

Karen's Journey – Part 1

“She fell to her knees and began to smile because she had been in darkness for a long, long while”

The beginning

My journey began one morning in May 2018, like so many other people I just woke up with ringing in my right ear, describing its sound like a cicada on amphetamines. Whether it was coincidence or not, my ringing started 24hrs after receiving multiple vaccines for Hepatitis A, Typhoid plus a Tetanus shot.

At first, I wasn't too worried and went to my local GP expecting that a simple course of antibiotics or medication would do the trick, or the ringing would simply go away by itself. I was healthy 45-year-old and never experienced constant ringing or any other major health issues before. My GP didn't seem concerned at all - prescribed Amoxicillin (suspecting a bacterial infection) and told me to come back in a week if the ringing persisted.

Unfortunately, the ringing did not stop and by then I was starting to get increasingly stressed and sleep deprived. I returned to my GP, who referred me to an ENT. Living in Regional Victoria, the earliest appointment was two weeks away. By this stage, as most people do, I started to use the internet to self-diagnose potential causes and treatments of the ringing. Some of the search results started to concern me.

The ENT journey and lack of answers

I remember entering my ENT appointment on edge. I had so many questions about this ringing, treatment, timeframes, but more than anything hoping for answers and solutions.

After some quick examinations of both ears (clear), nasal passages (clear), hearing test (normal for my age) and brief questions, the ENT said he thought I had a virus and prescribed a 10-day course of prednisolone (steroid) and anti-viral drugs (famciclovir) and said he gave me about a 50/50 chance of the ringing going away. He also warned me that the prednisolone would make me anxious, and to focus on a positive attitude.

Although normally an upbeat person, I left the ENT rooms already feeling highly anxious. I was disappointed the odds of a full recovery weren't much higher and I had a gut feeling that my journey was going to be difficult.

As a Scientist by profession, I thought the best way of testing the response to the steroid and anti-viral drugs was to measure/rate the level of noise morning, afternoon and night each day. On Day 1 and day 2 there was no difference, other than the drugs started to make me feel queasy, reduced my appetite and stripped any happy emotions I usually had. Either on day 3 or 4 I had an incredible day when I woke up with my tinnitus (referred hereafter as 'T') levels so low, I could hardly detect the buzzing. I remember this day well, with tears of happiness and relief. I genuinely thought I had turned a corner and my T was abating. I went to bed that night fully expecting to repeat this day, if not improve on it. However, when I woke up the following day, the buzzing was blaring and so intrusive. This set the scene for a new and very terrifying journey for me having to think of this dreaded ringing as something I may never be rid of. Also, I did not know it at the time but by constantly measuring my T and searching for it, I was only making my condition worse.

Falling into a dark hole

After about 6 weeks into my T journey, I was starting to get myself a terrible state of anxiousness, fear and depression. Up until this point I was juggling a stressful full-time job while looking after two primary-aged children. Life was always busy; I rarely had any time for myself and the household function relied on me holding everything together.

Like any T sufferer, I was focussing continually on the ringing, hating this change the T was bringing to my life. It meant I could no longer lie quietly in bed at night and hear pure silence. I couldn't think clearly because of this dreaded ringing 24/7 in my brain, driving me crazy. Telling people only seemed to make it worse because of the constant response of "Oh - that would make me go mad if I had that all the time".

For me in the early months, my T was dramatically fluctuating on a daily basis, which was a huge emotional issue. On good days, I could function quite OK but predominately the usual daily volumes were intrusive and so harder for me to stay calm and ignore.

I am describing the above to let anyone new to tinnitus know that you are perfectly normal to feel totally broken in these terrible early months. I think it would be impossible for most new T sufferers to not be knocked down by the mental and physical affects T places on its sufferer. My husband and Mum were of great support but after 6 weeks or so, I couldn't worry them too much, as they had to function to pick up the pieces of our daily life that I wasn't coping with.

I took sick leave from my job because I didn't want my work colleagues seeing me in this state. I didn't feel myself and very scared for T affecting my quality of life. It was consuming me. I was quickly learning being on the T journey was as much a mental one, as the actual condition itself.

Evenings were hell. I started to see a local counsellor for support, who knew nothing much about T, but could see how anxious I was. On two very dark nights I did call the 'Beyond Blue' hotline to talk about how broken I felt with no way out. I mean, let's face it, and to first time T sufferers having to adjust to this sound permanently seems incomprehensible. I didn't want to accept this as a permanent thing. It wasn't fair and wasn't what I imagined life in my forties to be. I was absolutely grieving with despair for this intrusion to my silence.

