

Saturday 20<sup>th</sup> April 11am (1<sup>st</sup> speaker)

# Power of the Website Voice

---

**ADI Taipei**

## Introduction

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, so painful and so isolated by our rural location ... that I decided no-one should ever have to do this journey alone ... (**slide**)

Today I am not alone ... and the fact that I am speaking here at an international dementia conference in Taipei is testament to the power of the website. How did this all happen?

## A Carers Voice

In 2012 I was awarded a Churchill Fellowship (**slide**) to travel to India for 6 weeks to find out more about Dr Amit Dias' lay programmes around carer stress. Part of my remit was to disseminate information and it seemed to me blogging would be an excellent way to go

- not only to let those back home in Scotland see what we were doing, (**slide**)
- but also to show the world a dementia family can still live a life.

Indeed when I was awarded the Fellowship, my husband immediately said, 'I'm going with you, aren't I?' I gulped and said 'of course dear'. The professionals all said 'you're not taking him with you, are you?' Again I gulped and said 'oh yes I am!'

And so began our journey from isolation and loneliness to one where we are now part of a community that is socially inclusive and totally supportive.

In order to blog, I discovered to my horror that you need to do photography and have access to a website, but more importantly be able to juggle all the technological wizardry needed to produce a blog that others might want to read (**slide**) ... I knew absolutely nothing about any of this and in desperation turned to the younger generation – this was after all their world – and worked with my young nephew to develop a site that would send out the right message.

And after much trial and error, (**slide**) **A Carer's Voice** was born

## Blogs from India

We duly arrived in India and quickly settled into a routine of living and working in our small village of Colva (**slide**) and my blogs began to reflect life there: visiting the market (**slide**) each day for fresh food, learning about the culture and the people (**slide**) and how to cook Indian food... And I blogged about this ... (**slide**)

I met Amit Dias and his team (**slide**) and spent fascinating days on the back of Shezmin's bike (**slide**) learning about the work being done in Goa confirming my belief that at home we had to move from an ethos of dealing with crisis to one where prevention became the norm; and I blogged about this ... (**slide**)

And when I visited care homes (**slide**) I realised we had got so carried away with protection (**slide**) and care in our care homes in Scotland that we had forgotten the HOME (**slide**) part of care ... a message reinforced again and again at care homes I visited in Kerala (**slide**) ... and I blogged about this(**slide**).

## Andrew began blogging

And then Andrew decided he'd like to blog (**slide**), but had difficulty remembering the various sequences getting the blogs online. So each evening:

- he would chose five photographs
- from those he'd taken during the day
- reflecting his view on our life in this different world
  - the beach near our home (**slide**)
  - a visit to an animal sanctuary (**slide**)
  - his fascination with whole families on mopeds (**slide**) – something that would simply not happen in our country
  - the puppies he adopted (**slide**)
  - the beautiful flowers (**slide**)
  - the crowing of a cock that woke us at five each morning (**slide**)
  - and of course the monsoon (**slide**) ... something else we've never experienced (**slide**)
- And as he talked, I typed furiously
- Making the blog entirely Andrew's
- With absolutely no editing on my part (**slide**)
- They were:
  - his pictures and
  - his words and
  - his thoughts
- Which in fact became the key to the success of his blogs

## On our return

While we were in India we had absolutely no idea how our simple blogs were profoundly affecting our dementia world back home:

- **Carers** were reading them (**slide**) and suddenly understood they were not alone
- **Professionals** were reading them and gaining insight into the world of dementia families

- **People with dementia** were reading them (**slide**) and understanding that here was immediate
  - peer support and
  - a platform to tell their own 'inside story'
- The **local community** was reading them and discovering a new understanding about the world of dementia
- **Heads of hospitals** and
- **managers in local government** were reading them
- **Care home managers** and their staff were reading them and also wondering if their care homes had forgotten the 'home' part of care home
- And **voluntary groups** were reading them
- all wondering how (**slide**) they could help make their communities better places for dementia families

Suddenly dementia was not such a terrible word and the awful myths and stigma around the illness were being seen for the nonsense they were.

