

Life On The Level – Members Share their Advice and knowledge

Coping with Anxiety and a Balance condition

This section is created from the contribution of members and others who have experience of loss of confidence, anxiety and depression all caused by having a serious balance condition and the disruption to their lives.

Our section will grow and improve over time, so do check back to see the latest information in the future.

We are not professional experts on psychology, but we do want all of those in our balance community to have access to our “non expert” shared advice and tips so that they perhaps can find help, relief and comfort faster with this help than feeling isolated and alone. Our advice is to always seek professional help if you feel things are beginning to overwhelm you, as our section here is to compliment what clinicians do , not replace it.

Anecdotal feedback from our support group and work with the main balance charities suggests that the vast majority of people who are impacted by a serious balance condition (acute or chronic) will go on to experience resulting anxiety - that can be as devastating as the balance symptoms themselves. Whilst the balance symptoms are experienced physically, the anxiety, loss of confidence and sometimes depression are very much an assault upon our own mental health. The combination of a physical disability plus a draining of our mental well being is in essence what can make many balance conditions so devastating upon our lives and families.

Please note that in some cases for our group members we can introduce them to other members with relevant experience in this area to help by sharing their experience on a one to one basis. These ordinary members and are not trained counsellors and are not intended to replace any professional treatment and consultation, but sometimes an understanding and sympathetic ear can work wonders. Contact our staff to learn more at contact@lifeonthelevel.org - this service is for our members only, but we are free to join.

We hope you find the following contributions useful, followed by a list of relevant sources of help and resources.

Our first member’s contribution here :-

Anxiety with a balance condition

Stay as calm as possible - sounds impossible when dealing with anxiety but the anxiety will definitely make balance symptoms worse.

Meditation - I listen to relaxing music, relaxing songs, guided meditations on Spotify/YouTube etc, count my breaths. I try and do some sort of meditation every night before bed.

Focus on breathing - try and breathe in and inflate your tummy and breathe out and deflate your tummy, this helps you take deep breaths and not breathe from the chest which is what most people tend to do when anxious (and can also cause you to feel lightheaded which will increase the balance symptoms and the anxiety).

Talk to someone trusted - tell people how you are feeling. If you feel unable to do this, writing it down also massively helps. Even if you write it down and throw it away/delete it, it will still help

Try and think of practical solutions to help - if the anxiety is caused by certain things try and think of things to help in that situation. E.g. Lots of people get anxious in supermarkets where we get very symptomatic. A practical solution to this could be asking someone else to shop, order online, pop in to the shop regularly to get used to it and train your brain that it is ok and gradually increase over time, take a family member/friend with you.

Remember the bad symptoms won't last forever - you have got through every bad day so far.

Research your condition - I feel like knowing as much as possible about your balance condition helps with any anxiety because you know what you are feeling is 'normal' and it is just part of the condition and you are safe.

Join the right support groups - obviously the Life on the Level support group is great but when I first got my balance conditions I joined every group I could find to try and find ways to help me. I soon left a lot of the groups because they focused on the symptoms too much and how bad they are. I understand people need to vent and this could be the

only place they have to do that and that I don't have a problem with but then I feel people need to be positive to help and comment helpful reassuring things which some groups just don't have. Leave any groups you don't find helpful for you.

Take each day as it comes - maybe each moment sometimes especially with fluctuating symptoms. Just because you feel terrible now doesn't mean you always will do.

Reduce your calendar - say no to things that you don't really want to do. Save yourself for activities you really want to or have to do. Pace yourself. If in a weekend for example if I know I am going for a meal on the Saturday I will make sure I don't plan anything else that will have an affect on my balance condition for the day of the meal and also make sure I have time to recover from it on the Sunday.

Make time for you - life is crazy and busy but make sure you try and plan your week so there is some time to do something you really enjoy... even if this is something as simple as listening to an audiobook or going for a short walk.

Lists - I make lists for everything. They help me feel organised, in control and that I won't forget anything important due to brain fog! I use an app called Todoist, I prefer it to a written list because if I don't get chance to do something on my list because of a bad symptom day or plans changing I can just add it to another day without feeling bad about not getting it done. This helps keep my priorities in order and if I suddenly feel too symptomatic to get everything done, rather than getting stressed out I just change it to another day.

Thank you to our member for sharing some great practical advice.

“You are not going Crazy”

The first thing to really understand if you are affected by strong feelings of worry and anxiety due to your balance problem, is that this is very very normal (it is less normal not to be affected!). So please relax as you are not going crazy, you are not being stupid or weak, this is a normal response to an abnormal situation. Not only does it help you to know that this is normal, but it's a good idea to let your partner, family and friends read this as well, so they understand that “its not you” but “its what the condition does to you”. Too many people with balance conditions have to then endure the mistakes of many, even loved ones, that wonder incorrectly if balance issues are "all in your head" and somehow we are perversely making it all up!

