

From: Julie R Bjorem [REDACTED]
Sent: Sunday, 23 February 2025 2:13 PM
To: IGAC Royal Commission
Subject: TRIM: Need for Rules Flexibility in Management of People in Aged Care

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Dear Sir/Madam,

I am a GP with 43 years of experience, now retired, who has a husband in Aged Care.

He is 80 yrs of age and has the genetic disorder, Huntington's Disease.

This is a progressive neuro-degenerative disease, which causes excessive, uncontrolled movements, mental decline similar to dementia & worst of all - bad behavioural changes.

The higher functions of the brain are most affected - such as reasoning & insight.

If he makes a decision, he has no insight into the implications of his decision. Furthermore, he changes his mind frequently and cannot be reasoned with at all.

Doesn't help that he is very strong-willed!

He is in denial of his symptoms & refuses a lot of help, because he can't see that he needs it.

Won't take medication designed to help his condition.

These people all become abusive (physically/verbally) to others - but particularly to the one closest to them - usually their spouse.

They become a different person, due to their disease, unfortunately.

Always, the changes in them are for the worse, and they make life/care VERY difficult.

I still love my husband, after 39 years of marriage, and only want what is best for him. As do our 2 adult children.

I feel strongly that the management of people with conditions similar to his - of whom there are many - falls through the cracks of the rules the staff who care for them, have to abide by.

I am well aware that there has been a lot of Elder Abuse, in its various forms, and that this has driven the introduction of rules intended to curb this.

I am all for this.

One of the most troublesome of these rules is that the elderly person is in charge of what they want & don't want.

There is no provision here for the limitations I outlined above, that many elderly people have.

They can no longer reason out what is best for them, lack the insight to see implications of decisions & frequently change their minds.

Families need to get a Lack of/Reduced Capacity Letter from a Health Professional, before an existing Power of Attorney can be enacted - to be able to make decisions for them.

I, as a Health Professional myself, have been trying for many years to get one of these letters written about my husband! Very frustrating!

His own GP would not do it, as he wanted instead to be his friend & not write anything negative about him.....!

And the Doctors & Professionals at the big Huntington's Disease Clinic in our state capital city wrote reports on his deterioration, but would not do the "Capacity Letter", instead referring me to the Qld Health Legal Articles on Capacity, which state that only 1 area of capacity can be mentioned, and these are known to change, etc, etc..... useless in the real world!!

So I am back to stating there is no provision for the individual circumstances of people like my husband. The Aged Care management rules need to be FLEXIBLE, and provision made for individual difficult circumstances.

I would be happy to engage with the appropriate people who are assessing the impact of these rules, if they wish to contact me.

Yours Sincerely,
Dr Julie Mitchell