together! She has **Postural Tachycardia Syndrome (PoTS)**, which means her autonomic nervous system functions abnormally and frequently leads to her fainting without warning. Understandably this placed many additional challenges on her as she completed her Bronze and Silver expeditions. While looking for open expedition groups for her Gold award she found 'Rich Adventure' who could provide expeditions for reduced mobility groups and the rest is history!

My fears going on Gold Expedition...

I had many fears prior to completing my Gold expedition. Of course, the large majority of them turned out to not be an issue at all, and even those that did happen did not stop me from completing it! I feared:

- That I would not be able to cope with the additional length of a Gold expedition
- The distances I would need to cover and that there would be more height gain involved this time around (my heart races when I reach the top of hills despite being chilled for the rest of the climb)!
- A repeat of the rucksack issues!!!
- Getting to know a new group of people and that I would need to understand their health conditions in order to keep them safe
- That my team, supervisors and assessors would not understand Chronic Fatigue
- I often suffer from extreme nausea if I have overexerted myself, have been outside all day experiencing temperature changes and/or I have been out walking all day
- Feeling inadequate as I don't always accept my limitations and often get frustrated at myself
- Ironically, I find walking boots heavy and even just wearing them tires me out

The biggest fear I had was that I was balancing the expeditions with my university studies. I was going to be completing both the practice and qualifier whilst on placement. I know that exercise puts me out of action for a while and I didn't want to be struggling to complete my work. I have always joked that my body is incredibly inefficient! I was especially nervous about this as I knew I would not be able to take any more time off of work as I had used it all up for the expeditions.

The practice expedition...

The practice expedition is the best time for you to work out with your teammates and supervisors what works best for you and what will help you. This was the time for us to gel as a team and learn to support each other. On our practice our supervisors helped get us familiar with the variations they had submitted for us to the 20 conditions (some adaptations to the typical DofE expedition requirements for those with additional needs). We would be completing reduced distances and spending a greater proportion of our time on our purpose work. The majority of the team would be walking with heavily reduced rucksack weight (only carrying the essentials for the day). With my condition I am able to walk longer distances and at a quicker pace if I'm not carrying anything. In order to still be challenged while we were taking things at a slower pace and covering shorter distance I chose to walk with an almost full rucksack.

We worked out what our pacing was like together and how to navigate each other's challenges. We brushed up on our first aid skills (with a massive emphasis on the more likely medical emergencies for our team's health conditions) and got extra navigation practice. We also decided on our aim work for the qualifier and worked out what things would keep us entertained on our breaks and in the evenings. Although it took us a while to carefully plan our qualifier routes, we left feeling positive that we really could get through our qualifier together!



The qualifier...

We were joined for the qualifier by my old school friend Lauren (she had previously completed her practice expedition many years ago and didn't need to do it again with us). Once again, we worked so well as a team and our supervisors said it seemed as if we had all known each other for years!

Health-wise I actually coped better with the practice than the qualifier. My fatigue levels are always highly variable throughout the day and day-to-day, but I really struggled in the evenings of the qualifier. I was incredibly nauseous and just wanted to sleep. I didn't really feel like drinking much and lost my appetite (not good things when you're trying your best to be in peak health and tackle your expedition)! I tried my best to eat and keep up my fluids; my team were great at helping me with this. While feeling like a massive weak link in the evenings, I was able to more than make up for it in the mornings. We were so considerate to each other and were totally focussed on the whole teams' success. This meant we naturally rotated throughout the day in lifting each other up in their low moments and taking on different tasks.

The pacing and flexible breaks we had worked on in the practice certainly came into their own on the qualifier, and despite a wobble on the first day, we were awesome in smashing out the miles and kept fairly close to our route card timings. Flexible breaks were particularly useful for the ascents as we each struggle with them in different ways and it ensured we didn't overexert ourselves.



I absolutely loved being in the peak district and thoroughly enjoyed being out in nature! I love camping and the expedition certainly reminded me of the enjoyment I had on my previous expeditions (and there I was enjoying my Gold even with chronic fatigue, which I never thought I could). It is really important to reflect on your achievements and there was a moment atop Lord's seat on the 3rd day where we had lunch, and all just looked over Edale in awe of how far we had come as a team! We were absolutely ecstatic (and of course wobbly and tired) when we finished, and it was pure joy to see our assessor and supervisors waiting for us at the visitor centre!

We succeeded as a team because each of our limitations was someone else's strength!



Top tips/things that helped me...

Polo mints and dry, plain food for nausea

Look at how far you have come and be proud of your achievements!

Food organisation - have a separate labelled bag for each day's food. It makes your life simple when you're tired and can't think straight

Make sure that you have a substantial breakfast – it will help keep your energy levels up while walking

Have an easily accessible pocket of handy things like lip salve, hand sanitizer, and tissues

Your energy and morale levels will peak and dip and this may not match up with how your teammates feel – take the time to lift each other's spirits and they will do the same for you when you need it

Sleep whenever you get a chance!

Hydration is tough when you feel sick – I wish I had taken a platypus! (although knowing me I'd have sat on it and sprung a leak)

In the weeks leading up to my practice and qualifier I was sure to write list of everything I needed – my fatigue makes me very forgetful and it took the stress off, especially as I was working at the time

I highly recommend doing your DofE with a reduced mobility group but if you're doing yours alongside able bodied members be sure to explain why you have variations in place and how your teammates can help you to succeed [don't forget that you will be bringing strengths to the team too!]

Be transparent with your team and supervisors - they are better able to help you if they know the full picture

Layers!!!

Frequent snacking

Use your practice to work out how to succeed as a team

Know yourself well and what works for you but don't be afraid to let your teammates suggest things too – there may be things you have never thought of!

Pack a well-balanced and nutritious menu

Eat and sleep really well the week before your expedition

Have someone bring you a set of clean and comfy clothes for the journey home

Be patient with yourself – I found this particularly hard being previously fully able bodied

Take quick easy dinners with you; you won't want to move after a long day out walking!