

A Carer's Perspective

**Big Lottery Carer's Event,
Murrayfield, Edinburgh
26th February 2013**

Introduction

I live in a tiny village called Portgower, in the rural Highlands of Scotland (slide)... with my husband Andrew (slide) ... and Lollipop (slide) ... in our old croft (slide) with a rambling garden (slide) beautiful flowers (slide) ... a wonderful view of the fields (slide)... and the lambs (slide) ... and the birds (slide). We retired there eleven years ago ready to do all the things we'd planned to do before we got too old to do them!

Disaster

And then 7 years ago disaster struck (slide)... at age 58 Andrew was diagnosed with vascular dementia and within two years my power of attorney was activated. Besides being Andrew's carer, I am also a Crossroads' care attendant and many of my clients have dementia. So everything I know about dementia has been learned at grass roots and over time I've realised that whenever I think Andrew or one of my clients is perhaps getting a little better, I realise with a jolt that it's not them getting better ... rather it's me getting better at coping!

And how have I learned to cope better? With knowledge! I've found if you know what to expect and at least are warned of what's coming, you can much better plan your life so that you can in fact go on living a life and not put it on hold the way I did for nearly four lonely years.

So what is dementia?

So what does this word *dementia* actually mean? (slide) I think of dementia as an umbrella name e.g. like cancer with breast cancer and say bowel cancer describing the specific diagnosis, in the same way that Alzheimers and say vascular dementia describe the different kinds of dementia.

These illnesses cause brain cells to die off far more rapidly than is normal and how the illness affects someone will depend on which area of the brain is damaged. We all know it's a progressive illness with no cure and is different to say damaged skin which will regrow in time. When brain cells are damaged, they cannot grow again. Dementia can also result from brain tumours, strokes, Parkinson's, Down's Syndrome and even as a result of dehydration linked to urinary infections and incontinence.

Typical Symptoms

Everyone here is probably very familiar with the typical symptoms (slide) and that it is **short-term memory** that usually goes first:

So while James can remember exactly where he went and what he did on holiday in France

in 1963, he simply cannot remember whether or not he took the dog for a walk that morning. In fact many people with dementia cannot remember from one hour or minute to the next.

My husband often forgets when and what he has eaten ... he loves to eat! I usually freeze extra meals when I cook, but daren't leave too many in the kitchen freezer - which is easily accessible - because if I'm out during the day, he sometimes ends up eating a whole bunch of them ... and then tells me he hasn't eaten a thing since I've been gone!

Short term memory loss will also be the reason why a person with dementia won't remember where they are or what they're supposed to be doing or even where the toilet is ... Why they keep asking these same questions over and over: it's simply because they've not remembered the answer and indeed forgotten they've been asking the same question over and over again!

Some of my Crossroads' clients really surprise me because although their short term memory is bad, they can talk at great length about things that **happened in their childhood**. I visit a 91 year old lady who grew up on the Shetland Islands and she has the most vivid memories of World War II, not only her own experiences e.g. seeing the Bismarck being hunted down and chased by the Allies, but also those of her late husband who was badly wounded in North Africa at the battle of El Alamein. My father fought in that same battle, so we often share reminiscences and it fascinates me the detail she remembers. But she can't remember that I've just told her that her daughter will be back home later at 6ish ... probably for the tenth time that afternoon!

Interestingly, I once had a client who lay alone in her bed terrified when she suddenly woke up and began remembering specific incidents from way back very clearly ... she wondered if she was seeing her life pass in front of her ... and thought she was dying! Imagine how frightening that must have been!

Another typical symptom is maintaining the ability to think things through, understanding instructions, concentrating and calculating risk but above all being able to use **reason and judgement**.

We have a deck at the back of our house and unbeknown to me my dear husband decided to attach a folding table to an old wall ... didn't think it through and so didn't realise he was breaking down a 200 year old wall so that he could cement in a bit of wood into it and nail in a table ... hadn't calculated the risk, so was surprised when the wall fell down and because his reason and judgement had gone, instead of getting in a professional to fix it, he rebuilt and cemented the whole thing leaving it not very aesthetically pleasing ... and moreover the bit of wood couldn't even hold the weight of the table ... so by the time I found all of this, we ended up having to put a sturdy leg on to the table to keep it up anyway, negating the whole reason for having the fold-up table there in the first place! And the saddest part is that Andrew didn't even realise that the whole thing had been a disaster ...

Collectively or independently, all these issues make carrying out everyday tasks somewhat challenging to say the least ... for both the person with dementia and you the family carer.

