



David's Blog

May 13 2011

Welcome to my second blog. Having just returned from working in the USA – in Grand Rapids, Muskegon on Lake Michigan and Lansing I thought I would share my experiences and my thoughts from this trip.

The Heart and Spirit of Caregiving

This was the 2nd Annual Conference on Dementia Care – Celebrating Direct Care Workers of West Michigan organised by Clark Retirement Community. The theme of the conference was “on finding ways to nourish the human spirit in caregiving relationships and the need when caring for others to start with tending to the human spirit in ourselves”. It was so clear to me how from many visits to the States whilst services are not as developed in the daily practice of person centred and relationship centred care and support that care organisations there have so much more made the connection between working in dementia care and the importance of nourishing the human spirit within ourselves and the people we aim to support. In particular Anne Robinson and Roxanne Chang from Optimal Life Designs in Dementia Care who worked in collaboration with Clark to design this conference have a particular gift in conceptualising and designing dementia care conferences focusing on care workers “being valued, uplifted and receiving life affirming support by emphasising how dementia care is all about the human spirit within us all”. There is such a need in the UK to place less emphasis on skills

and competencies and to make more direct links with staff on how to unlock the strength of their true spirit in themselves and in people they provide care and support to.

Things that stood out for me from this conference were :

- A real attempt to not place a person living with a dementia as a “token” speaker by instead having a family member, care worker, person living with a dementia, and a panel facilitator all speaking together, without any reference to job titles or who was living with dementia, about what matters most to them in life and the commonality between us all – I had discussed this with Anne and Roxanne when I was speaking at a conference last November in Michigan as a more inclusive way to involve someone experiencing a dementia in contributing as a whole person as I feel increasingly uncomfortable seeing people living with a dementia being used to validate a conference in a very tokenistic way.
- Listening to Alissa Anderegg a teenager who featured in Maria Shriver's Emmy Award – winning segment of the HBO documentary, The Alzheimers Project called “Grandpa Do You Know Who I Am”. She is, through her experiences of her relationship with her Grandmother Mary Fran Anderegg, doing significant work to raise public awareness in the USA on the impact a family member with dementia may have on children and teenagers. She has a Facebook group called Alz4Kidz and Alz4Teenz.
- Meeting Joyce Simard, Adjunct Associate Professor, School of Nursing and Midwifery, University of Western Sydney, Australia who has developed The Namaste Caregiving Approach meaning “to honour the spirit within”.

“Namaste Care recognises the body and the spirit need to be nourished and offers practical methods ending of life care which sustains the inner core” Dementia Care Matters hopes to explore with Joyce further her coming to the UK.

- Ken Saulter’s poem “My Mask and I”. This really fascinated me given Dementia Care Matters emphasis on the central importance of removing the mask. Ken summarised his poem as “exploring the idea of dementia as the wearing of an internal mask every day. The poem also recognises the important role that caregivers serve by supporting and encouraging personal expression among those who have to deal with the burden of the mask and the struggle to keep one’s identity“. An excerpt of the poem is below:

“I’ve lost a lot of memories, but plenty remain.
My mask and I stand stoically as memories shift in and out.
Do you know who I am?
The world is smaller with a heavy mask on and where is my smile?

.....

And I become more, rather than less.
And my mask melts day after day and
People look at me directly and see me as I am
And there’s no more “through a mask” living.

One of three presentation that I gave at this conference was a first for me on “Rituals: A Pathway for Restoring Balance”. This looked at the role and importance of rituals throughout our life and how “Rituals are never just about the doing but always the feeling and spirit and how “Rituals are avenues for our emotions” and how key it is that “Rituals are personal and not institutionalised routines”. This has triggered a new piece of work in Dementia Care Matters about how rituals are a tool to focus care workers and nurses on the individual meaning of rituals in people’s lives and how during

personal care rituals staff can develop their skills to enhance people's lives.

Consultancy in the USA

These days were a reminder of how services have so many parallel issues to address whether in the UK or the USA. It was great to see care organisations in the USA using Dementia Care Matters 50 point checklist "Inspiring Action: Leadership Matters in Person Centred Dementia Care. Like in the UK the culture change agenda is massive, requires strategic and heartfelt senior management leadership, clarity of purpose and in the end an acceptance that meeting commissioning and regulatory requirements does not mean the key purpose of ensuring quality of life will be addressed. As in the UK services are struggling to accept that a proportion of a care services budget has to be to invest in real qualitative observation of the lived experience of people and then investing on acting on the findings. It appears to me that in the USA they have captured the language of being person centred and the spirit of care giving far better than we have in the UK but they are struggling to make connections with this purpose and transferring this into real non institutionalised care. In other words there is more evidence of passion and connection to self in the USA and less evidence of what this then really means in terms of real culture change. I met many people with a hunger for improving quality of life and quality of service in dementia care but who were experiencing massive frustrations at the slow pace of change.

A Useful Product

At The Edna Gates Conference on Alzheimer's Care in Lansing where I presented the whole day conference on "Achieving Outcomes in Dementia Care That Really Matter" I came across a stand selling a really brilliant product. Diner Wear produces a clothes protector which is like a modified scarf/waistcoat effect which is far more dignified than any clothes protector I have seen in the UK. Their logo is Dine With Dignity: Protect your clothes with class. They are

machine washable and stain resistant. Dementia Care Matters has no commercial link or interest with this organisation but I would highly recommend taking a look at this product their website www.DinerWear.com and Kathy Steck is the CEO/President her email is ksteck@dinerwear.com

Date for your Diary

If you ever fancy experiencing a dementia care conference in the USA I highly recommend The Edna Gates Conference on Alzheimer's Care which is usually attended by between 400-600 people. The conference is organised by Anne Robinson, Roxanne Chang and the team at Optimal Life Designs in Dementia Care and it is certainly the most cutting edge, conceptually innovative and rich in resources event that I have experienced in my travels and being fortunate enough to have attended and spoken at this conference for a number of years, it's certainly been a source of rich inspiration for me – heartfelt thanks to Anne and Roxanne for facilitating my latest trip to the USA even though I was really ill (more of this in my next blog). The next Edna Gates Conference is scheduled provisionally for the second week in November 2012 in Detroit. For further information www.optimaldementiacare.com

Blog number 3 will look at the need or not for Evangelism in Dementia Care and the very real difficulties of being person centred towards oneself.

Hope you will await my next instalment and that they are proving to be of interest – my very best wishes to everyone, David.

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