Many people here will not know this, but for the last few years I have been desperately trying to get my **Vestibular Migraine** (neurological) condition under control. After necessary extended sick leave, I have now been welcomed into the **Dons Local Action Group** (DLAG) community. In doing so they have helped me more than they can possibly know! DLAG has given me support, purpose, connection and community when I really needed it. Thank you! ❤️
There sadly continues to be a huge stigma surrounding sick leave, especially with non-visual/invisible conditions, even when they are so often also physical. I've heard "You/They don't look sick" too often to remember... So whilst I rarely ever post on LinkedIn (and a post as personal as this is far outside my comfort zone) I think it is important to raise awareness of my personal experience living with this condition - taking me from a successful and high performing e-commerce and CPG lead for 12+ years, to recently becoming unemployed.

So what is Vestibular Migraine?...

Vestibular Migraine (VM) is a condition that, before I was diagnosed I had never even heard of but in fact had likely had for years prior. It has since gone on to consume my life and dealing with it has been the toughest experience I have ever gone through!

Vestibular Migraine isn't "just a headache", it's a chronic neurological disorder that holds your balance system hostage. While most people's brains balance them automatically, mine is stuck in an exhaustive 'manual override' mode. The result is a constant cycle of excruciating vertigo, debilitating fatigue, and relentless sensitivity to light and sound (photophobia/phonophobia), all punctuated by severe nausea. It has thrown my work and home-life upside down!

Sometimes this condition can be managed quickly - alas, I did not fall into this category and it led to me needing significant periods of sickness leave.

The challenges of dealing with VM...

I wanted to share what many people don't know about dealing with long-term sickness and chronic neurological conditions like VM...

1. 😷 **Sick leave is not a choice and you do not want to be on it** - Being unable to work is not enjoyable. It is not a holiday. It is often a necessity - I never wanted to stop working.
2. 📝 **There is constant stressful administration** - it is the toughest "job" you will ever have as you juggle rehabilitation, GPs, Specialists, Vestibular therapy, insurance companies, referrals, tests, procedures +++. The admin is never ending and managing this is exhausting.
3. 😵 **You risk pushing yourself too far, for too long** - I kept going until I couldn't open my eyes or see the screen in front of me. It impacts basic activities such as walking, talking and even thinking. Illness makes people uncomfortable. Sometimes it is easier to say "I'm fine" or "I'm grand" to save the awkwardness.
4. 💔 🩹 **Recovery is not linear** - You may have a good day, maybe more than one, but then you crash. That crash could last 2 hours, 2 days, 2 months or more. The physical side is tough to take, but it's the dashed hope that's really the worst. You lose faith that, even on the good days, you will get better.
5. 🤯 **You begin to wish for more visible symptoms** - Seeing is believing right? It is for a lot of people. What I would do for more obvious wounds, more visible trauma (a cut, a

bandage, a broken leg…) anything that someone else can see or feel so they can better understand and empathise.