And memory is not only about remembering events. It's also about being able to remember **how to do things for yourself** e.g. remembering you need to get up in the morning, wash and dress, eat and drink, keep cool or warm, even go to the toilet.

It's also all about daily tasks like cleaning the house, shopping and cooking. So memory loss can have quite unexpected and dramatic consequences when you don't realise your memory has gone.

Memory also forms your **identity**: remembering your family, your role in your family, your likes and dislikes, your attitudes, also your interests and hobbies. Imagine losing the ability to know this? No wonder this is such a frightening illness. And no wonder people want to deny they have it.

Andrew has never gardened in his life and can't actually tell the difference between a weed and a plant. But he's forgotten this and so loves taking pictures of flowers in our garden (**slide**), and can talk so long and hard about the garden and how we won 'best garden' cup in our local gardening competition (**slide**) ... and he is so very plausible too ... about how he is the gardener in our family and indeed even how he used to grow carrots and potatoes and dahlias when he was young – never grown 'em in his life ... that many genuinely believe he is the gardener in our house!

Fantasy World

And because he so loves this gardening world he has become part of, and so wishes he'd done it all his life, he's become incredibly adept at masking the memory loss that this is a new hobby, and inadvertently ... I really don't believe it is intentional ... he has covered up the truth because in his mind this is the truth. He doesn't understand that he is masking the truth and that his reality is now a different reality, not the true reality anymore.

So when the person with dementia is having difficulty interpreting what is going on around him, we must remember he may be too afraid to ask ... and so instead **reinvents the truth** or masks the fact that he doesn't remember how to do it ... I knew a lady who suddenly insisted she didn't like the microwave meals we had been making and freezing for her lunches. She'd been enjoying them happily for over a year ... and then I realised it wasn't the meals that were the problem, but the fact that she couldn't remember how to use the microwave. So we put big white labels on the buttons numbering the steps and suddenly she was famished again!

Professionals call this 'confabulation'. A polite word for not telling the truth! I call it Andrew's fantasy world (**slide**).

In his old life, Andrew was a person who always told the truth and as an engineer he was very precise about all aspects of his life. During those first four years after diagnosis when I started noticing untruths, I not only accused him of lying but also insisted on correcting him which of course he hated.

It became a huge issue, with me getting more and more angry and Andrew getting more and more frustrated. I remember so clearly the day about four years ago when I was standing with my hands clenched tightly, shouting at him to stop lying to me ... such harsh words when I think back on it ... but thinking I can't take too much more of this – I don't remember the incident that caused this outburst, but I do remember the absolute bewilderment in his eyes ... my husband has the most beautiful blue eyes ... and I remember looking up at him and thinking 'he doesn't know he's doing this ... he really does not know!'

And with that realisation (**slide**) I was able – mostly - to step back when he fantasized because I knew he was not doing this on purpose and certainly not doing it to annoy me. It was rather a symptom of his illness, so I tried to see the man and look beyond the symptom.

Now when Andrew - a man who went to a public school in England and grew up playing cricket on the local village green (**slide**) - tells people he went to school in Scotland, wore a kilt and played the bagpipes (**slide**) – I just smile and let it be. It does no harm, so I

- don't correct him,
- don't contradict him nor
- back him into a corner

because does it matter if he tells the world he played the bagpipes as a child when in reality he played cricket on a village green? No, I don't believe it does!

QUESTIONS...

Being a Carer

Being a carer has probably been the most difficult thing I've ever had to do. (**slide**) And that's because I've never felt so alone in all my life. Not lonely, but just so alone!

I remember in those early first years being very angry because although Andrew was the one who had been diagnosed with dementia, I was the one who had to learn to:

- change to accommodate this illness
- keep the peace at all costs,
- diffuse difficult situations,
- deal with an unsupporting family and
- live with this totally changed man in our home.

Holistic Approach

Despite realising all of this, one of the biggest learning curves for me was to understand that my husband really does have the right to be actively (**slide**)

- engaged in everything to do with his life
- and involved in all decisions about his life.

And while this is easier said than done, ... how easy it is to say 'oh he's got dementia ... he can't do that' ... there's a long journey between diagnosis and the need for admission to a care home and because someone is diagnosed with dementia it doesn't mean they suddenly can't do anything anymore.

Other people are so often surprised that Andrew can manage things e.g.

- go on a bus alone,
- nuke a meal for himself in the microwave,

- use the internet ... although sometimes he'll say 'how do I send a letter' forgetting how to do email or 'how do I delete a file' having forgotten the right click/delete route, something most of us all just do instinctively these days.

