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The sad tale of carers, left to save themselves

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Mar 17



This is the story of a maiden in a tower. She's tired, but there's no rest for this Sleepy Beauty.

Once upon a time twelve months ago, a Facebook notification trumpeted across the land.

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‘Hear ye, hear ye - The great bald gnat doth proclaim that the Whaikaha guidelines that once were flexible shall now be inflexible. All thee helpful support doth no longer exist!’

The village folk scattered, not knowing where to go or what to do. They couldn’t believe such a cruel cut could be announced in such a cold and uncaring way.

A terrible blonde witch cast a spell over the village folk to make them believe that all carers were wasteful, lazy ogres who deserved to be banished to a bog of eternal anxiety, with no way out; Carers become stranded in this place with no hope of rescue. They teetered perilously on rocks that once were part of a pathway leading forward, but now go nowhere.

They survived on crumbs of support left from long ago, while the village folk assumed they dined on wine and ciggies, and wiped their tears with lotto tickets and overseas holiday boarding passes.

After many weeks and days, the carers made their way back to the castle where they were met by suspicion and distrust by the other village folk. They look around for someone to defend them, but everyone is struggling with their own troubles. They retreat to their homes, never to see the light of day while the hex still exists across the land. They wait for a hero to come and save them from their rapidly shrinking world.

But no knight in shining armour arrived.

All the knights of the kingdom who would normally support the carers are tired and battle weary, their armour is dull and pock marked, and they have no time or supports left to patch them up. Their hands are tired from writing submissions. Their voices are hoarse from talking in pointless consultations. Their faithful steeds haven’t been fed or watered, and can’t carry the weight of responsibility any longer.

The castle walls that once stood tall and strong have been dismantled. As each organisation closes its doors, unable to continue on less gold coins than before, the bricks and mortar turns to rubble beneath our feet. Hereth lies EGL, and all our hopes of a good and full life for our children.

This fair maiden is no Sleeping Beauty - she can’t get a rest. She sits and waits in her tower to be save, or even a signal that hope is on the horizon, but as the days pass - her hope is fading. She’s tired alright, but there’s no rest.

...And thats where we leave this story. There’s no happily ever after whatsoever. Not in the next two years anyway.

.....

March 18th 2024 is the day everything changed for the worse for our families.

Once we were mighty, now we have fallen silent. Even the staunchest advocates are battle weary. 'Why bother with consultation when they don't listen,' is a line I have heard many times over recently.

In the last year us carers have been forced to face our greatest fears, mostly in silence and away from the gaze of people around us. We are not martyrs, we just want to live a good life, be a good parent/partner/friend like anybody else.

People ask how we are, we reply 'fine' but if I told you how I really am, you would not think I was remotely inspirational.

I get by, I'm fortunate to have a husband who works close to home. That's my privilege. I have held down a part time job for almost a year now, which has helped to pay for all the things that our funding no longer covers. Life is busier, and balancing is even more of a stretch, yet oddly that's a privilege too.

Do I think about running away someday? Yes. Would I go through with it? No. Is the stress so overwhelming some days that I wonder how much more I can possibly take? Yes! Am I coping? **Today, yes I am, thank you for asking.**

I still regard the day I had minor surgery under general anaesthetic as one of my most relaxing days ever. Closely followed by the day I fell asleep during a wisdom tooth extraction and mistook my snoring for the saliva sucky apparatus thing. Grim but true.

A carer friend told me they were driving down the road and considered driving off the road if it meant they might be able to get a night's sleep in a hospital bed.

Another one drinks enough to sleep at night, but wine time is creeping into hours much earlier in the day now.

We have no supports in place any more, with no flexibility in budget allowances to give ourselves some respite. Our worlds are shrinking, and we hide the pain of it.

That's why I stand with [Awhi Ngā Mātua](#) and [Emily Writes](#) in asking for an official apology from the (then) Minister of Disability Issues for her comments, that caused so much harm in our community. It's not a fix, but it's an acknowledgment of the harm they caused us a year ago.

We need to mend the damage already done to bring us back to a safe place to start a conversation. Then we can korero about what needs to happen next to help our carers get the supports they need to live a good and happy life with their families. We need less restrictions and more joy. It's that simple.

Please like and share Awhi's video [here](#):

And please sign the petition calling for an apology [here](#):

Sending love to all our carers xx

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