

P-04-456 Dementia – This Could Happen to you – Correspondence from the Petitioner to the Committee, 12.05.14

Hi Kayleigh,

The meeting with Lynda Chandler was as I thought it would be, a waste of her valuable time and a patronizing waste of my time. Lynda Chandler is a very pleasant woman who was just doing her job but nothing was achieved and I felt that she was there simply because the health department had to be seen to be doing the right thing following having ignored the fact that they had written to the petitions committee inviting me as petitioner to become a stakeholder and not bothering to follow through. I came away feeling warmly encouraged and praised which presumably was the object of the exercise. Sorry if that sounds cynical.

If the Welsh Assembly Government Health Department and their special advisers don't listen to Professors of Law and Dementia Experts who have been battling away for years in an attempt to address the multitude of unjust ineligibility decisions that have been wrongly made by abuses to the National Framework and the incorrect withholding of Continuing Healthcare Funding, then what hope have I as a mere member of the public.

I will say this though, as long as there is breath in my body I will continue to stick pins in those who blatantly and pompously bend the rules for financial reasons.

As I see it the only good thing to come out of the hour or so I spent with Mrs. Chandler was the suggestion about forming a Dementia Task Force, but I would suggest that it should be made up of people who have been in the unfortunate position of being badly treated by the system as it stands, and not NHS cronies, so that in addition to the charities who support people who find themselves in a position of coming up against (.....and I use this term from experience) the hugely complex system as it stands, there is another option, that of choosing to be supported by those who managed to get a handle on the National Framework and jargonlike terminology like Multi Disciplinary Team Assessments and Decision Support Tools (the tick box administration). Often this data is not properly understood or correctly implemented/completed by the very people who are using them on a day to day basis, which is really scary, and of course there are those who are advised how to complete forms in a way that will ensure their continued employment, and YES I did say that!

Kind regards,

Helen