

What Happens When It Goes Wrong?

Speaker: Ann Pascoe



- **Pre-retirement**
 - Managing Director of Companies
 - **Athens 2004 Olympic Games**
 - Project Manager, Kodak Digital Picture Centre
 - **Caregiver/Carer**
 - to husband with Vascular Dementia
 - Experienced Care Attendant with Crossroads Caring East Sutherland
 - www.acarersvoice.com
 - recognised the need for a carer's voice so set up a website
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- **Alzheimer Scotland**
 - Member of ND CAN (National Dementia Carer Action Network)
 - 2011 Appointed Alzheimer Scotland Carer Ambassador for the Highlands
 - **Winston Churchill Memorial Trust**
 - 2012 awarded Churchill Fellowship to study community intervention and support in Goa India
 - **Stirling University**
 - MSc in Dementia (ongoing)

In rural Highlands of Scotland



With my husband Andrew ...



And Lollipop ...



In an old croft ...



Big garden ...



Beautiful flowers...



Wonderful view of the fields ...



And the lambs ...



And the sea ...



Credentials

- 6 years ago at age 58 my husband was diagnosed with Vascular Dementia
- My understanding of person centred care comes directly from:
 - *that lonely dementia journey*
 - *my work as a Care Attendant for Crossroads Caring East Sutherland*

Person Centred Care

- Feel-good factor from
 - *Making your own choices and decisions*
 - *Being treated with respect and dignity*
 - *Having services tailored to meet need*
- Being allowed to do things you enjoy doing
- Feeling safe and secure
- Enjoying close relationships
- Freely expressing your views and emotions

3 Crossroads' Case Studies

- Preventative stage
 - *could have been red flagged/acted on*
- Complications set in
 - *could still have been red flagged/acted on*
- Crisis point
 - *too late*
- Carer perspective

My Carer Experience...

- Angry
 - *because it was my husband who had the dementia diagnosis*
- But as Carer I was the one who had to
 - *learn to live with this totally changed man*
 - *change to accommodate him*
 - *deal with an unsupporting family*
 - *keep the peace*
 - *diffuse difficult situations*
 - *simply get on and deal with it*

Holistic Approach...

- See the man and not the illness
- A long journey
 - *between early diagnosis*
 - *and need for care home admittance*
- for both
 - *person with dementia*
 - *and the caregiver*

Watering the garden ...



Taking risks...

‘Protection and care are important but quality of life is more important’

- After Andrew’s diagnosis
 - *he asked me never to stop him doing normal everyday things no matter how bad he got*
- So I had to learn to take risks.....

Building the pergola ...



Small risks...



Bigger risks...



Unacceptable risks?



The beach near our villa ...



The monsoon starts ...



A life long dream fulfilled ...



Life With Dignity ...

- Both of us have the right to be
 - *actively engaged, and involved, in all decisions in everything to do with our lives*
- That might be different
 - *to what health and safety protocols dictate*
- But surely it remains our choice?

How Do We Find ...

- A cost effective solution
 - *that can be easily implemented using existing resources*
- To give patients quality of life
- To reduce carer stress
- While meeting government priorities to
 - *use preventative measures to reduce crisis costs*

Churchill Fellowship

- 2012 researching Dr Amit Dias' work in India
- Grass roots cost effective lay programmes
 - *Developed/taught by Goa Medical School*
 - *With funding from WHO*
 - *Won prestigious International Health Awards*
- Went looking for a dementia solution
 - *came home realising it is a frailty issue*

Grass Roots Intervention...

- Train lay people
- To red flag (not diagnose)
 - *potential frailty issues across the whole health spectrum*
 - *as well as carer stress*
- Then do something about it ...
 - *So that appropriate support for patient and carer*
 - *Can be put in place early enough*
 - *To prevent later costly crisis interventions*

Conclusion

- Person Centred Care Strategies Are Not Filtering Down To Grass Roots
 - This Needs To Change ...
- Because Poor Practice Is Impacting On *our vulnerable, our frail and their carers*