6. 🥵 **There is a constant feeling of pressure, guilt and shame**. Of letting down your team, your company, yourself. Of being unable to work, to support and contribute. Getting asked "What did you get up to in your time off?" - suggesting you should have "been productive", such as setting up a business, taking up new hobbies, running marathons etc. You are constantly asked when you are going back to work, as if you can click your fingers, be better and hop straight back into your role.
7. 😳 **You regularly feel embarrassed** - Even when you have had a successful career, when you meet someone and they ask "what do you do?", you often avoid the question, lie or change the subject. Inside you're squirming.
8. 😞 **You can't just "heal yourself".** Whilst I am a strong advocate of mindfulness and a positive mindset, self-healing is everywhere now. In podcasts, social media etc. This comes with a pressure that you should be able to self-heal but sadly, it is not just 'mind over matter'. This brings extra shame when you don't 'cure yourself'.
9. 🤦‍♀️ **It results in a lack of connection** - Being sick is lonely, it is isolating. Other than medical admin there is nothing to stimulate you. Even in moments of relief, everyone else is working, and by the time they are done, the symptoms may have struck again or you're simply just too tired.
10. 💦 **Spontaneity goes out the window** - everything has to be planned in minute detail to ensure you can get the required rest before and after. Yet, even with this planning, you can't achieve 95% of your plans and end up cancelling at the last minute. 5% of the time, you will force yourself so as not to be flakey but you will suffer the consequences after.
11. 🤷 **Lack of motivation and purpose** - WIth VM, mornings are the hardest but you have nothing forcing you to get up. Even if you did, you rarely have enough energy to accomplish physical or mental tasks.
12. 🥶 **The feeling of being frozen, stuck in time** - whilst your friends and colleagues get promoted, change companies, have kids or even emigrate. Some days you are just lucky to have the ability to get out of bed.
13. 💸 **You lack financial security** - I have been forced from a good salary -> 60% salary -> £0. This is a blow to your ego, never mind your bank balance!
14. 👥 **You will lose people close to you** - people that were friends (or acquaintances I guess) will stop contacting you. They will stop checking in. It's sad but that's life.

Conditions and experiences such as these are very much misunderstood, in society, in the workplace and in life. It's just a headache, pop some paracetamol. They are definitely faking it, I get dizzy sometimes too. I'm tired too, I just get on with it. Mostly this is from people who have fortunately never been sick themselves or never had someone close to them affected by such a condition.

I will admit (and I am ashamed to say) that I also may, occasionally, have had these thoughts regarding neurological or "invisible" conditions.

Having now been on the other side, I thought it was worth sharing my journey with the hope that this may help someone experiencing something similar. If it also enables people to understand and empathise vs making assumptions, that would also be a win.

For those that aren't close to me, this is how I have had to spend most of my sick leave:

1. 🩺 Trying multiple treatments from 8 different medical specialists,

2. 💊 Being prescribed ~10 different medications, many with severe side effects - this is trial and error, there is no quick fix,
3. ⚖️ Retraining my brain how to balance again and "conditioning" myself to be able to walk for longer than 5 minutes (I used to do 45min HIIT sessions multiple times a week),
4. 🕶️ Learning how to use screens again and trying to train my eyes (so I don't need to imitate a celebrity by having to constantly wear sunglasses),
5. 🏄‍♂️ Building myself up to go back into society regularly and cope with being visually triggered by EVERYTHING,
6. 👴 🤝 👴 Searching for purpose and connection in day-day life,
7. 👂 Resting and listening to my body. This sounds easy - it is not...

In summary, I have had to focus on getting better. Trying to recover. This is what my time (and energy when I've had it) has been focused on.

The road ahead with a positive outlook...

I have zero regrets about taking the time to heal. I know if I didn't address this now, then I may never. Whilst my illness has constantly been there waiting to pounce it hasn't all been doom and gloom... I have a supportive husband, constant love from my furry friend and a close circle who have cheered me on and gotten me through these dark days. **Dons Local Action Group** is now also a big part of this and has brought me support and purpose. 🐶 ❤️
To take some more positives from this situation it has forced me to build toughness and resilience, patience and determination and the ability to deal with ambiguity with a distinct lack of clarity or path forward. Overcoming these challenges is a hard way to learn these skills and whilst I wouldn't recommend the journey I am definitely taking away positives! 💪

I am hopeful that, with some new treatments and specialist advice I am finally starting to come out the other side and feel excited for a healthier future. 🙏

END OF ARTICLE

Life On the Level says –

"Brilliant Post – Niamh highlights the additional challenges facing anyone with a a busy family life and dynamic career. A balance condition can completely de rail everything you once took for granted as "normal life". Thank you for such a brave post.

https://www.linkedin.com/pulse/my-experience-vestibular-migraine-stigma-surrounding-sickness-barron-1uhke/

Life On The Level
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