Finding life changing support and answers through the TAV

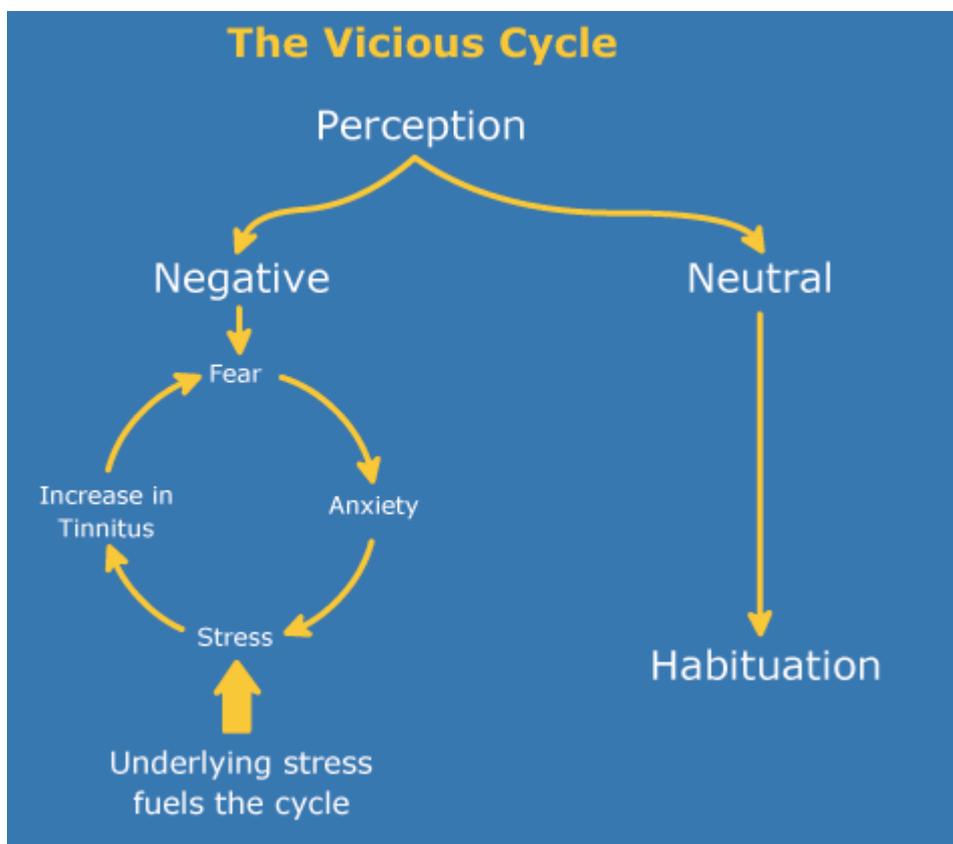
Searching the web for treatments and answers wasn't really helping that much (as there is plenty of horror stories and bogus treatments available) but one vital search to the Tinnitus Association of Victoria was a solid steppingstone forward and out of the dark hole. The advice on this site seemed factual and helpful and clicking on the contacts number I saw three mobile numbers listed; three wonderful volunteers that would be help me out of this hole and get me into recovery.

From the moment I made that first call to Sam, I knew instantly I was speaking to a person who understood what I was going through and could help me with practical advice. Similarly, Marg was the gentle female touch I needed, as was Ian to provide the experience and factual information I needed to read through to reinforce to myself there was management tools available that actually worked.

Perception is nine tenths of reality

Watching the video on the '4 Keys to successful Tinnitus Management' (plus reading the summary of it on the TAV website) gave a complete overview of T and how important perception was. I could quickly identify that I was spiralling within the negative cycle (see diagram below) and needed to somehow see this horrible buzzing as a neutral, insignificant noise and move on. Of course, everything is so easy in theory.

Nonetheless, I was so curious about this wonderful end state called 'habituation', which for everyone is described differently but generally speaking - a state where *after many months of neutral perception, sufferers DO NOT have tinnitus intrude their normal activities and RARELY give attention is given to it*. If such a marvellous state did exist, I had to get to it and my focus started to shift at how I could achieve this. Rather than T managing my life, I had to learn how I could start to manage it.



