

The background features abstract, overlapping green geometric shapes in various shades of green, creating a modern and dynamic design. The shapes are primarily located on the left and right sides of the slide, framing the central text.

My Journey through Cluster Headaches - Colin Simpson

Sunday 8th June 2025

Agenda:

- ▶ The early days....
- ▶ The symptoms....
- ▶ Treatments tried and tested....
- ▶ A Carers view....
- ▶ Life after Occipital Nerve Stimulation....
- ▶ My future....



The early days....

- ▶ I've suffered with Cluster Headaches for 14 years
- ▶ Getting an actual diagnosis took a long time
- ▶ Trial and error with tablets
- ▶ I've felt like a guinea-pig
- ▶ You can't describe the disappointment when drugs or treatments failed
- ▶ I would have tried anything.....

The symptoms....

- ▶ Excruciating pain - 10 plus
- ▶ Agitation
- ▶ Frustration
- ▶ Irritable and short tempered
- ▶ Exhausted
- ▶ Depressed
- ▶ Desperate and tortured
- ▶ Personality changes - mood changes
- ▶ Suicidal thoughts.



Treatments tried and tested....

- ▶ **Lots of tablets** - Paracetamol, Anadin, Aspirin, Brufen, Paracodol, Codeine, Morphine, Gabapentin, Pregabalin, Amitriptyline, Verapamil, Propranolol, Topiramate, Valproate, Prednisolone, Pizotifen, Methysergide etc....
- ▶ Cannabis Oil (legal!)
- ▶ Alternative or complementary medicines/therapies
- ▶ Gamma Core trial
- ▶ Oxygen Therapy
- ▶ Sumatriptan injections

A Carers view....

- ▶ “It affected the whole family - we couldn’t plan anything, the kids avoided seeing him as he was so poorly or simply exhausted from the night before”.
- ▶ “I would feel guilty as we couldn’t always go places that the kids and grandkids wanted to go to because Colin was exhausted or experiencing an attack, we had to cancel things at the last minute. I felt guilty leaving Colin and going places myself”.
- ▶ “You feel helpless, lost, nowhere to turn to, we had tried everything - I needed to try to keep Colin's spirits up but you can’t help feeling downhearted”.

A Carers view....

- ▶ “It got worse over the years - I tried to make him feel more hopeful about the next option, tried to instil a bit of hope in him”.
- ▶ “I felt frightened - seeing your husband in the middle of the night asking for a gun, hit me with something so he could be knocked out”.
- ▶ “I was pushed away by Colin sometimes - it was really hard, I didn’t know how to make things right”.
- ▶ “I was really frightened for his safety and at times thought he was going to die”.

Life after Occipital Nerve Stimulation....

- ▶ I feel energised
- ▶ I have a spring in my step!
- ▶ Everyday I wake up and look forward to the days challenges either at work or my wife's jobs list!
- ▶ I look forward to the weekends to be with the grandkids
- ▶ I'm excited because I can do DIY jobs all day, I can watch the whole of a football match
- ▶ I'm thinking ahead - I've just bought a fishing boat to enjoy semi-retirement
- ▶ I hope this is going to continue!



My future....

Happy,
pain-free
and looking
forward to a
future!

