

Dementia for Crossroads' Care Attendants

23rd July, 2012 ...

Helmsdale Community Centre

Credentials/background

- **Caregiver** for husband
- Crossroad's **care attendant**
 - Learnt everything I know doing this grass roots work
 - but no-one would listen

- Earlier this year I was awarded a **Churchill Fellowship**
 - And now people are starting to listen
 - I travelled to India
 - 1.2 billion in small area vs 5 million spread out ...
 - problem the same re crisis solutions
 - What they have discovered is Caregiver Stress number 1 issue to address ...
 - Which is absolutely in line with our **Crossroads mission** ...
 - i.e. give the caregiver support and the person being supported will be able to stay at home so much longer.
 -

Scottish Dementia Strategy

- One of the few countries in the world who has one ...
- And it's an excellent strategy ...
- Trouble is it's not reaching us ...
 - the people with dementia and their caregivers ...
- at grass roots

Strategy is based on 5 concerns around the support, care and treatment for people with dementia AND their caregivers:

- **Fear of dementia** means people delay in coming forward for diagnosis
- **Information and support after diagnosis** for those with dementia and their carers is poor or non-existent
- **General healthcare services** do not always understand **how to respond** well to people with dementia and their carers, leading to poor outcomes
- People with dementia and their carers are not always **treated with dignity and respect**
- **Family members** and people who support and care for people with dementia do **not always receive the help** they need to protect their own welfare and to enable them to go on caring safely and effectively.

And this is where we at Crossroads **come in ... if in our small way we can help those family caregivers to receive the help they need to look after themselves, then not only will we have done a good job, but we'll also have enabled those family caregivers to go on caring safely and effectively.**

So how exactly can we help to get that national dementia strategy down to the people who need it?

- While they are fighting at the top to change things
- we need to do our bit at the bottom
- i.e. we who are working at grass roots need to understand dementia
- and be doing what we can to give people with dementia and as

- importantly their caregivers the right to live their lives with dignity
- Your work will be very challenging and extremely stressful at times
 - But don't ever forget you have only a couple hours a week there
 - the family caregivers live with the situation 24/7
 - or as one of my carer Activist colleagues pointed out: 168 hours/week
 - **Minus the 2 hours Crossroads come in ...**
 - **There's a** lot of talk lately about being given the right to die with dignity
 - **Tony Prachett who has Alzheimers ... even Hugh Jamieson in Aboyne, Aberdeenshire**
 - But let us give these people and their families the right to live with dignity ...

So how can we do this?

Let's start with reminding ourselves what is dementia?

So what is dementia?

- Dementia is a generic name like cancer
- **Same as breast cancer, bowel cancer etc ...**Alzheimer/Vascular dementia/Lewy Body dementia/Pick's disease/
- These illnesses cause brain cells to die off far more rapidly than is normal
- How the illness affects someone will depend on which area of the brain is damaged
- A progressive illness – no cure
- unlike damaged skin, brain cells cannot regrow
- Dementia also encompasses **brain tumours ... Strokes ... Parkinsons ... dehydration linked to urinary infections/incontinence ... even Downs Syndrome ...**

Typical Symptoms

Short-term memory loss

- Short-term memory goes first
- So while the person can remember exactly where they went and what they did on holiday in 1963,
- they simply cannot remember whether or not they took the dog for a walk that morning
- In fact many cannot remember from one hour or minute to the next
- People you are caring for may forget that they have just eaten
- Not remember where they are
- Perhaps not remember where the toilet is
- Not remember that they have just asked the same question several **times ...**
- which **of course this means they've not remembered the answer!**

- Some clients will surprise you because although their short memory is bad, they can talk at great length about things that happened as far back as childhood
- This **long-term memory** usually lasts longer than short-term memory because it is held in a different part of the brain and may not be affected until the later stages of the illness.

- Memory is not only about remembering events
- It is 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/warm, go to the toilet etc
- **It's all about daily tasks like cleaning the house, shopping and cooking**
- Memory also forms your identity:
 - Remembering your family
 - Your role in your family
 - Your likes and dislikes
 - Your attitudes,
 - hobbies, (New interest gardening ... will talk about how a person can reminisce about being a garden when he wasn't ...
- **Fears ...I had a client who once thought because she could remember so far back so clearly, she was seeing her life pass in front of her ... and wondered if she was dying??**
- -which means a person with dementia could have great difficulty interpreting what is going on around them ... and then could **mask** the fact that they don't remember how to do it ... e.g. another client said she didn't like the microwave meals in her freezer ... she'd been using 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

Another symptom is maintaining the

- **ability to think things through,**
- **understanding instructions,**
- **concentrating ..**
- **calculating risk**
- **Using reason and judgement**
- E.g. client who wanted to attach a 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 put a bit of wood into it and nail in a table ... hadn't calculated the risk, so was surprised when 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 won't even hold the weight of the table ... they ended up having to put a sturdy leg on it to keep it up!
- And the most difficult part for the family to understand is that he **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 for both the person with dementia and the family caregiver.

