



*Read our CEO, Jonny Wilkinson's regular column in*

***The Northern Advocate***

***"A different Light"***

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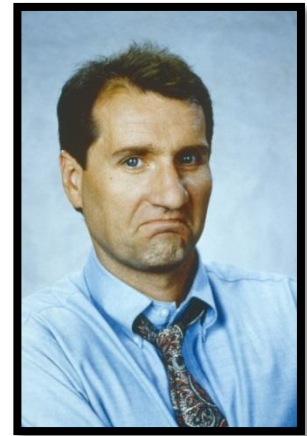
## Real pain in neck

"When you hit 50, it's like being trapped in a run-away bobsled to hell."

I forget where I picked that line up from. It was either Archie Bunker from All in the Family or someone from Married with Children.

Yeah, I know, I am showing my age. Interestingly, the two protagonists from Married with Children have both had spectacular career comebacks.

Al Bundy has been reinvented as the patriarch of Modern Family and Katy Sagal in Sons of Anarchy.



*BACK AT YA: Like Al Bundy (Ed O'Neill) off Married with Children, I hope I have a good comeback.*  
PHOTO/GETTY IMAGES

Do I watch too much TV? Yes, but back to the bobsled.

I have had a pain in the neck for years but over the last two years, I have tingling down my arms into my fingers. So, I have been on that elongated process of seeing a specialist.

Round 1: Referral from my GP to a specialist for an MRI. That took a year.

As you all probably know, the secret to a clear MRI is keeping still for 10 minutes while a giant metallic toilet roll slides back and forwards over your body.

So I asked my GP to ask for sedation. When Radiology rang to book the appointment I repeated, "I need sedation".

Radiology: "You need sedation for anxiety because of claustrophobia?"

Me: "No, because I have cerebral palsy and can't keep still."

The day of the MRI:

Radiology: "You need sedation for anxiety?"

Me: "No, because I have cerebral palsy and can't keep still."

Radiology: "Put your hand up if you need more sedation."

Me: Wave hand in the air for the second time.

Radiology: "No, you can't have more sedation."

Round 2: The report from Radiology came back. 'Significant motion' is noted, the following comments made: 'Multiple levels of degenerative change and significant spinal stenosis and bilateral neural foraminal stenosis at multiple levels extending from the C3 level to the T1 level. Findings are limited by motion ... '

Round 3: Appointment with surgeon and registrar.

Nurse: "Hi Jonny, this is Matt, he's a registrar."

Registrar: "Hi Jonny, I'm a registrar."

Me: "Right, hi."

Registrar: "So you live on your own?"

Me: "No, I live with wife, daughters, son-in-law, mokopuna."

Registrar: "Do they look after you?"

Me: "Not really, it's symbiotic."

Registrar: "Incredible!"

Me: "Really?"

Registrar: "Can you feel this, does this feel weird, how about this? Let me just try this, does this feel weird, what does this feel like, can you take your shoes off, I just want to feel this, what does this feel like?"

Me internally: What am I, an unknown species and you are an eight-year-old prodding me with a stick?

Outwardly: "Yes, kind of, okay, if you really want to, what do you mean?"

Enter the surgeon.

Surgeon: "Hi Jonny, your spinal cord is being narrowed in your neck because some of the vertebrae are deteriorating."

Registrar: "His spacity is so severe I can't even tell his reflexes, but I think his tingling in his hands are a result of carpal tunnel as a result of his cerebral palsy."

Me internally: WTF?

Outwardly: "But my CP is very different in each hand, however the tingling in each hand is exactly the same."

Surgeon: "Okay, so what I recommend for you is to go in through the throat, take a piece of bone out of your hip and fuse some of the vertebrae together. Then you will need to wear a halo or a big collar for at least two months. You don't have to give me a decision right now, it's not like you've got cancer."

Me internally: WTF!

Outwardly: "Will I be able to move my head much afterwards?"

Surgeon: "A little, we always like to leave the top two vertebrae free."

Me: "I don't know if my cerebral palsy will be compatible with wearing a halo."

Flashback: I was five years old, staring at my grandfather who had exactly the same operation. I could feel my eyes bulging wide as I stared at the gleaming stainless steel bolts screwed into his skull, attached to a gleaming circle around his head, supported by a scaffolding of four stainless steel rods; the halo. My mind flashed forward imagining me falling over wearing a halo and our Sydney silky terrorists licking brain matter off the floor.

Surgeon and the registrar: Silence.

Me: "I don't know if my CP will be compatible with not being able to move my head."

Surgeon: "So what do you want to do, shall I book you in for surgery?"

Me internally: WTF!

Outwardly: "Well, given the long process, yes, book me in now and I can give you an informed decision after I do some research."

Surgeon; "Okay, we will get a cat scan done. You'll be all right, it only takes 30 seconds and then we will talk to you again. Bring your wife."

I will keep you posted with Round 4. Needless to say, like the actors off Married with Children, I hope I have a good comeback.

***Jonny Wilkinson is the CEO of Tiaho Trust - Disability: A Matter of Perception, a Whangarei-based disability advocacy organisation.***