Exploring the treatment options – the necessary path for acceptance

Although learning that once you have T for longer than 6 months, there is rarely any cures...I still had to explore what was happening in MY case to rule out what was treatable (or not) or complicating the issue. I'm thinking most people go down this path. I had and MRI (normal), blood work (normal) and sought a specialist second opinion in Sydney, which all resulted in nothing treatable or fixable. The specialist concurred with my Regional ENT, that he thought I had a virus, where the T may go away in a few months, or by then I would've 'adjusted' to the ringing.

Starting my recovery

My advice to sufferers in a bad emotional state is to FIRST focus on reducing your anxiety, then worry about managing your tinnitus SECOND. As the two go hand and hand (with T feeding off your anxiety), this is paramount.

For me, this was achieved slowly over a few months several keyways. The first is through talking with my TAV counsellors and recognising the things I was doing right and the things I was doing wrong in moving towards recovery. I felt so lucky to have their advice and past lessons of others to learn from. I could choose to continue to make the same bad choices others had made or learn from these and turn this around. My TAV counsellors gave me the journeys of other sufferers to read. I printed these out and put in plastic pockets to read on my down days to give me hope and inspire me.

The second keyway I reduced my anxiety is through regular acupuncture from a genuine Chinese practitioner/herbalist. A combination of acupuncture and a prescribed personalised herbal tea (drank twice daily) to reduce anxiety genuinely helped a sceptic such as me, whom had never ventured into acupuncture before. I recognise that this may not work from everyone, but for me this unquestionably helped.

Do whatever you can to reduce your anxiety and get a solid 6 or more hours of sleep each night to help your recovery. I very much wanted to take anti-depressant/anxiety drugs to help me through the TAV counsellors advised that IF I could avoid this step, my recovery would be smoother less hindered by drug dependencies. I had to find the strength to pick myself up, accept and get on with life.

Be kind on yourself and expect to go backwards, tinnitus can and will fluctuate when it's in the front of your brain every minute of the day (if you let it). The intrusiveness fluctuation was so hard to deal with – on good days its volume was only just detectable. On bad days, it sounded like a zinging fire alarm which a pitch that somehow was accentuated and amplified by car engines and by compressor type noises, such as a washing machine and exhaust fans. On bad days when my T was spiking through the roof, I used Diazepam prescribed by my GP to help me sleep. Yes, this drug is addictive and shouldn't be taken long term, but I used sensible amounts to help me through this chronic time.

Progressing to habituation (maintaining the hard work to ignore and get on with life)

I returned to work after three weeks, scared and emotional. Getting through the first weeks was so draining and hard work. Normally a night owl, I was crawling into bed each night at 9pm so completely zonked.

By the three month mark, I had accepted my T more as the new norm and sleeping better (but getting into bed earlier). I was doing everything I had usually done previously, except down a notch or two as my T was still making more fatigued. I could usually ignore my T for the best part of the day. I wasn't deliberately searching or measuring my T *as much* but I knew that the volume had not subsided. For me, its intrusiveness was most difficult during the evenings (when I sort out a quietness after the kids were asleep), or that time THAT time of the month when my T would spike through the roof for three or so days. On these days I was usually shedding tears by the end of the day from the sheer drain of T's intrusiveness, as much as I was always trying my best to ignore it.

Things I learnt that 4 four people in my workplace of around 80 also suffered from T – this helped put in into some broader perspective.

After following the advice of the TAV and past sufferers, I backed off the internet sites searching for remedies or support. I had also backed off talking about my T to only with my husband, mother and TAV counsellors, so to not focus on it during the daylight hours. Like most conditions, I did find that speaking to the TAV counsellors was the most helpful as my family had become somewhat desensitised after a couple of months. The TAV counsellors know only too well what a private hell this was for every new sufferer.

In the initial few months, I would wake up to hear my T as a negative sound. A change I noticed from 8 weeks, it was accepting it more as my 'new norm' and didn't bother me as much. My TAV counsellors had really praised me for turning a corner and to continue to be fearless about my T, search for it less and remain positive and committed. Just hearing their calm happy voices telling me I would reach the 'good times' was the only thing keeping me continuing really. To be honest, I still couldn't fully believe there was a process where my brain would accept and cancel out this noise. Would this indeed happen to me, to what extent and what timeframes? There were no absolute answers and timeframes other than to wait and see.