## Stats

We then analysed the data and were astonished at what we learned:

1. over a period (**slide**) of 7 months the pages on our website had been viewed just under 12,000 times (**slide**)
2. In total (**slide**) over 1500 people(**slide**) logged on to the site (**slide**)
3. Of a total (**slide**) of 2600 visits, the average time spent per page was over 6 minutes.
4. 57% (**slide**) of the traffic were new visitors and 43% returning ones.
5. Readers (**slide**) logged in mostly from the UK, but also from (**slide**) India, the US and Canada, Europe, the Middle East, South Africa, Australia, Singapore and the Philippines. No-one from China!
6. And although over 2600 readers (**slide**) used English, translations were also done into German, French and Russian.
7. with an average (**slide**) 4.4 pages visited

Over the last 3 months (**slide**) our rank has remained stable with no relevant variation. The site was launched in March last year – just over a year ago - and we still reach roughly **870** users and deliver over **1,900** page views per month.

## A Dementia Voice

We then discovered another interesting anomaly: we looked at the website 'comments' (**slide**) and discovered again and again readers commenting on how refreshing it was to see into the 'unedited' mind of a person with dementia: it seemed Andrew's blogs were causing a stir out there. So we decided to do something about this. And **A Dementia Voice** was born (**slide**).

Soon we had other people with dementia joining us. The first was **Agnes**, (**slide**) then Chair of the Scottish Dementia Working Group, who gave us an insight into her world we could simply not have guessed at. She also blogged from Vienna and we heard firsthand about the new European Dementia Working Group.

Next to join us was **David (slide)** from our own village who had in his retirement set up a community website. He immediately added on a dementia friendly page with links to our websites and regularly blogs a dementia diary.

And then there was **Ian (slide)** from the Shetland Islands to the north of Scotland, who had recently been diagnosed with Alzheimers. Together with his family he travelled to South Africa last Christmas and sent us inspiring blogs from Cape Town ...

## **Blogging Tool**

However a universal problem was that, similarly to Andrew's discovery, people with dementia found it extremely difficult to blog without support: and the frustration of relying on others to assist them became increasingly obvious. So again we looked for a solution: **(slide)**

Greenwich University in London is planning to build us a simple blogging tool to facilitate

- the uploading of blogs,
- including pictures
- with caption;

And in partnership with Alzheimer Scotland and Stirling University, we hope that by giving people with dementia the wherewithal to blog and express themselves freely, it will dramatically reduce their loneliness and sense of isolation.

## **A Care Home voice**

Another unexpected result of our website work was a high level request from the National Health Services in the Highlands, who wondered if a care home website could do for care homes what the Carer and Dementia websites were doing for dementia families.

In Britain the media is very quick to report so-called abuse in care homes – very rarely getting the balance right in serious issues – and this manager made the surprising observation that every time an abuse is reported, no matter which care home is the culprit, her entire care home staff across the Highlands are tarred with the same brush.

And thus **A Care Home Voice** was born **(slide)**. A key step forward was when we introduced **Sunset House, (slide)** a fictitious home where fictitious characters say it as it is without fear of retribution because it is apparently fictitious. However, the stories always have an element of truth which usually means our fictitious character is talking about real life issues generally pushed into the deepest closet!

## **Dementia Friendly Communities website**

Finally it was time to establish **A Dementia Friendly Community** website **(slide)** which is not only fast becoming our flagship site, but is also the vehicle to promote our dementia friendly community work **(slide)**.

Indeed, the website has become our shop window to

- spread the message
- sustain the work
- report the evidence of what does and doesn't work.

## **Conclusion**

In conclusion, (**slide**) I worked for Kodak in Russia in the early 90s, long before email know-how was the norm. In fact the fax machine hadn't yet reached Moscow. But once the cyber technological giant had been awoken, the Russians simply leapfrogged fax technology and went straight into email.

Much in the same way that our little Highlands' community used the power of the website to leapfrog old fashioned ways of dealing with dementia so that people like my husband can be part of a society and community and not be alone and isolated in his dementia world.

And it all began with a lonely voice crying out into cyber space ...

**Thank you for listening ... (slide)**

Ann Pascoe  
Portgower  
6<sup>th</sup> April 2013