

Changing attitudes to Dementia and
Tackling stigma
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Good Afternoon. I was diagnosed with early onset Alzheimer's disease just over a year ago.

Everything changed after my diagnosis.

I could no longer carry on with my job
The practice manager in a busy chiropractic office.

I could no longer provide the level of support
I had been giving my dad who is 86 and also has dementia.

I had to come to terms with having a progressive illness.

It felt as if my life was over

Pause Look up

As my daughter said "The one thing my mum prided herself in was her brains, and ability to cope and reason with what life dealt her,

And this illness was affecting these abilities."

On top of these changes I found that my family and other people treated me differently.

I'm not the way I was. I know that from the reflection mirrored in people's eyes, when I become emotional instead of the Agnes they know and love the one who takes charge solves problems not this female who reacts and cry's

This was very apparent on Saturday when the chemist refused to give me my Arisept they told a close relative that the Doctor's surgery would not sign my prescription till Wednesday as I should still have 5 tablets left and Guess what me a patient with Dementia had the audacity to misplace two tablets

I search the house totally traumatized I pulled
the wardrobes apart
All to no avail the 2 tablets are still missing.
I phoned the chemist and they have loaned me 2
tablets till Wednesday
Alan could not cope with my reaction to not
getting my Arisept

What's 2 tablets he said
Then left the house" I'm out of here this is
insane" shaking his head and left me to deal with
it all.

My daughter who is living in Bulgaria phoned me
and I explained the situation She is phoning my
Doctors surgery to ask that they accept the loss
of the 2 tablets and putting a complaint in
writing as her mum spent all day Saturday upset
being physically sick searching searching.

She had to phone my friend Anne and like
Humpty dumpty she put me together again.
But who put Anne together
Alzheimer's Scotland 24 hour helpline.

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Later that evening Alan phoned and apologised
you see he cannot cope with the changes he sees
in me.

I've recently discovered that too much stimulation can cause me to get confused and overcompensate causing me to behave, react strangely

My friend's daughter who is 8 noticed this at first.

Other times I withdraw and become very quiet which is taken as moody.

It was only when I met other people with dementia through the Scottish Dementia working Group that I again felt safe and experience the sensation of belonging

I found that I still had skills and in using and maximizing these that I found once again my self-esteem and self-confidence.

Pause

The attitudes I've experienced in the last year range from denial to rejection.

Just because I don't fit the stereotype of the older person who is incapable of doing anything for themselves, people have suggested that I can't possibly have dementia.

They don't see how much extra effort is involved in coping with daily activities

For me it feels like being a swan - I may look OK on the surface but my legs are going like crazy to keep me afloat.

Pause

Because of These reactions I started to be very Careful about whom I told that I had dementia.

I even started to say that I had a cognitive impairment

It seemed more socially acceptable

And didn't conjure up the thoughts of an older person unable to function

- No Stigma attachment
- No preconceived idea's

The reactions I've described indicate a lack of understanding about dementia - particularly about people in the early stages of the condition.

The first time I realized that dementia was classified; as a mental health condition was very difficult for me

I stigmatized myself.

The word stigma refers to behaviour, which treats someone as a label, not as a person.

That's what I had done

I heard the word Mental Health and seen the Disease and not me AGNES

At a Mental Health Service Users Conference

I saw a group of mental health users

The Theatre Nemo Group

Get their message across through Drama

That was a profound moment for me

I felt Empowered Not Ashamed

I decided that I too would speak out not hide

To quote another member of the Scottish Dementia Working Group "By hiding our diagnosis we help to create the stigma. The people creating the stigma are ourselves because we are ashamed of the condition."

Pause

It won't be easy to change attitudes. It's a good idea to start with children and young people - they are much more accepting of differences. When it comes to adults we must challenge intolerance, confusion and ignorance. It's justifiable to feel angry and to show it. Above all, we must not feel ashamed, because that feeds the attitudes we want to put an end to.

Pause

Whoever you are- but especially if you are a professional working with people with dementia - you can be part of the battle to combat stigma. If like me you have dementia

- Do not be ashamed
- Don't hide
- Join with me
- Confront Stigma

And help bring about a more understanding and caring society that accepts and welcomes people as they are.

Thank you