

## HIDDEN DEMENTIA

A couple of days ago I had a e mail from someone who thought they could help me by sending me some information all about dealing with a diagnosis of Dementia and making plans ahead of the inevitable (Unless a cure is found, and I am, as you know , fully convinced this will happen!) Anyway, so far so good, so I welcomed the correspondence as any information is better than none at all, as you all know. Sounds good up to now doesn't it? Well, they sent me all the info and also a programme about an up and coming Conference where the main topic is indeed all about making plans and dealing with the last stages of this awful disease, now this is where it gets interesting?

As I "perused" the programme it had a list of invites, they have invited people from the medical field of research, leaders of the dementia causes, Carers, Drs, consultants ect, but guess who they haven't invited ?????? YEP!! people who have a diagnosis of dementia. Now I am not talking about me specifically, as for one, it's too far for me to travel, and two as you can imagine I cannot be in ten places at one time LOL. So, as you know me only too well, I wrote back and asked what I called a simple question which was this :

"HOW ON EARTH" can you discuss, late stages of life in Dementia and make plans for whatever future they have left if you don't ask them themselves? I know when it gets to a point that trying to sort plans out with someone who is in late stages is practically impossible, but surely these questions of "what people want" should be asked and talked about before the later stages arrive!! Am I wrong in this? Please let me know your views. On a personal basis, one of the best things I ever did was to put my house in order once I was diagnosed and made sure everybody knew exactly what I wanted, it not only give me piece of mind but also took so much stress and worry away from my full time carer (who is also my wife) I ask the question how can anybody be so selfish as not to do this? This is where it gets really interesting:

When I asked this question to the person over the e mail they responded by telling me that they Write to people with Dementia "Privately" I was absolutely Astounded!! Whatever happened to "INCLUSION?" Why should people with a diagnosis be invited "On the Quiet" Do you invite people with Cancer or a heart condition, to conferences separately to everybody else?? NO! I don't think so!

## Thoughts by Norrm's Mcnamara

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My point is, if professional bodies (who shall forever remain nameless) are not including people with a diagnosis about what THEY want and instead, are having a conference about what other people THINK they want, then I am afraid we will never move forward!! To me my friends, it's so simple. It's staring us in the face

Early Diagnosis = Acceptance

Acceptance = More understanding of this disease

More understanding= Raising awareness

Raising awareness= More funding (it happened with HIV and Cancer)

More funding= A cure

Or is it just me with too much passion? Please let me know, Norrms

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