

Monday 3rd June 2013

Dementia Connections ... Glasgow

Building Bridges for Better Support

Introduction

I'm a member of Alzheimer Scotland's National Dementia Carers Action Network (NDCAN for short) and we believe that people with dementia - and family and friends who care for them - have a fundamental human right to participate in and be part of community life as equal citizens. This is true regardless of whether we live in a remote rural community or in a town or city.

I live in the rural (**slide**) Highlands of Scotland, so far north that in the middle of the winter we only see the sun (**slide**) four or five hours a day, but it was only when my husband Andrew (**slide**) was diagnosed with vascular dementia seven years ago that I realised just how isolated we were (**slide**).

Isolation is a word that resonates throughout the journey of dementia ... at the beginning when you don't know which way to turn ... and also along the way as everything changes around you. Our particular journey was so lonely and so painful and so isolated by our rural location that one day I said 'enough' and decided to do something about it ...

And **today I'm not alone ... today I'm** surrounded by like minded people who understand the importance of social inclusion, who understand that my husband does not wish to participate in activities designed only for people with dementia, but rather be accepted for who he is and just get on with living in the community like everyone else.

Dementia specific community activities are of course essential and valuable when they are therapeutic and delivered by dementia skilled professionals, but there is an important distinction between therapeutic supports and simply creating activities and resources only for people with dementia. If we do so then we only create dementia ghettos.

So how did we move from complete isolation to being supported as an integral part of our local community? What bridges were built to achieve this?

Speaking out

The first one was with Alzheimer Scotland (**slide**): they gave me not only the **support and courage to take what I'd learned one step further**, but also the wherewithal to start advocating for change. In 2010 I heard Henry Simmons speak about the key **challenges identified in Scotland's first National Dementia Strategy**. (**slide**)

- he talked about the **fear** of dementia,
- and how the betrayal of **respect and dignity** for dementia families was probably the single most important reason why there was fear of dementia, why the stigma was so profound
- He talked about the lack of **information and knowledge**, and
- how the general health and social care services **didn't** always understand how to **support** dementia families;
- but the chord that really resonated with me was when Henry talked about the need to **teach Carers** that we too had rights, that we too needed help on this dementia journey and that we were truly an integral part of our **loved ones' care**.

I sat there riveted, **thinking** 'goodness someone knows how we feel out here'. And I must admit I went home and waited for the Strategy to filter down to us up in my **beloved East Sutherland**. **It didn't take too long of course to realise it wasn't** remotely filtering down but that **since Andrew and I simply didn't have the luxury of** time to wait for it to reach us, what was it that I could do to make it get to us faster?

After studying the Strategy I discovered to my astonishment that besides addressing those key issues around dementia itself, it was also absolutely enshrined and underpinned by basic human rights. (**slide**) Basic human rights that Andrew and I as a dementia family were entitled to. And it also became very clear to me that those at the top knew exactly what we needed down here at grass roots ... but how to get it down to us?

Credibility

In those early days the hardest element to overcome was the fact that those who made the decisions simply would not listen to a non-professional, despite the fact **that I'd** carefully analysed what was happening to us as a family and in survival mode had developed coping strategies that seemed to work. But because I was simply a carer, no-one in authority would listen.

What I needed was credibility. So my next bridge (**slide**) was becoming a member of NDCAN - **which I'm representing today** - and working nationally with a group of like-minded carers to advocate **change** ...

Being part of the collective voice of NDCAN increased my credibility ... (**slide**) and indeed joining this group turned out to be the catalyst and subsequent platform to everything that has since happened.

What is the Solution?

It was at an NDCAN meeting 18 months later that I first heard the magical words **dementia friendly communities**. And I quickly realised this was what we needed ... **that** if as a community we could push **upwards**, we would have a far better chance of meeting that Strategy coming down.

The next bridge (**slide**) was contact with local authority.

Asset Mapping

The first person I approached was a local councillor elected to local government on the strength of her concerns for the elderly. She knew nothing of my dementia world but one morning after taking a deep breath, and many tears later after sharing the loneliness of that isolated world with her, we made a pact to work together for change. (**slide**) And over the next months we mercilessly

- used her extensive public sector knowledge and networking
- to identify,
- compile and
- link local talent and resources.