Because he has dementia doesn't mean he suddenly lost all these skills overnight ... but because he CAN manage to do these things, some people, including himself, think his diagnosis is wrong.

So while I believe it's imperative to take this holistic approach, that is, to see Andrew as a man and not as an illness, it's not always easy and I've had to learn that while I'm desperately trying to see the man he was **before** the dementia diagnosis, Andrew is now a man living **after** a dementia diagnosis and is all the while changing and becoming a different man.

But above all else Andrew is a man and not an illness which means although he still knows where most of the dots are he just doesn't always know how to connect them:

E.g. I watch him make the fire every night. He was a boy scout so he knows the order is newspaper, firelighters, kindling, coal and finally logs once the fire has taken. But every night the fire is laid differently, sometimes with the logs where the kindling should be ... sometimes with the paper on top so that he can light it easily... and sometimes the order is right and he gets the fire going in a few minutes. But when I see him lying down in front of the fire, blowing away to get a flame going, my heart breaks for him ...

And moreover it confirms to me that Andrew doesn't know **when** the dots aren't connecting. And so although the illness is making him forget how to do things sometimes, the man is kicking in and instead of just giving up, he's diligently figuring out over and again how to make that fire work. That is really quite remarkable when you think about it.

So (**slide**) see the man and not the illness ... help reduce the fear in his life by letting him get on with things as best he can ... and let him manage his own life in his own way as much as possible ... it might be different to the way he used to do it – or the way you would like him to do it - but does it really matter how it's done, as long as it's done??

QUESTIONS ...

Taking risks

This brings me straight to another stumbling block on this dementia journey of ours. Soon after Andrew's diagnosis, we sat down and he asked me never to stop him doing normal everyday things no matter how bad he got...

So contrary to my pre-empting problems and solving them before they happen nature, I had to learn to take risks (**slide**)

Small risks like:

Letting Andrew pack and unpack the dishwasher ... a seemingly simple job, but I'm sure many of you sitting here are thinking about

- dropped dishes,
- forks put back into the drawer with bits of food still stuck in them,
- crystal put in by mistake and
- mucky roasting trays put over delicate china.

Things that can drive you scatty, but when you think about it, none of this is life threatening, so you can actually live with it by changing the way you do things e.g.

- Unobtrusively check what's in the dishwasher as he's packing it
- Nimble extract stuff that shouldn't be there ...
- Repack what is there if necessary ... I'm constantly amazed at the creativity of Andrew's dishwasher packing
 - when I find e.g. cutlery sticking out of inverted cups at the top ...
 - Or a glass pushed into the cutlery basket
- And check everything before you use it!

A small risk, which might end up with some broken dishes, but does it really matter in the whole scheme of things? I think Andrew's feeling of independence 'having a job' far outweighs any of the negatives ... And I hide my really special dishes and glassware ...

Then there are **bigger risks**, like:

Taking Andrew with me to India ... Last year I got a Churchill Fellowship to travel to India for two months to study dementia, and particularly carer stress at grass roots.

Andrew's first reaction was 'you are taking me with you, aren't you?'

I gulped and 'yes dear, of course!' thinking oh my goodness how am I going to do this.

All the professionals said 'you're not taking Andrew with you, are you?' Again I gulped and said 'aye ... that I am!'

And he did come along with me (**slide**)... and we had a wonderful trip ... and managed at the same time to show people you can still live a life even with dementia.

But then there are the **unacceptable risks**:

A couple summers' back, out of nowhere Andrew suddenly announced he needed some money because he was planning a holiday alone ... hitch hiking and staying in youth hostels as we had done around Europe when we were young ... for two weeks to the Outer Hebrides ... remote islands far to the north west of us. I tried diplomatically to remind him that it was far too dangerous for him to do this alone at this time in his life.

He would have none of it. I even threatened to use the Power of Attorney to stop him from going because I thought the risk too great. Within days he had spiralled down into a TIA which left him so depressed and unhappy and me so stressed out, that I was forced to come up with something to fix the situation.

In desperation I told him to go on the trip and that if he got lost, he could call me and I'd come and find him. His immediate reaction was 'no, I don't want to go' and so I had to wonder what this had all been about. And finally came to the realisation that he was pushing the boundaries ... seeing just how far I was willing to let him be independent.

