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Blogging for dementia

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by Gill Phillips



Both of my parents-in-law have died of dementia. I have experienced first-hand how dementia affects individuals and families and how isolating and painful it can be, particularly if [good information, advice and support](#) are not readily available. I am passionate about raising awareness of this and [other conditions where people face loneliness, stigma and ignorance](#). In the second part of my post, following on from ['Blogging to share good practice'](#), here I discuss the importance of online communities in building awareness of dementia, and how we can work together to make a real impact on the lives of those living with dementia and those around it.

So, last May, I got an idea. I get lots of ideas but this was a good one – and I followed it through. For the Alzheimer's Society's 'Dementia Awareness Week' 2012, I would aim to get a mix of people from different perspectives (i.e in true *Whose Shoes?* style) to write an "in my shoes" guest blog on each day of the week. [Five days: five blogposts](#); simple. Ideally a manager or commissioner, a carer, someone living with dementia, a provider, a clinician... you get the idea.

But of course life doesn't work like that. I had no real expectation about who would be interested and so, because I didn't want to put pressure on anyone, I invited quite a lot of people. And they generously responded. And suddenly we were in [Week 2...](#) and [Week 3](#). And, of course, success breeds success so more people agreed to write blogs – indeed they started to ask to write blogs...

Well [twelve weeks later](#), I was struggling to know how to end this daily series. It was very rewarding but also extremely time-consuming! I loved learning about and sharing [poignant stories, funny stories, inspirational journeys, innovative projects, campaigns, wonderful resources](#)...and all the networking that went on behind the scenes. I was very flattered that several posts were included on the Department of Health's '[Dementia Challenge](#)' website; the quality of the posts was excellent; and I had received posts from more perspectives than I could ever have envisaged. But it was taking over my life and keeping me from running my business...

Anyway, I was very honoured to receive a guest post from brand new [Minister of State for Care and Support](#), Norman Lamb, so I used this 'finale' as a way to end the daily series – and continue on a more ad hoc basis, interspersed with my own pearls of wisdom.

So how has blogging changed my life? As well as giving me an amazing communication channel, Twitter and blogging together have given me a [confidence that I would not otherwise have had](#). A confidence in what I am doing and in what I stand for. I meet up with people who have posted guest blogs and it is exciting – relationships develop much more quickly – we already feel as if we know each other.

I am sometimes invited to post guest blogs for other people. Blogging can be liberating and therapeutic. I recently agreed to write my '[personal story](#)' for my friend and much admired business associate, Sarah Reed, Founder of Many Happy Returns and [creator of wonderful Chatterbox games](#) and other fascinating '1940s and 1950s games, gifts and goodies.' I also last week posted a [guest blog for Community Catalysts](#), a chance to be part of a series sharing the fascinating workshop I ran with Extra Care residents as part of Leicestershire County Council's 'Innovation Challenge'. Indeed it was a [guest blog for my original social media guru, Shirley Ayres](#), that started me on the road to blogging – thank you, Shirley!

I have been thrilled, through my guest blog series, to give a voice in turn to many "first time bloggers". A few have gone on to [set up their own blogs](#), which is brilliant. Perhaps some more will be inspired to do so by this article – if you do, please let me know, as that will be a very important outcome for me. One very special person who falls into this "new to blogging" category is my 90 year old Mum. She has posted several really revealing and popular articles, [writing as 'Gill's Mum'](#): a way of giving her a voice while protecting her anonymity. Mum has been genuinely surprised that people are interested in what she has to say – a sad indictment of how many older people see their position in an arguably youth-obsessed society.

I am very grateful for the support and encouragement I have received, not least through the wonderful 'Disruptive Social Care Podcasts' by the innovative duo, Shirley Ayres (Shirley gets everywhere!) and Stuart Arnott and their studio guests. I was extremely honoured to receive a mention most weeks on the series, including lovely tributes from [Andrea Sutcliffe, CEO of the Social Care Institute for Excellence](#) (video – mention at 42 mins!) and [Richard Humphries, Senior Fellow, Social Care at the](#)

[King's Fund](#). It is great to think that the *Whose Shoes?* blog is helping thinkers and policy makers stay in touch with “real people” and this is all serving to build credibility for Nutshell Communications Ltd, my small (but noisy!) business.