Greatest challenge ...

We also gave ourselves an identity, setting up a Dementia Friendly Community Social Enterprise and unexpectedly, the greatest challenge was pulling together the public and private sector individuals sitting around the boardroom table. In other words getting people with different philosophies to understand

- that to fund social change you needed money, and that money was not a bad word
- That the public sector board members were not deliberately hiding behind bureaucratic rules, but were rather ensuring total transparency for public scrutiny
- And that the private sector element was not planning to stash away huge amounts of money for personal gain
- but that the **Social Enterprises'** function was to combine the best of both worlds, (**slide**)
 - remaining transparent and cutting through the bureaucracy
 - while ensuring sustainable funding for urgent social change.

Thankfully, we eventually got there. I have to say it was touch and go during many board meetings, but the underlying need to make our vision work finally got us **through the tricky bits ... and today we are stronger for it.**

DFC Collaborative

The next huge supporting bridge was NHS Highland (**slide**) who gave us a platform to speak out about the Strategy, (**slide**) **about how it wasn't reaching grass roots** and what it was we needed from professionals to give us better support. And they listened.

I sometimes think of NHS Highland as a dementia Titanic: and while I think a couple **years' back they were heading straight** for that iceberg, today I believe they are on course to steer right by it.

We now had to make sure our work was informed by the people we had set out to help. So in partnership with dementia families we built our final bridge, (slide) and formed a Collaborative (slide) with local agencies, service providers, voluntary groups and businesses who shared our vision of a dementia friendly community.

Together (slide) we identified people of influence in our community who had the passion and potential to be dementia capable community leaders. We engaged with them around the dementia agenda and built on the skills, strengths, interests and enthusiasm that people already had. **And it's amazing how many we actually found** in our rural community.

Task Groups

Our next step was to establish task groups to make dementia friendly visions become reality.

A key early task was to begin to ensure that people who worked and lived in the community had a better understanding of dementia and how to respond to it. We developed a short dementia awareness training tool and needless to say soon learned **there is no such thing as 'ten minute training'**: what we did discover however was that this initial awareness education would be the introduction to further dementia instruction from the professionals. What we did was open the door.

Other task groups (slide) are working on issues around

- Promoting our dementia friendly community
- Reducing dementia isolation
- Changing the crisis ethos to one of prevention
- Complementing the work we do directly in the community with a series of online resources
- Putting local Care Homes at the heart of the community
- Promoting telecare services so essential in our remote regions
- And our latest task group is working with our local newspaper - delivered to 97% of residents in our rural area – to run a campaign in conjunction with our awareness education to make all businesses in Sutherland dementia friendly.

Beacon of Excellence

With all these innovations, our rural community is slowly turning from one with little dementia support into one that is fast becoming a model of excellence (slide) and which can be used as a beacon for others to follow:

- like our local Community Centre
- which allows dementia families
- to be *engaged with*
- rather than *isolated from* the community by:

- regularly running a range of socially inclusive activities (**slide**)
- using music (**slide**)
- and art (**slide**) to bring people together

Funding Challenges

Without funding however, as most of us here will have discovered, **it's** virtually impossible to do these kinds of projects effectively.

A key ingredient (**slide**) seemed to be that once we could show potential funders like BIG Lottery that projects could be sustainable and they would not have to fund us forever, they were forthcoming with funding.

To this end when we assess facilitating community projects, we look for innovative ways to move project merchandise e.g.

- cakes and jams from a **working kitchen ...**
- cards from art projects
- vegetables and plants from a sustainable garden or
- **refurbished tools from a 'men in sheds' project**

Conclusion

So, in conclusion, by taking that first step and as a carer volubly speaking out about the loneliness of being a rural dementia family.

- I found a group of like-minded people and organisations
- who shared my vision of a dementia friendly community
- and helped me build the bridges we needed for better support

We're not alone anymore. (**slide**)

- My husband is not in a dementia ghetto
- is socially included in our community
- and we really are pushing up and closing the gap between our rural grass roots' needs and the national Dementia Strategy.

I hope that our experience of building bridges and helping maintain connections between people living with dementia and our community in East Sutherland can help inform others who are working towards the same goal across Scotland

Thank you (slide) for listening ...

Ann Pascoe

Portgower

30th May 2013