

A Carer's Perspective

Speaker: Ann Pascoe

In rural Highlands of Scotland



With my husband Andrew ...



And Lollipop ...



In our old croft ...



Rambling garden ...



Beautiful flowers...



Wonderful view of the fields ...



And the lambs ...



And the birds...



Then disaster ...

- 7 years ago
 - at age 58
- Andrew was diagnosed with vascular dementia
- How have I learned to cope?
- With knowledge ...

What is dementia?

- Dementia is umbrella name with
 - Alzheimers
 - Vascular dementia
- describing the different kinds of dementia
- Same as cancer is generic name with
 - breast cancer
 - bowel cancer
- describing actual diagnosis

Typical symptoms...

- Loss of short-term memory
- Retention of long-term memory for longer
- Loss of reason and judgement
- Forgetting how to do things for yourself
- Forgetting your very identity

Our favourite...



Best in garden...



Fantasy world...

- Reinvents the truth
- Professionals call it *confabulation*
- I call it Andrew's *fantasy world*
- You really can't rely on what he is saying
- When he forgets things
 - he makes them up
 - as he thinks they should be
 - or how he would like them to be
- He doesn't know he's doing it

Step back ...

- I step back when Andrew fantasizes
 - he is not doing this on purpose
 - or to annoy me
- A symptom of his illness
- See the man
 - look beyond the symptoms
 - smile and let him be
 - don't correct him
 - don't contradict him
 - don't back him into a corner
- Not easy
 - but getting it right has made our lives better

Cricket on a village green ...



Playing the bagpipes...



Being a carer...

- Felt so **alone**
 - not lonely
 - just so alone
- **Angry** because I was the one who had to
 - deal with it
 - change
 - keep the peace
 - diffuse difficult situations
 - deal with an unsupporting family
 - live with this totally changed man

Holistic approach...

- I had to understand Andrew has the right to be
 - actively engaged in everything
 - involved in all decisions
- There is a long journey between
 - diagnosis
 - need for admission to care
 - and subsequent bereavement

See the man ...

- See the man
 - not the illness
- Let him manage his own life
 - in his own way
- It might be different
 - to the way he used to do it
 - but does it really matter how it's done
 - as long as it's done?

Taking risks...

- Health and safety person
 - who pre-empted problems
 - solved them before they happened
- 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

Bigger risks...



Dementia Families *can* lead all sorts of lives...

Unacceptable risks...



Seagulls on Achmelvich ...



Great pictures...



More...



Life with quality...

- I take risks knowing if our 'risk taking'
 - leads to a serious injury
 - or even death
 - there could be consequences...
- Some people might deride me
 - for not taking better care of a person
 - whom I know has dementia...
- But I keep in mind
 - if there is a choice
 - then Andrew has made it very clear
 - he would prefer
 - to have a shorter **life with quality**
 - than a longer life with
 - **nothing but four walls** surrounding him

Denial..

- How often I said
 - I'm tired of fighting the world for you
 - AND you too
- We can cope together
 - if you would accept your diagnosis
- But I can't do it alone anymore

Tell the truth...

- After a nose bleed
- I told him
 - he had to take responsibility for his illness
 - I could no longer do it alone
 - I wasn't prepared to get sick because of his illness
- He was so shocked
- we looked at the symptoms of vascular dementia
 - and in astonishment
 - he said 'but I have them all'

Life with dignity...



Creativity...

- Creativity and imagination
 - deteriorate at much slower pace
 - than loss of memory
- Celebrate creativity
- Increased sense of well-being worth it

Andrew's studio...



Our beach in Goa...



Andrew's first attempt...



Andrew's puffins...



Problems or opportunities...

- Turn the problem into an opportunity
- Five rules:
 - Don't confront
 - Don't contradict
 - Diffuse difficult situations
 - Look at the person not the illness
 - Don't take things personally

Grief

- Suffering from grief
 - watching my husband changing
 - and grieving
 - watching him deal with his frustration and anger
 - and grieving
- tears behind my eyes
 - for the man I have lost
- burden I'm carrying
 - is unresolved grief

Not socially understood...

- Biggest mistake
 - not recognising my grief
 - not getting help
- Worst is that the loss
 - is not socially understood
 - nor can it be openly acknowledged
 - or publically mourned
- I resisted looking at anything on the emotional level
- But I had to learn to do this

Remember...

- Carers are human
 - they get annoyed
 - they get upset
 - they take things personally
- Learn to step back
- Look for the person inside
- He/she really is still there ...

Scottish Dementia Strategy...

- Basic concerns around
 - support
 - care
 - treatment
- for people with dementia
- **and** their carers

- Don't be afraid to **ask for help** from
 - the professionals
 - your peers
 - people like you and me doing a carer's jobs

Lollipop again...



Avoiding Lollipop ...



A favourite corner ...



Wonderful colour ...



So friendly ...



A Carer's Perspective

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