I also realised how deeply he trusted me and so set about finding a different way to do this
And in the end:

- he settled for a three day trip
- to Achmelvich (**slide**) on the Scottish West Coast
- just three hours away if I needed to reach him
- to photograph birds (**slide**),

But more importantly

- while he believed he was doing this trip on his own
- behind the scenes to keep him safe
- I had arranged everything
- From getting in touch with
 - bus drivers,
 - hotel staff and
 - local restaurants ...
 - to asking the B&B to keep a special eye out

And he came home exhilarated with great pictures (**slide**) (**slide**) and an incredible feeling of accomplishment.

The thought also occurs to me that one of these days (**slide**) if our 'risk taking' leads to a serious injury or even death, there could be consequences. In fact some people might deride me for not taking better care of a person whom I know has dementia, but I just keep in my mind that if there is a choice, then Andrew has made it very clear that he would prefer

- to have a shorter life with quality,
- rather than a longer life
- with nothing but four walls surrounding him.

QUESTIONS ...

Denial

The most difficult of all the issues we had to face has been how to deal with Andrew's denial of the illness (**slide**) How often did I say to him

- 'I'm tired of fighting the world for you
- and you too ...
- we can cope with this thing together
- if you would only accept your diagnosis ...
- but I can't do it alone anymore.'

I finally realised it was the **label** of dementia that was so unacceptable ... not necessarily the symptoms. That it was that label that my husband was denying, not the illness itself.

So how far does one go to see the man and not label him with the illness, especially when this same illness has the potential to result in danger to himself and/or others, e.g.

- Driving my car up to the busy road above our village because he forgets he doesn't have a licence.

Eventually the stress of this ongoing battle around Andrew's denial became so bad that my blood pressure shot up dramatically and I started having nose bleeds with the real worry that I might have a stroke and then what would happen to the pair of us.

One day after a particularly bad nose bleed, (**slide**) he asked why this was happening to me. I took a deep breath and gently explained he simply had to take responsibility for his illness, that it was now making me ill and where would we be if I got sick?

In shock he agreed to check out the Alzheimer Scotland website and in astonishment said

- 'but I have all the symptoms'.
- I said 'yes'.
- And that evening he came home and said
- 'I told Angus in the village that I have dementia'
- and I said 'hooray ... that's wonderful!'
- and then he added the rider
- 'but of course I might forget by next week!'

Which of course he did! Andrew hated accepting his dementia diagnosis and I think it was probably the most difficult thing he ever had to do in his life. But he finally faced it late last year and this acceptance of his illness has probably been the most significant turning point in our dementia journey. We may not be able to lick this wretched illness, but we sure are learning to live a life with dignity and some happiness (**slide**) rather than trauma and complete despair.

QUESTIONS...

Creativity

Over the last year or so I've also learned how important creativity is and how much it can help families on this dementia journey. Andrew does wonderful photography ... he too most of the pictures you're seeing here today ...) and early on after his diagnosis, he thought to paint some elephants, using photographs from an earlier trip to South Africa.

One has to remember that besides the person with dementia/carer relationship, there is also still the personal relationship e.g. husband and wife. Of course I took one look at his effort and said 'better stick to your photography darling!' or words to that effect! So he did.

And then last year I read about creativity and dementia and how creativity and imagination deteriorate at a much slower pace than loss of memory (**slide**). And to my horror I realised I'd totally messed up: again! That rather than denigrate Andrew's paintings as I

had, I should have celebrated the fact that he was trying something new. So with a heavy and guilty heart I decided to do something about it.

At the beginning of last winter ... always a difficult time in our house ... I suggested we cover everything in the garden room and turn it into a studio (**slide**) so that he could paint, that he choose his favourite photograph from India (**slide**) and that together we'd go out and buy paints and canvasses and all the stuff he needed.

Needless to say, his face lit up with joy... which of course added to my guilt ... and over the winter he's happily beavered away (**slide**) ... making me realise it doesn't matter whether what he produces is good or bad by whoever's standards, the key is that he enjoys doing it, (**slide**) is absorbed for hours doing it and his increased sense of well-being is worth all the aggravation of having paint over everything, including rugs, jerseys and trousers.

It really is worth it ... as you can see samples of his work.

SHOW SAMPLES + QUESTIONS ...

Problems or Opportunities

These are some of the issues I've learned to cope with ... but what about the practicalities of living with a person with dementia. Do I want a clean and starched Andrew or do I want a happy Andrew? I guess there's only one answer to that! So are the problems we face actually problems or can they be opportunities?