Make no mistake the T journey is not an easy one and I realised most days how much of fine line there was between coping and not. I desperately wanted some abatement in the intrusiveness level, making it easier for me to tolerate. My TAV counsellors said that after several months I should see some improvement, whereby expect to have more good days than bad with my brain tuning out from it most of the time and best of all, a reduction in volume. It was coming into spring and I wanted to use this as extra motivation to progress towards habituation.

I am writing down my journey in more detail to hopefully help other new sufferers. The TAV counsellors described that people who tended to be worriers, or perfectionists (in my case a bit of both), tended to take longer to habituate. Just great (!!) ...but better to know and be aware of this.

By the three-month mark of ignoring and getting through the days, I was desperately hoping for detectable improvements. One thing I did notice is that the fluctuations in the intrusiveness had trended to be less. It tended to stay at the same level, on the louder end of the spectrum. It was slowly getting easier to forget about measuring and being aware of my T and focus on getting on with life. On weekends when there were quieter periods and I tended to worry more, I did as the TAV counsellor suggested, and create a "toolbox" of personal distractions to focus away from the T. From me, this included reading, walking my dogs, bike riding, gardening and vacuuming (where my T couldn't be heard...winning!). I would cycle through a number of these in sequence depending on how bad I was.

Coping with T every minute of your life it is completely normal to not stay positive all day, every day. I would generally track for 3-4 days OK, then feel a bit down and need some reassurance from the TAV counsellors, utilise my 'tool box' and go to bed early on the crappy days to hit the reset button and try again the next day.

I asked my TAV counsellors to describe the occasion they remembered when they had first noticed they had habituated. Hearing these personal reflections was so inspiring. I can't wait until I detect such a little sign. I suspected I had a way to go, with the counsellors always understandable reluctant to giving me a timeframe.

The very gradual extinction of the negative reaction to tinnitus.

At the 4-month mark, to be honest I don't feel as though I've made any more progress towards habituation. I have tried my best to live my life pretty much the same way the I would've done before. To nearly everyone, I would appear normal. I am disappointed that I haven't seen a solid reduction in my T volume. Maybe at best 3 days this past month. For the rest of the time, my T volume has been just as intrusive as the last. I hate this and hate that I can't put timeliness on my brain tuning out from this shitefulness.

I mostly keep my T in the neutral state during the days...my busy daily and work routines keep my pre-occupied. For this I am very grateful. I don't go consciously searching for it but my goodness, my T is zinging high above engine noises and compressor type engines, it is so annoying. When I get most frustrated is in the evenings. With less distractions and wanting some quiet time, it is the hardest. Fortunately, I am sleeping OK (with some help from a sleeping tablet on bad nights).

What I've come to realise at this point is that:

Will take a significant amount for time for my brain to adjust to this buzzing as a completely neutral sound, hence the extinction of all negativity

In this acute phase, T is intrinsically stressful as the natural state...changing the perception is so hard to do all day, every day. Some days I feel as though I'm failing when I let me T get me down. Yes, I distract myself and get past it but this struggle never leaves me.

What keeps me on track is the communication I have with Ian, Sam and Marg when I need some reassurance. It is vital to be to tell some who really knows that you just feel like crap or need some encouragement on days where you can't see a way through this. In many ways I think the T journey gets harder as it draws out, with only the very odd day of improvement. As your mind has been taken over by the cricket zombies, it also plays tricks on you too – doubting if you've travelled very far at all along the recovery road.

The scientist in me wants more answers, evidence and positive trends. Counsellor Ian, with an engineering background helps me in these instances and earlier this week emailed me some very helpful words of wisdom, which I have read over repeatedly the past week:

“Your positive attitude to life, your work and family life indicate to me that you will have a significant reduction in the level of intrusiveness and will have no problem habituating. The key for you in my opinion is to accept that it will take time, there are no shortcuts and it will not happen overnight. Your intelligence and desire for answers which are wonderful attributes in most life situations tend to work against you in this instance”.

Habituation will happen as is indicated by your 'good' days, at some stage all your days will be 'good' days and your life will not be impacted by your tinnitus in any way - guaranteed! 😊👍

Key points from the above that really stand out:

- ✓ Significant reduction in my level of intrusiveness with time (Ian had a 90% reduction) – yay!
- ✓ I will have no problems habituating – yay, assurance that I won't be the anomaly
 - No shortcuts, will not happen overnight, stop overthinking – um OK, true
- ✓ Guaranteed, (at some magical point) in time that my life will not be impacted by tinnitus in any way – Gold!....almost seems too good to be true

All I can say at this point in time is that it's still hard yakka but I'm doing my best to see this T has insignificant and 'boring'. I'll keep on trying...

