

READING

NHS Annual Event

Eden Court, 5th September 2012

Introduction

- I wonder if anyone here saw the headline '**Stigma prevents treatment of dementia?**
- And how it described
- A young woman, who had never heard of dementia,
 - Thought her mother was 'going mad'
 - And was afraid to leave her with the grandchildren
- So in desperation every morning when she left for work, she tied Mary to a beam with a long rope in the small shed next to their house and left her there until she returned.

This happened in Sri Lanka ...

Thankfully Scotland is one of the few countries in the world that has a Dementia Strategy which was launched in June 2010.

- When you read it, it's very clear those at the top –
- know exactly what we need down here at grass roots ...
- the problem however, is that it's not reaching us ...
- And that's what we have to correct
- Unless we want our dementia families to be metaphorically tying people with dementia to those beams ...

Fear of dementia

The Strategy is based around 5 concerns:

The **first one** is about the **Fear of dementia**. And how this deep fear means people delay in coming forward for diagnosis

A man once said to me

- 'but ignorance is bliss' ...
- 'You're absolutely right ...' I said
- ... ignorance is bliss: but there're two excellent reasons why staying in that blissful state is not such a good idea:

Firstly: You can ... while you're still able ... tell your family exactly what your wishes are e.g. my husband who has Vascular Dementia loves his photography and has told me in no

uncertain terms I'm not to stop him wandering down on to the beach in fear he might get lost, fall over, hurt himself or worse ... that his choice is not to end his days sitting in front of a television ... and if getting lost or hurting himself is part of allowing him to continue his photography, then so be it.

And secondly I told my 'ignorance is bliss' man: with an early diagnosis you can put your financial affairs in order, again while you're still competent to do it. Because one thing you can be quite sure of, is that if you have a dementia diagnosis, the day will come when you can no longer do this. ... this got my man's attention.

Information and Support

The Strategy's second concern is around information and support **immediately after diagnosis**.

We walked out of that consulting room 6 years ago and didn't know where to turn. And worse, my husband categorically refused to accept the diagnosis, so I was totally on my own.

Six years later I've realised that when you have an early diagnosis ... which usually means the person with dementia is nowhere near crisis point or ready for care home admission... it's imperative the family caregiver be taught how to deal with the progression of the illness i.e. don't confront, don't contradict, diffuse difficult situations but above all else remember to look beyond the illness and see the man ... he really is still there.

And doctors and CPNS and nurses really and truly need to know where to send those dementia families for that early help ... and more importantly tell them they'll need help and that they shouldn't feel guilty about asking for that help. Before the crisis actually happens!

Professional Response

The Strategy's **third concern** is around **General healthcare services** and how they don't always understand **how to respond** well to people with dementia and their caregivers ...

And my question is why do professionals pussyfoot around with dementia? They don't do it with cancer or strokes or heart attack patients. They tell it how it is.

And as a caregiver I'm just as guilty ... I've learned not to contradict ... I don't confront ... I walk away from abusive behaviour and I try to diffuse difficult situations ... simply because it makes my life easier at home ... and while this can be seen as best practice because it makes my husband feel good about himself ... it could also be construed as bad practice because not only does it do awful things to the caregiver's stress levels, it also reinforces the patient's own belief that there is nothing wrong with him or her ... compounding the whole denial issue which gets us right back to square one ...

We have to change this ... We have to get to a point where the stress levels in families are from the pain or anguish of supporting a loved one with dementia, rather than from the **stress of living with someone who has an illness that no-one wants to say is an illness**. Dementia is now the number one fear of adults over 55 ... professionals call it as it is with cancer, strokes, heart attacks ... so why can't they be as honest about dementia?

Dignity and Respect

The **fourth concern** of the Dementia Strategy is about **dignity and respect**

Think of Mary in Sri Lanka and your heart can break. How will this woman who has raised 7 children and even more grandchildren be feeling ... confused? Abandoned? Bewildered? Scared out of her wits? Do you suppose she wants to live like this? I doubt it ...

While we may not tie our Mary's to beams in sheds, the betrayal of dignity and respect for dementia families is probably the single most important reason why there is fear of dementia, why the stigma is so profound and why denial of the illness on the part of patients and their families is so prevalent.

We have to get to the root of this indignity and disrespect and rip it out from the heart of our society.

Support for Caregivers

And finally, the **fifth concern** of the strategy is that **family members** who care for people with dementia, do **not always receive the help** they need to protect their own welfare and to enable them to go on caring safely and effectively.

Besides the fact that caregivers feel too guilty to ask for help, right now the threshold for support is too high ... patients and caregivers generally have to be in crisis before support is forthcoming ... but if we don't monitor and address the stress levels in these caregivers at an early stage, we'll have an unprecedented epidemic of stress related disorders with caregivers themselves needing medical attention ... and then what will happen to our people with dementia?

Solution

So how exactly can we get that national dementia strategy down to the people who need it?

Is it lack of resources and can existing resources be redirected to this? Is it poor communication ... do those in middle management understand just how important it is to get that strategy down to us? If not, who can show them? Do we need to change our local strategies – as bigger countries like India and China with their aging populations have been forced to do?

If the heads of NHS and indeed the Government keep pushing down from the top to change things, shouldn't we as citizens be pushing up from the bottom, so that eventually we can meet in the middle?

Imagine if every town and village in our Highlands did something at grass roots like -

- establishing dementia friendly communities to ensure the frail, the elderly and dementia families are socially included in all community events or
- within 24 hours of diagnosis, someone knocked on your door and said 'I'm here for you' or

- having our professionals – our GPs, CPNs and nurses – accepting that dementia is an illness and not being afraid to say it as it is
- So that every person with dementia can venture out, safe in the knowledge they will be accepted ... with dignity and respect ... as part and parcel of their community.

And imagine if every town and village

- Had a lay worker programme that not only red flagged early signs of dementia and caregiver stress, but actually did something about it.

We're starting to do all of this in East Sutherland! With a group of like-minded people we're slowly turning our rural county from one with little dementia support in those first early days into one that is a model of excellence and can be used as a beacon for others to follow.

There's been a lot of media hype about allowing people to die with dignity ... Today I'm asking you to let dementia families live with dignity so that no-one can ever metaphorically tie us to those concrete beams in sheds ...