So how can we as professional carers **going into people's homes** actually help them??

Problems or Opportunities?

First of all

- by looking at the so-called problems
 - not as problems
 - **but as opportunities ...**
- and in every case looking at the person involved
 - be it the person with dementia or the caregiver
- **to try and determine what it is that is actually happening ...**
- **and how you can help fix it ...**

Also by remembering **5** very simple rules:

- Don't confront
- Don't contradict
- Diffuse any difficult situation by walking away
- Look at the person and not at the illness
 - which includes both the person with dementia and the caregiver
 - **story about bagpipes ...**
- And above all else, don't take things personally.
 - If the person with dementia is having a bad day,
 - they'll say things in frustration or to hit out,
 - but will of course forget what they said
 - **or that it was hurtful within a short time ...**
 - whereas if you've taken personally,
 - you'll stew about it for really no reason.

Let's get the real nitty-gritty of opportunities where we can try and make a difference

- not only by using our own best practice
- but also by helping the caregiver to understand how he or she can deal **with what is happening ...**

Aggression

There are different kinds of aggression:

- Physical
 - Verbal
 - More often than not the clients we deal with are just irritable about something
 - and have no idea the strength of their verbal or physical abuse
 - She may be defending herself for something silly she said or did
 - Or letting someone know she's had enough
 - or trying to cope with pain
 - **or protecting something precious ...**
-
- Story of Mrs B **and picking flowers from her garden ...**
 - Had a new carer starting and I told her Mrs B loves flowers
 - why don't you go into the garden and pick some for a vase
 - **she'll love that ...**
 - Well, that sort of backfired when Mrs B told me she didn't like the new carer
 - didn't trust her
 - and wanted her out of the house ...
 - we all backed off
 - then I went back to see if I could find out why she didn't like this young woman she had only just met
 - turned out she'd **seen her cutting flowers in her garden**
 - **a place she treasured**
 - and thought new carer was '**stealing**' them ...
 - **Once I explained I'd suggested it as a surprise ... she laughed and all was well!**

And by following the 5 point rule ... we diffused the situation: when Mrs B insisted the new carer get out of her house we walked away to another room and tried to figure out what had triggered this outburst and see if we could **link it to anything ... when we couldn't, we went back again and eventually by talking, turned the 'problem' into an opportunity by coming at it from a different angle.** The new carer took Mrs B **regularly for walks in her garden ... letting her suggest which flowers to pick for the vases!**

Question: what kinds have you experienced?

Wandering

- Problematic from whose perspective??
- Listed as a symptom
- But is in fact something we all do
- Walking is a fundamental human activity
- **We all stroll, amble, hurry or roam ...**
- Why should it be any different to people with dementia?
- Wandering – more than any of the other apparent dementia symptoms – **can tell us a lot about the tolerance of others ... we the carers!**
- And our challenge should be to use this as an opportunity
- Talk the person for a walk instead of sitting watching the television
- I remember visiting a lady in Seaforth and when I first visited her, because rules precluded me taking her outside, I used to walk her up and down the passages, chatting as we walked.
- **She loved it ...**
- Later when her legs couldn't hold her up any more, we still did the passages, but in a wheelchair!

Turn the problem into an opportunity!

- Wandering can also be indicative of being reluctant to settle down.
- People with dementia are often unable to just sit in a chair all day unless they're in the final stages of the illness.
- At certain times in the day they may just want to be on the move.

So ask yourself if this is really a problem ...

- or is it just a problem for you
- because you want
 - to vacuum or
 - clean the bathroom or
 - make the lunch.

People move around for many different reasons e.g.

- looking for the toilet
 - looking for their room
 - boredom
 - a need for exercise
 - looking to find their way 'home'.
-
- **It may be that it is okay for the person to be on the move ...**
 - in fact it might actually be a positive thing to keep them mobile.

- So trying to keep the person in one place
- because it suits you,
- may well create other behaviour problems such as
 - agitation
 - or even physical problems bearing in mind that long spells of immobility
 - e.g. **sitting in a chair for hours on end ...**
 - can sometimes lead to
 - urinary and
 - chest infections.

Finally remember

- if you are encouraging your client to walk,
- then ensure a safe environment for that person

Routines

- Crucially important
- But don't be regimented
- And if your client suddenly changes a routine, look for the reason ...
- **Intimate tasks** ... remember their generation ... lady in Tain (towel)
- **Mealtimes**: do they have to be **set times** ... are you always hungry at exactly 1pm?
- Would you resent someone who was not your family sitting with you at a table day after day?
- I know we do it to keep our clients company, but there's no harm in **asking ... every meal time, whether they want company or not?**
- Are we always careful to ask **what** they **would like to eat** ...
- **And as long as you're balancing the diet, if** they feel like roast chicken dinner on Tuesday instead of Sunday, does it matter?
- **Remember often the person will revert to likes and dislikes ... habits** from when they were young
- And if they hated fish as a child, they could well go back to that dislike ...
- **Keep an open mind** ...
- This is an opportunity to **give the person a choice** ...
- **Dress in a different room** ... does it matter
- **Man with pajamas** ... slept naked ...