How to get this phantom noise out of my head!

Five months into the journey and I've been working very hard to ignore my T and get on with life. It's a personal mental battle of keeping a positive attitude to not let this silly ringing get the better of me.

One thing I've been focusing on is going back to the 4 keys of Successful Tinnitus Management and looking into developing correct perception to T. I am wondering if the level of intrusiveness I experience, is more about how I *perceive* it to be, particularly when I find it spiking or worse than normal. Could it be that in actual fact am I just in a more silent room when I can hear it more, or I am a bit more stressed or tired than normal? What is the difference between perceived or genuine intrusiveness? I can't really say. I know that in months previously, I would never be able to think about this as rationally and ask myself these hard questions.

At 5 months, I am doing a better job at ignoring my T as I am not measuring it as much. I know this because there are times when I don't think I can't hear my T but when I listen hard enough, it's still there and just as intrusive. I think this must be the beginnings of my brain 'tuning out'. However, my T is just as intrusive as ever in the mornings and evenings. It is much less noticeable when I am at work, or at home focussing on other things.

One key point I learnt this month regarding the levels of levels of 'perceived or actual' intrusiveness....The levels of intrusiveness will not decline until **after** I start to habituate, not before. When a sufferer has habituated, the levels of intrusiveness for most people are just a fraction of when they first develop T. How good will that be!

My mood is generally more stable and unlike previous months, I don't feel as though I am simply treading water, just waiting for this transition period to be over. I am lucky that spring has arrived, and I am using this changing of the seasons as a motivator to transition into a solid state of recovery.

Six months into this forced journey and I realise now I have passed the 'early onset' phase and now entering a phase of awareness that I will now have this phantom ringing for the rest of my life.

My tinnitus counsellors, whom have helped hundreds like me, say by 6 months some sufferers are well on their way to habituating, stressing though that every brain is different. Unfortunately, I feel as though I haven't progressed that far towards habituation in the past couple of months but have been managing mostly OK.

However, one counsellor, whom knows me too well has warned me not to go looking for empirical evidence of improvement of my T, as in this way I am focusing on my T too much (which I know I have). This is due to my scientific background and wanting to see sequential or quantifiable improvement. He told me to stop monitoring my T all together and get on with life – it's the only way I can train my brain in the subtle way needed to change its perception of T to a neutral noise. This is so hard for me.

At this point in time, the amazing T counsellors have probably done everything they can to support me through the acute phase, providing me with the correct knowledge I need to help me to habituate. It is now up to me to do the rest and let them focus on new sufferers. Because I don't feel sufficiently 'better' – just in a trance-like state of constantly ignoring my T and getting on with time – I do feel somewhat disillusioned and on my own to get through this period. It is an isolating self-journey to

keep ignoring regardless. I'm not trying to resist the changed state and strong enough not to cry "poor me", as I know there are far worse medical predicaments to have. It's just the sheer intrusiveness in my head that prior experience tells me I must not let this get the better of me and keep fighting for control and normality.

For most of my day, I am either not aware of my T, or ignoring it by focussing on other things. Because I am not focussing on it, I can't say which of these it is the most. But there remains a period of the morning and nights, as previously described, that I am very aware of its loudness and annoyed that I can hear it. I was hoping to be further along in my journey by now. I still have some periods of certain days in the week when I am terrified that this is as good as it gets for me. I hear that when I am fully habituated, I may not be aware of my T for several days. This all seems so far away.

I spoke to one of my work colleagues yesterday, whom, in a simplistic form described acclimatisation to T similar to getting a dirty smudge on your glasses. He said, when you first put the glasses on, you immediately notice the dirty smudge but then after a few minutes you get used to it.