My own problems started with worrying that when I left my home I could fall over at any time (Menieres) and how humiliating and embarrassing that would be, with everyone thinking I must be drunk or high on something. Plus, just the thought of not being somewhere warm, safe and with help close at hand if I had an attack was another reason to fear leaving my home. Now that “worry” went through phases, where some weeks it was a “little” worry and other weeks it was a “wall of fear” that could not be overcome. I think the strength of this anxiety was related directly to my frequency and severity of my attacks plus how all other things in my life were going – as it seemed that my mind had an ability to collect all current “bad news / stress / pressure / bad luck” and roll it into one big ball of anxiety about my balance condition and ability to live – many weeks leaving me feeling useless, worthless, and trapped in my home.

How did things improve Well being a stubborn man I did not seek any counselling or help (I now know that was so stupid – so don't copy me on this please). It took well over a year to begin to start to make sense of what was happening to me in terms of the balance problem and my mind problem. I slowly worked out some key things that really help me so much in once more going out and generally in living with my balance illness.

- a) All my fears and worries were turning out to be far worse than the reality, so I had to start telling myself that it was pointless to have such extreme fears that may never ever happen. That diluted them and their impact on me
- b) My attacks were unpredictable but only once every 2 weeks or so, which left me with at least 90% of the time “attack free” – so I began to see it as a shame to stop 90% of my life for the 10% bad bits, and that gave me the courage to start venturing out on my own
- c) My fear of embarrassment was purely in my own head and of my own making. No one had ever complained or been insulted or angry or affected when I was ill, so why was I so worried about “offending” strangers when I was out of my home, and to be honest since when did any of us running our lives for the benefit of people we have never met make any sense. So, I was finally free of worry if I had an attack out of my home.

- d) As I gained more freedom and the inevitable attacks happened away from home – at work, at meetings and socialising, those experiences proved that “life did go on”, nobody minded and I was right to get back to participating in normal life as much as I can.
- e) I didn't know it then, but gaining that ability to leave my home, take part in work and life was the key to finally “mentally overcoming” my balance condition, and being able to wake up in a morning and not want to analyse if I could stand up OK, or worry if an attack was coming later. This gave me my life back and put my Menieres into a much smaller corner of my life, rather than “be my life” (as it had been for far too long). That was how “I beat Menieres” and got back to my life and loved ones.

I am not saying we are all the same and I know other conditions can be more continuous with their symptoms and less “episodic”, but I still think the process of understanding that the fear we feel is far more bigger than the reality, can help to start fight back and given time and growing boldness in our actions, can eventually allows us to escape from the mental prison that our balance condition leads us to build in the early days. I hope that is of help to someone.

On Ongoing Path

As anxiety and depression are fairly understandable when one has lost balance or in pain, helping to relax and be less afraid can help both the original symptoms as well as the accompanying anxiety. I can list some books and websites that I have felt helpful.

"The Way Out of Chronic Pain" by Alan Gordon, also on audio. Based on reputable clinical trial in Boulder, USA. A clear and helpful explanation of neuroplasticity of the brain and *how to retrain it*. Although it's for pain, it also covers any chronic condition. I found it easy to read, but lots of clinical information on how it's the brain that 'decides' the pain, in chronic conditions.

Barry McDonagh's "Dare"(A Way to End Anxiety and Stop Panic Attacks.) His is more a staying with the panic and breathing through it.... maybe not for some, but I'm having a go with it.. Again the notion that staying, watching the fear with curiosity ... the brain settles down and stops that arousal.

The Curable App. is great, even my neurologist thinks well of it. www.curablehealth.com . Very reassuring, informative, meditations, journaling, education, and users' success stories. So often, pain and depression and anxiety are all connected.

Nicole Sachs, Joey Remenyi, Howard Schubiner are all great names in pain and anxiety, and have books, websites and free Youtube help. Joey Rimenyi particularly deals with all balance issues and tinnitus. She is a trained vestibular audiologist, and has book "Rock Steady" and lots of free on line videos

There seems to be the approach in other areas of *distracting oneself* - concentrate on your breathing, where you feel it entering, leaving; find as many green (red, blue etc) things you can see in your environment; look for rectangles, and breathe short breath in, as your eyes travel along the short end, then long, slooow breath out, as you look at the long end (e.g. door, picture frame etc)

CBT has many suggestions on coping with anxiety, that you can look up on line.