The blog has certainly been educational. It is shaping up into a unique on-line resource where people can indeed see dementia from many different perspectives and learn from others, realising that ‘experts by experience’ have huge expertise in their own lives in a very different way from the expertise of professionals. Hopefully this is reinforcing the key message of my [Whose Shoes? concept and products](#), encouraging people to work more closely together. As equals.

There is a lot of practical knowledge being shared, with people finding out about what is happening in [different parts of the country](#): use of [photographic history](#), [singing](#) and [creative arts](#); [reminiscence media](#) and [re-living favourite sporting moments](#) to name but a few. From a professional point of view, topics include safeguarding both at [CQC level](#) and [within a large council](#); [dementia-friendly cities](#); [the importance of good design](#); the appropriate use of [assistive technology](#); and [involving school children in raising awareness of dementia](#).

In a nutshell, the blog helps people to see that people who happen to be living with dementia can and should [carry on with their lives, enjoying their favourite things, going outside in the fresh air](#) if they want to – and not be ‘written off’. We convey the message that everyone has a contribution to make and it is never too late to try something new!

The blog has also been used for campaigning. The only blog in the series that I really ‘chased’ and was *determined* to trumpet about was the [evolving story of the Healthy living Club](#) in Lambeth. I felt a huge sense of injustice that this wonderful community-based hub, which embodies all the values of person-centred support for people living with dementia, had lost its funding and was surviving on a wing and a prayer (or more accurately a dedicated team who refused to roll over and die.) I am proud to have offered a channel for this story to be heard – repeatedly! – and to have played a part in raising the profile to enable a [successful funding bid](#), in which this blog was directly cited.

Most significantly, this achievement shows how the *Whose Shoes?* blog has helped improve the lives of people needing care or support and the lives of their carers. In addition to all the indirect ‘raising awareness’ type benefits, there are [many very direct outcomes](#). I have had some amazing contributions and comments from [people living with dementia](#) and [carers](#).

Only this week ‘Audrey’ (caring for her father with dementia) read a [guest blog by Sheila Merriman](#), Specialist Intermediate Services Dietician, Norfolk & Norwich NHS Trust, about nutrition and said how helpful it was. Through the comments section, I was also able to refer her to Lee Stribling’s excellent new [dementiachallengers.com](#) website, set up by carers for carers, for more practical help and support. We are able to link people to others in a similar position, often [helping them go on to make real and enduring friendships](#), or to direct professionals to other innovators in their field. People who make really significant comments, or bring up an issue where there is a ‘gap’ in the series, are invited to write a post themselves, adding yet more depth of insight and shared knowledge.

Why [dementiachallengers.com](#), you may ask? [#Dementiachallengers](#) is a powerful hashtag we use on Twitter, coming together as like-minded people who are impatient for change in dementia care. I could write a much longer blog about that! Suffice to say that our common aim is simple. We want a world where people living with dementia are put in the centre and valued as human beings; with carers supported and recognised; with everyone learning how to make people, including those with dementia, feel happy and safe.

But [#dementiachallengers](#) are not just aspirational; they (we!) are [making it happen in all sorts of situations](#) across the country – and beyond (apologies to Buzz Lightyear).

Many of our guest bloggers are wonderful examples of how to enter the reality of the person with dementia, rather than trying to force them back into ours. My friend and fellow blogger [Andy Bradley](#) teaches us about a “quiet heart and an open mind” and how we can all ‘stand for compassion’.

So, I hope this blog about blogging has been of interest. I hope some of the ideas help you find new ways to share good practice in social care and health and make a difference.

But, in the spirit of moving forward together, I’d like to leave you with Andy’s powerful TED talk and ask you this question: Do you stand for compassion?

Closing the Compassion Gap: Andy Bradley at TEDxBrighton



Gill Phillips, the Director of Nutshell Communications Ltd and creator of [Whose Shoes?®](#), an exciting tool allowing you to 'walk in other people's shoes'. Through a very wide range of scenarios and topics, the tool helps you explore many of the concerns, challenges and opportunities facing the different groups affected by the transformation of health and social care. For more information please visit the [Whose Shoes?® here](#), or check out the [Whose Shoes?](#) blog

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