Early into 9 months and I took a dive in my acceptance of T. The longer I have the acute symptoms of T, the harder it seems to believe that I will successfully habituate. For a normally positive person, it's fair to say my optimism is well and truly worn down. The thought of intrusiveness levels this bad has brought on panic attacks in the evenings, when I find myself having several mini panic attacks: diving down a black hole very quickly, and then having to make a very conscious mental effort to pull myself out of it. I can't say I have experienced anything like this before and annoyed with myself for recognising what I'm doing this and yet not being in better control. Why can't I accept this T better and move on? I am thinking I need to go back on some more of sleep medication to calm me down and get me through the nights, like I needed in the acute phases. My counsellor Ian has been so wonderful & reassuring but stresses it's up to me to find my own means to see the ringing as neutral and acceptance. I'm clearly not going about this the right way. No one can do this part but me but trying not to focus on my T in any negative way whatsoever is proving to be so very difficult in the evenings. I just can't seem to fully accept and not be annoyed by T then when I most searching for some peace and quiet in my head.

Later in the 9-month mark and thankfully I have taken a two-week beach break with my family. Re-reading my last paragraph from 3 weeks ago and I can tell how much I was focussing on my T and being hard on myself. In addition to my chat with counsellor Ian, I also called counsellor Marg before I left for my holidays and she told me just that – I was being too hard on myself, enjoy life, relax and things will be get better. She told me there were days when she wasn't aware of her T, the same as Ian had. It really settled me down and was just the tonic to take with me on holidays.

While I was on holidays, I kept in my mind what Ian had said to me about finding my own way through this. I kept myself mentally and physically busy, tried to reassure myself each time I was aware of my tinnitus that it was fine, part of the new 'me' and continued to enjoy myself. With so much distraction noises like waves, seagulls, birds, swimming, boat rides, conversations and general children's sounds, there was plenty of white noise to drown out my T. This really helped. I've done really well to relax and turn myself mentally around. More importantly this break has helped break the constant pattern I had gotten myself into at home measuring my T as a regular habit when I was doing my regular quiet activities, such as washing the dishes (searching, measuring), doing the ironing (oh this is boring, why I don't I just search and measure), cleaning my teeth (where are you....oh yes, there you are!). These bad habits were sabotaging any progress to habituation.

I can now confidently say there are clearly SMALL periods of the day when I am completely unaware of my T. These chunks of time are noticeable now and of greater quality as I'm not interfering with them anymore by measuring them. I know the best thing I can do is continue to do nothing and just hope these chunks of time increase with time. Habituation is a reality for anyone who starts to get these periods in non-awareness of T, due to distraction/preoccupation. These are the small building blocks. When I return from holidays, I need to continue this path of completely ignoring my T whatsoever, staying stronger than I've ever been more, and simply enjoy life and be kind to myself. Whatever change in me this T has caused, it must not get the better of me.

10 months and I have been pretty good seeing T as a mild annoyance during the days, it is not much of a problem. I recognise this a critical switch

Night times are still a mid to moderate challenge to not to focus on. Now that I'm back from holiday and into my usual routines, I have lots of solitude doing boring jobs when this is bloody hard.

About mid-way into the month, I run around in the knowledge that most people have usually habituated before now. All the journeys I have read and the counsellors' own experiences, their stories tell of reaching habituation by 9 months or less. Ian doesn't have any journeys from sufferers after this time. He says that it does take people longer 1 -2 years, but these people don't write down their journeys. Those poor sods, I can understand why. But in reality, how many of those sufferers just don't habituate and give up calling as they can see it not working? How I regret writing this sentence but it this what I am facing? My neighbour, from across the road, admitted to me earlier in the week to having very intrusive T for two years with no relief. This shocked me a little as I've seen her quite regularly and didn't know her struggle. This could easily be mine.

I want to trust Ian and all the counsellors with all my heart that I will "get there". I am not seriously messed up in head the with emotional issues to complicate the process but trying to break the pattern of not focussing on my T at all is so hard.

My better days are only defined by my emotional acceptance and degree of how successfully I ignore it. Nothing more. I am quite amazed and frustrated how easily a hormonal day, mild irritations and frustration on life can all just wear down that acceptance, leaving you dangerously on a depression-type downer. It takes control of you very quickly unless you stop it. I recognise all these signs, have all the knowledge I need to know the best approach, yet struggle to stay solid each and every day.

This ends Part 1 of my journey and you can see all my painful emotional rollercoaster of how badly tinnitus consumed me. Detailing my journey in this way probably did slow down my acceptance of tinnitus by focussing on it too much. However, at least it shows you, the reader, the raw emotion and mental 'hell' I was in. If this is currently you, then feel absolutely comforted in the fact that you are not alone and please read Part 2 (which I promise isn't as long).