Hope these suggestions, all of which I've tried and which have helped me to some degree, may be useful for others.

I feel learning to slow down, have compassion for myself, knowing when to avoid, and when to have a go, despite the anticipatory anxiety, all helps me. Oh ! and I mustn't forget - Tapping - look up **Emotional Freedom Techniques (EFT)**) - again clinical evidence how tapping on meridian points on the face whilst bringing to mind the anxiety or fear, calms the amygdala (proved by changes on brain scans as evidence) is a wonderful, easy self-help technique to calm oneself .

Thanks to our member for another great raft of practical tips

My Anxiety and Depression with a Balance Condition

The most useful things I have done are therapy and mindfulness.

The best therapy for me was Acceptance and Commitment Therapy (ACT); it doesn't ignore the suffering that's going on in your life, it teaches you to cope with it and move forwards regardless. It's a form of Cognitive Behavioural Therapy, and can be done on the NHS – I had my sessions over the phone. My therapist asked me to buy the book *The Reality Slap* by Russ Harris, and each week I would read a couple of chapters for us to discuss in the sessions. It was helpful to talk things out with the therapist, and have her point out my thought processes and biases, but the book contains all you need so I'd definitely recommend it.

Mindfulness has also been great, as it has made me much more aware of my thoughts – I notice quickly if I'm going into a negative thought spiral, which means I can do things to stop it (like the ACT techniques). I started off meditating for a few minutes each morning, and then went to a meditation course online. This led to me joining a group who meet online to meditate for half an hour every morning. I've found meditating in a group much more motivating than doing it on my own, I think because of the social aspect.

Other little things that have helped me:

- Scheduling weekly video chats with a couple of close friends who don't mind if I have to cancel at the last minute. Even if I'm feeling down, they're set up in advance so it's easy to go, and I always feel better afterwards.
- Doing one small thing a day I enjoy, which often leads into doing more things I like.
- At the end of the day, thinking of at least one good thing that happened or that I'm grateful for.
- Prioritising my time and pacing myself (I feel more emotional when I'm tired).

Thanks to our member for mentioning ACT, as you will see links relevant to this at the end of this page

Once upon a time

Is how my 8 year old granddaughter advised me on how to begin my story on the balance issues I experience and how they, affect me in my day to day life. So, 'Once upon a time' I had no balance problems and could walk in more or less a straight line. Now I can't and this has had a devastating effect on how I live with this life changing disability . I also suffer from a genetic disease, Mitochondrial Myopathy, which almost certainly contributes to my balance issues and just at the start of the pandemic, March 2020 I was diagnosed with Kidney Cancer. It was around this time my stress and anxiety levels reached a new high and I spiralled into a severe depression.

How have I coped during the past 2 years? Well if I am honest about it I haven't, and I have to admit to experiencing some very dark and distressing times and wondering if I was ever going to be part of society and enjoy life again. Depression I now realise came upon me slowly. The balance disorder had been with me for some time but it was quite mild and I just veered a bit on walking and I just accepted it as part of the genetic disease and it had no great impact on everyday life, I was still able to do everything I wanted to do. Then I experienced a severe attack of vertigo. I woke up one morning and just couldn't stand up without the room spinning. I crawled to the bathroom on my hands and knees and there had my first panic attack. For those who have experienced such attacks they will identify with the symptoms, nausea, sweating, palpitations, feeling faint, shaking, hyperventilating. I thought I was going to die. Seeing a doctor became nigh on impossible during the pandemic but I eventually received treatment and after 3 weeks the vertigo subsided, but my balance was so much worse. I became afraid to go out even for a daily walk but as I had been shielding for almost a year anyway it didn't seem too big an issue at the time, it would rectify itself soon and everything would be back to normal.

Weeks became months with little improvement and I became more and more anxious and isolated, only going out for my many invasive hospital tests and scans for my other condition, hardly joyous excursions. I stopped driving, I didn't feel safe, the panic attacks continued and I wobbled around the house convinced I was now really ill, even taking a shower I felt I was going to fall over, I lost all my confidence. Staying in bed was safer !

After 3 months I came to realise that I couldn't cope with this situation by myself. I needed help. I was very used to seeing a doctor for my physical health issues but never about my mental health so I waited until I could see a GP with whom I felt understood me and would show some empathy. My initial conversation with her did not go according to my plan, she wanted me to take a low dose of antidepressants and I was reluctant to do so, counselling was also prescribed and so I went for that option first. But, I was ill prepared for the mental strain counselling involved and for a short while I actually felt worse, but I was encouraged to become more knowledgeable of my anxiety symptoms and so I read books, leaflets anything I could find on balance disorders living with a disability and anxiety, a mammoth task, as there is so much material out there and not all of it helpful. One thing that appeared time and again was how medication could work along side other therapies such as mindfulness, meditation, relaxation, counselling. So, back I went to my GP and agreed to take a relatively low dose of antidepressants. This, a sunny day at the end of March I remember was the start of my recovery process.