We are so quick to think of all the difficulties as problems, but sometimes by turning these difficulties into opportunities we as carers really can make a difference: to both our lives and the person we're caring for ... like Andrew's painting. There is paint all over his clothes and the rug and the table ... no matter how diligently I try to cover everything ... but in the end, paint on his jumper is a small price to pay for his happiness...

The key perhaps is when there appears to be a problem

- look at the person you're caring for
- and try to figure out what is actually happening ...
- then try and look beyond the illness
- Look at the man ...

At the same time remembering **5** very simple rules: (**slide**)

- Don't confront
- Don't contradict
- Diffuse any difficult situation by walking away
- Look at the person and not at the illness
- And above all else, don't take things personally.
 - If Andrew is having a bad day,
 - he'll say things in frustration or to hit out,
 - but will of course forget what he said

- or that it was hurtful
- within a short time ...
- whereas if I've taken it personally,
- I'll stew about it for real no reason.

QUESTIONS ...

Grief

Before closing I want to touch on one more difficult subject: that of grief.

Two years ago at an International Alzheimer Conference in Toronto, one of the plenary sessions covered grief. I came away from that with the overwhelmingly powerful realisation (**slide**) that I too had been

- watching my husband changing: and grieving ...
- watching him deal with his frustration and anger - this man who used to have such a happy sunny nature: and grieving ...
- that the tears behind my eyes were for the man I had lost
- and the burden I was carrying around was actually unresolved grief.

And instead of being able to have closure as in a normal bereavement, my life had gone on hold. But worse was that I hadn't recognised my grief and therefore had not sought help. And the speakers in Toronto were absolutely right when they said the worst (**slide**) was that while trying to come to terms with all these losses, my reaction to this loss was not socially understood, which meant I could not openly acknowledge that loss or publically mourn it.

When I think back on my own internal processes, I was very resistant to look at anything on an emotional level ... I could barely cope with what was happening around me, never mind trying to understand deeper influences. And an integral part of learning to cope was I had to learn to look at those emotions and learn to manage the impact of dementia on my own life and at the same time realise that I too was changing. Only once you understand this can you really begin to move forward.

QUESTIONS ...

Before closing

Before closing, above all else remember (**slide**)

- although we are carers,
 - we are also human ...
- you will get annoyed ...
- and you will get upset ...
- and you will take things personally ...
- and you will want to contradict
 - when the person is blatantly telling an untruth,
- and cry your eyes out

- when you think you can't cope one minute longer
- but the minute you feel your stress levels rising,
 - step back ...
 - just step back,
 - take a deep breath and
- look for the person inside that illness ...
- they really are still there ...

Scottish Dementia Strategy

In Scotland we are fortunate in that we have a dementia strategy and indeed are one of the few countries in the world to have one. It was put in place by the government in consultation with Alzheimer Scotland, the NHS and other relevant bodies ... and it's an excellent strategy ... and it's a living and ongoing strategy that is changing to adapt to the needs of people with dementia and their carers ... those at the top know exactly what we need down here at the bottom ...

The Strategy is based on concerns (**slide**) around the support, care and treatment for people with dementia AND their carers and it means there are certain basic rights that have been laid down and to which we are all entitled. Basically it covers:

- **Fear of dementia** i.e. removal of the stigma and myths that prevent people coming forward for early diagnosis
- **Information and knowledge** and what we should all be able to expect after diagnosis
- **Respect and Dignity** for dementia families and how lack of these two basic rights so dramatically affect our lives
- **Support** (or lack thereof) from the general healthcare services who do **not** always understand how to respond well to people with dementia and their carers; and the fifth concern is around
- **Teaching carers** that they need to protect their own welfare to enable them to go on caring safely and effectively.

In keeping with Big Society, I believe we the family should be caring for our loved ones at home for as long as possible, but we can't do this 168 hours a week without help. So don't be afraid to ask for that help! It is there to be had ...

- on a professional level from your CPN and Alzheimer Scotland amongst others,
- from key people sitting on the National Dementia Carers Action Network ... a number of whom are here in the room today ... and
- various websites from individuals like Tommy on Tour to the NHS teaching resources ...
- and of course there is help for each other from people like you and me doing a carer's job ...

Conclusion

To end, let me show you a few more of Andrew's photographs ... (**5 x slides**)

And say in conclusion that by sharing some of our dementia journey with you today and showing you my perspective on caring, my hope is that

- **if** you find yourself in a similar place,
- you will at least know someone else was in that same place,
- but that unlike me at the time,
- you will see a light at the end of that long tunnel ...

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

Ann Pascoe

Portgower,
26th February 2013