P-04-456 Dementia - This Could Happen to you - Correspondence from the petitioner to the Chair, 09.10.2013

Dear William

Thank you for your letter and for the copy of the letter from the Minister. I suspect that it may have been drafted by a mandarin in his department as it merely confirms what we all know, viz that the Framework states that financial criteria should not be a reason for refusing eligibility. However, many of the contacts I made while promoting and seeking support for the Petition were firmly of the opinion that lack of finance was one of the reasons that they were refused CHC and as the Wales Audit Office's report on CHC confirms, knowledge of the provisions of the Framework by assessors and administrators is limited. Furthermore, as you will have seen from the WAO report the number of cases being found eligible has declined over recent years, which coincides with the Health budget coming under financial pressure. As the number of elderly people who are more prone to dementia has increased, and proportionately more people are being diagnosed because of increased public and medical awareness, only the most naive of people would believe that the decrease in numbers being found eligible is merely a statistical blip.

The report also confirms in its guarded civil service jargon that there are <u>clearly</u> many problems with the administration of CHC across the country.

Hopefully when Lisa, Tony and I appeared before your committee we adequately conveyed to you the magnitude of the problem, and the reasons why I filed the petition, asking not only for the increase in the needs level for the Cognition domain from High to Severe, Severe having been there in the first instance before being removed after public consultation, but also for the Welsh Government to take active steps to make sure that Welsh Health Boards comply with the Framework. Among those steps compliance with the National Framework should surely be a given, however perhaps consideration should be given to imposing sanctions on those Health Boards who abuse the Framework because of budget constraints. From the WAO report it would appear that it would require additional funds to be spent in retraining many of those involved in the implementation of CHC in Wales as well as more effective management of the system, perhaps a more cost effective way of dealing with this would be to simply ensure that adequate training were blended within the current module.

I would be very much reassured if your Committee could keep a watching brief on the progress made on the review of the system referred to by the Minister and possibly list it on your agenda for the first meeting in the new year with a request that the Minister updates you on progress made by that time, with quarterly reviews thereafter. I would also be obliged if you would be prepared, as a committee to send a copy of this letter to the Minister and ask for his comments.

The collective fears of Lisa, Tony and me after several years experience of dealing with many CHC cases is that unless your Committee keeps a watching brief over this matter that it will be "kicked into the long grass." This would, and I'm sure you understand, be an insult to myself who launched

the petition and to all of those people who took the time and the trouble to sign the petition and the many, many more who are following the campaign with great interest and involvement on social media.

best wishes