I cannot say everything from then on was not without a few hiccups, recovery seemed very slow at times, but I did begin to explore new options, one of which was to join the support group 'Life on the Level'. Kevin was kind, understanding and non judgemental when I telephoned him on a particularly bad day with my balance. It was so helpful to share my symptoms with another balance sufferer. I feel connected by the group meetings and talks on zoom. I don't as yet contribute very much but I certainly learn a lot by listening. I have also been referred to the balance clinic at LRI and have learned how much anxiety contributes to my poor balance and along with counselling I feel I am beginning to understand the condition and acquire the tools necessary to prevent my anxiety and balance disorder becoming overwhelming.

My granddaughter would now say 'And they all lived happy ever after'. Well who knows about that. One thing is certain, I still have 'Mitochondrial Disease', I still have Cancer and am waiting for a big operation to remove a kidney and coping with my 'Balance disorder' is still very much a part of everyday life for me, I am slowly reducing medication, I still have counselling but I genuinely feel I have with help and support from so many people, professional and non professional I now have control and perspective over my life. I do not know what the future holds but I hope I can embrace it, enjoy it, face my fears and continue to learn how to change the areas I am in control of and to accept those that I cannot. It is hard work at times but I do know I am in a much better place now than I was even a year ago. That has to be positive doesn't it !

Thank you to our member for sharing that inspiring story of the onset of adversity and dealing with it one day at a time and finding that new better place, each year.

Menieres / Balance Conditions and the causes of anxiety and depression

- The unpredictability and fear of having a Menieres attack.
- Not being able to get a diagnosis and not finding any way to relieve the symptoms.
- Not being able to find the cause of the attacks.
- Feeling that you are a liability the moment you walk out of the front door because:-
 - What if you have an attack while you are out?
 - Would there be help at hand?
 - What if I was on my own?

- How would I get back home?
- What would I do about my car?
- Would people think that I was drunk or taking drugs?
- Having to cancel social arrangements at the last minute.
- Weeks of your life written off suddenly because of being ill.
- The effect it has on your ability to work and the financial impact of that.
- Feeling that it is your fault because, for example, you have eaten 'the wrong thing,' even though you don't know what that thing is! You end up going to the cupboard because you know you have to eat, but you don't know what to eat.
- Having your Driving Licence suddenly and unexpectedly revoked therefore losing your independence and having to rely on others.
- Guilt of putting others through the wringer, e.g. your loved ones, or, taking someone away from their work because they have to look after you. I was once told it was very distressing to see me being so ill!
- Feelings of being alone because no one understands how bad you feel and are at a loss what to do to make you feel better. I've come to hate the phrase, 'but you look well!' As if somehow you can't be that ill because you don't look it!
- Too much different advice from well-meaning people which confuses the issue and can make matters worse.
- Hearing difficulties - getting embarrassed and trying to disguise the fact that you haven't heard.
- Once getting a diagnosis - the actual procedure!
- Post treatment, if and when it will return?

And what helped

- To remember that **anxiety is 'a normal human response to threat or danger.'**
- Being able to **talk to someone who understands** what you are going through is invaluable.
- Get in touch with the Menieres Society and ask if you can talk to someone who has experience of your condition.
- **Join a Support Group** in your area.
- **Smile**

This came from a Support Group meeting I attended.

When the going gets tough, just smile.

Although that is probably the last thing you feel like doing, I tried it and it actually works!

- **Cognitive Behavioural Therapy (CBT)**

By contacting my local surgery in Lincolnshire, and asking for some counselling, I got a free, online CBT, NHS course, called Steps2Change. Maybe there is something similar in your area.

In Leicestershire, CBT is available through Dr Lynnette Simpson, a Clinical Psychologist.

- **Find coping strategies** for when you are ill, such as, when lying in a darkened room, take the opportunity to listen to some nice, relaxing music if you can and while you've got the time. It may stop your mind focussing on the negative thoughts and mask the tinnitus!

- **Be kind to yourself**

During one consultation, thinking I had brought on an attack by maybe eating the wrong thing, I was told, **'IT IS NOT YOUR FAULT'**. People don't usually find out what their trigger is. Don't beat yourself up.

- It may take a while to accept your diagnosis and come to terms with it, but **don't give up doing the things you enjoy**. Even if it doesn't seem like it at the time, your condition will get better.

