



# Wellness in CADASIL

A personal journey by Glenn Bate.

# Why Me?

- ▶ I was fit, I was strong.
- ▶ I was a good person, I didn't steal, I helped old ladies cross the road.
- ▶ I loved my wife, I was loyal to my friends.
- ▶ I had always worked, I had provided for my family.
- ▶ Basically I'm a nice guy.
- ▶ But on the 12<sup>th</sup> Oct 2015 I would have to survive something which was meant to kill me - a Stroke.
- ▶ On the 16<sup>th</sup> Oct 2015 I was told by a Consultant Neurologist I had CADASIL, my scans were showing all the classic signs of the condition.
- ▶ "I'm very sorry to tell you but there is no cure"
- ▶ What is happening to me?

# Help - Everything is changing

- ▶ My wife is coming to the hospital, how do I tell her?
- ▶ There discharging me from hospital, I'm going home to die.
- ▶ I'm home, I've looked at the internet, it's only a matter of time.
- ▶ What do we tell everyone ?
- ▶ I'm going to lose my job.
- ▶ I need to sort finances out so my wife is ok.
- ▶ I wake up in the middle of the night, I'm checking to see if I'm still alive.
- ▶ I can't imagine what it's like to die.
- ▶ I'm sinking, not sure how to handle this.
- ▶ I'm telling everyone I'm a fighter, I'll fight this, I was a boxer.
- ▶ I know I can't win but I'm keeping face.



# Next few weeks

- ▶ I've been out, bit wobbly on my feet but it's ok.
- ▶ Going to walk a bit further tomorrow.
- ▶ Starting to eat again, I've lost so much weight.
- ▶ Some friends come and see me regularly.
- ▶ Some friends don't want to see me and seem embarrassed and condescending.
- ▶ I seem to be interested in some things again, but not everything.
- ▶ My concentration levels are variable.
- ▶ I'm still scared but the brave face is working, well sort of.

# My Breakthrough Moment

- ▶ A colleague who was terminally ill could see right through me and gave me this advice.
- ▶ While you are busy dying, don't forget to live.
- ▶ Of course, he was absolutely right, I'm not dying today, I'm living today. I concluded "Many fears are brought on by imagining".
- ▶ What stops me from doing so many things at the moment "Imagining" because I concentrate on the negative, this horrible end which awaits me.
- ▶ I know I'm seriously ill so how do I get myself into situation where I can enjoy life more?
- ▶ I have been through a bereavement process, but the person I've lost is me.
- ▶ How do I find myself again?
- ▶ So I had to introduce wellbeing into my life, both physically and mentally.

# My Mind

- ▶ Mentally I have been suffering from depression, I just did not realise or accept it.
- ▶ I'm riddled with anxiety, that why I cant sleep or concentrate.
- ▶ I need something to change my mind set, so I come up with #defytheodds
- ▶ These words will define me, its now also the hashtag for CADASIL Support UK.
- ▶ I know what CADASIL can do, but guess what I'm fighting back, I will meet you head on, I will defy the odds.
- ▶ I will continue with my interests.
- ▶ I will remove myself from toxic people and situations.
- ▶ I will not hide my condition to make others feel comfortable about themselves.
- ▶ I will not apologise for my condition, this is not a path I have chosen.
- ▶ Everyday I will live the best life I can.

# Nutrition

- ▶ I will eat healthily.
- ▶ My diet will include plenty of fruit and vegetables.
- ▶ I will reduce my intake of processed foods.
- ▶ I will drastically reduce sugars and salts.
- ▶ I will reduce alcohol intake.
- ▶ But at the same time I will have the odd treat, piece of chocolate, small portion of fish and chips or a Chinese.
- ▶ I will not comfort eat.

# Fitness

- ▶ I've always been fit, now I'm unsteady on my feet.
- ▶ I'm going to start walking further everyday.
- ▶ Going to have bit of a jog.
- ▶ I'm go to start running.
- ▶ I'm joining the gym.
- ▶ I've joined a running club.
- ▶ I going to attempt and complete the three peaks challenge.
- ▶ I'm entering road races, I'm going to compete.
- ▶ Smashed my personal best time at the Dereham 5k road race 28 mins 40secs!
- ▶ At 62 years of age I'm beating people half my age, I no longer feel disabled.



# Summary

- ▶ For CADASIL sufferers positive mental health is crucial.
- ▶ Removing yourself from toxic people and situations (stress) is really important.
- ▶ Keep interested in the things you enjoy.
- ▶ Sensible eating will greatly assist.
- ▶ Exercise of any description will help - it doesn't have to be running.
- ▶ Remember you did not choose this path, its not your fault, don't blame yourself.
- ▶ Live each day of your life the best you can, always remember many good days lie ahead.
- ▶ Don't blame CADASIL for everything, even non-sufferers have bad days.
- ▶ Stroke/CADASIL you brought me to my knees, but I have risen.
- ▶ I am a Survivor.

# A final thought

- ▶ I wouldn't wish CADASIL on anyone, but in some ways it has enriched my life.
- ▶ It has removed people from my life who weren't true friends.
- ▶ It has introduced new people.
- ▶ I have the people in my life I want there, my true friends.
- ▶ It has given me a purpose in life - I'm doing something useful.
- ▶ There is perhaps a beauty in life that wasn't there before.
- ▶ I always had a close marriage, its closer now.



Thankyou for listening