- **'Be prepared'**

When you do pluck up the courage to venture out, have a back-up plan in place to make you feel safer, e.g. If enjoying 8 mile walks in the countryside, don't stop doing it, just never go alone and take your sick bags and pills with you. Have local taxi firm numbers on your phone, so that you can ring them to get you home.

If at work, talk to your employers, do a risk assessment, and have a plan in place in the event of an attack.

- **'Eating for your Blood type'** made a great difference to my condition and energy levels.

It was created by naturopath Peter J D'Adamo.

<https://www.webmd.com/diet/a-z/blood-type-diet>

- **Exercise**
- **Feeling the sun on your face**
- **Meditation** [headspace.com](https://www.headspace.com)
- **Acupuncture**
- **Meridian line patting or EFT (Emotional Freedom Technique)**

An alternative treatment for pain and emotional distress.

You can do this in just a couple of minutes a day as and when needed.

It makes me smile, energises me and sets me up for the day ahead.

Thank you very much for that personal guide to our members fears and solutions

Useful Links and Resources

Free Referral to the Health Psychology department in Leicestershire

Referrals to this service was commenced from the Leicester NHS Balance Centre in 2021. Where any patient of the centre can be referred at no cost to the department of health psychology for assessment to receive their counselling and CBT therapies. This department is focused on treating anxiety and related issues that stem from having a serious or chronic illness and do not treat patients who have a primary mental health issue. You can only be referred from another department of the Leics Hospitals, as a GP cannot refer you.

If you are living in Leicestershire and are treated by the Balance Centre, please do ask their staff for a referral if you believe that this may be of help to you. It is free and could make a huge difference over the long terms

Please see a detailed presentation to our group by their Lead clinical psychologist Dr Lynnette Simpson in 2021, where a detailed explanation was given on their approach and details of their treatment, based around ACT - Acceptance and Commitment Therapy - [Click here to view the meeting report and videos](#)

Private Treatment for Anxiety with Michaela Burton

Whilst we never assume any member can afford private treatment, we understand that those who can afford this will look to gain access to treatment as quickly as is possible when suffering from any illness, especially anxiety or depression. So we felt it important to provide a good example of private treatment available, based in Leicestershire but available everywhere via Zoom video consultation. Michaela Works at the

Renowned NHS Balance Clinic in Leicester, and treats patients privately at the London Road Clinic Leicester and at her own practice www.do-it-differently.co.uk . Many members have given very positive feedback on their experiences with Michaela and her warm friendly approach.

Using a mixture of therapy approaches and in addition a qualified hypnotist, Michaela gave a very useful presentation to the members on how to create your own “Anxiety Toolbox” . Please click here to visit this meeting report and view the meeting video. <https://www.lifeonthelevel.org/meeting-reports/meeting-report-saturday-7th-november-2020-on-zoom/>

Links supplied by Dr Lynnette Simpson for our members

<https://www.getselfhelp.co.uk/docs/ACE.pdf>

Nourishing and depleting activities: <https://www.getselfhelp.co.uk/docs/NourishingDepleting.pdf>

Poisoned parrot: <https://www.getselfhelp.co.uk/docs/TheParrot.pdf>

Emergency self soothe box: <https://www.getselfhelp.co.uk/docs/EmergencyBagBox.pdf>

Learning to live in the here and now <https://www.getselfhelp.co.uk/docs/APPLE.pdf>

Helpful when goal setting- follow SMART principles: <https://www.getselfhelp.co.uk/docs/SMARTgoals.pdf>

www.getselfhelp.co.uk – lots of resources for mental health Williams, M. & Penman, D. (2011).

Mindfulness: A practical guide to finding peace in a frantic world. www.franticworld.com

www.nhs.co.uk/livewell : www.mind.org.uk : <https://web.nrw.nhs.uk/selfhelp/> – range of self help

leaflets www.compassionatemind.co.uk – introduction to compassion focused therapy

www.psychologytools.com/ – self-help resources for mental health

A general link to find urgent mental health help is <https://www.nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline>

Remember if you are a member of our support group, we may be able to connect you with a fellow member who can give you one to one advice and encouragement. If you are interested in seeking that contact please email us on contact@lifeonthelevel.org

We hope this section on our website has been useful for you . Whatever your level of anxiety, fears or depression please do always try to open up to your family and friends. If you are with a support group do talk with the organisers and members – sharing and talking will help build a safety net around you and ensure that things cannot spiral out of control. Don't remain isolated and do accept help from others.

Please do give us feedback on the above and if you think you can offer any advice yourself on this subject or provide advice and support for our members applying for benefits please do get in touch.