Masking

Which leads me straight on to masking ...

- If your client suddenly says they've **lost their appetite**
- Check if that really is so
- or whether they are masking the fact that their eyesight is going and they can't see the food
- Or if they usually nuke it in the microwave or in the oven, check they **still remember how to do it ...**

- or if you put the **washing in the machine** and you see only one pair **of knickers ... check if others are where they shouldn't be ... or like my** good husband keeps turning the same pair inside out and thinks all is well!!
- And then when I suggest he puts on a clean pair every day, he masks that he's forgotten to do this by telling me it's far too hot to wear underwear (I'm talking about here in Scotland, not out in India!!) and that he's decided to go knickerless!!
- So now I look for his kickers every evening and put them in the clothes bin.
- He's happy 'cos he thinks he remembering and I'm happy because he's **wearing clean underwear ... problem was turned into an opportunity!**

Don't want to watch television/read/listen to music

- Is it hearing?
- Eyesight?
- Story of AMP and short stories ... **computers ... can flick back and forward**

Clever at masking **loss of memory itself**

- Confabulation

Communication

Bear in mind that as the person's ability to communicate deteriorates over time, their **behaviour will replace** the normal means of **communication**.

- Look for the emotion underneath the words,
- facial expression and
- body language.
- What do you hear and see?
- Is the person expressing
 - fear,
 - happiness,
 - anger or
 - sadness?
- Trust your intuition!!

Confront the issue ...

- If the person appears **fearful**,
 - say 'you look frightened ... has something happened?'
 - Or see what is making them specially **happy**,
 - so that it can be repeated.
 - Or why they're **sad** ...
 - or why they're **upset** ...
 - I always tell the story of my husband and the **marmalade jar** ...
-
- Always remember to approach the person face to face.
 - If they're seated,
 - get down to their level and
 - speak in a normal voice
 -
 - Remember to smile ...
 - be respectful ...
 - polite ...
 - never ever shout back ...
 - remember they are usually a generation above you and this is the **behaviour they expect** ...
 - especially if you're a guest in their home ...
 - don't ever forget that ...

Repetition

What do you do when the person asks the **same question** over and over again?

Bear in mind that people with dementia

- cannot remember asking the same question
- or receiving the answer.
- Try distracting them from the topic
- by giving them something else to do
 - e.g. **decide what television programmes to watch or record ...**
 - **or work on menu's for the week ...**
 - or take a walk in the garden to pick flowers to arrange in vases ...

I was at ADI in London earlier this year and a doctor actually stood up and said the best distraction they'd found in their local care home was

- to put a **duster in their hands** or
- give them **clothes to hang up on a pretend washing line ...**
- **I couldn't believe what I was hearing ...**
- and when a number of us challenged him,
- he backed down and mumbled something about our generation perhaps being different!

- **But perhaps with hindsight he may well have had a point ...** anyone heard of the **dementia babies??**

Also **asking** for 'mother' or their **deceased husband** is a common occurrence and usually indicates feelings of insecurity and fear.

- Try answering with 'oh, do you miss your mother? Tell me about her.'
- Or acknowledge the insecurity and say
- 'don't worry, you're safe here'
- and try moving off the subject to another subject or activity.

Gracey ... husband dead for 27 years ...

Best practice says always tell the truth ... but person with dementia's **reality is a different reality**, so why destroy that?

Searching and Hoarding

What do you do if the person is **constantly looking** for

- her handbag or
- wallet or
- keys

or at the other end of the scale, is constantly **hiding things**?

Understand that the person **can't** always remember

- where they've left something which could be
 - very personal and
 - offer a feeling a great comfort and security.
- So if she wants to keep her handbag at her side all the time,
 - **let her do it ...**
- **If she wants money in her purse ...**
 - even if you know she'll never use **it ...**
 - **let her be ...**
- imagine how you would feel if you thought
 - you'd lost your bag or
 - **didn't have any money in your wallet ...**
- absolute panic!

Hiding things is another issue and

- they could be doing this for any number of reasons.
- In fact it takes time to understand the reasons behind the 'hiding'...
- and sometimes you never find the reason.

Every time my husband sees a pair of secateurs ...

- **in the kitchen after I've cut flowers from the garden ...**
 - or in the greenhouse because I've been working with **them ...**
 - **or even in the garden because I'm pruning or cutting back stuff ...**
- **he'll pick them up and squirrel them away ...**
- drives me crazy!
- He'll even take them out of a drawer and
 - **hide them in his workshop ...**
- I've finally given up trying to figure out **why he does this ...**
- so now when I can't find a single pair anywhere,
- I check out his workshop and invariably will find a few at the back of drawers or on top of obscure cupboards!

Wanting to tidy up, set or clear the table, or empty the bin ...

- Let the person help.
- Tidying up can be very therapeutic.
- Being able to be active
 - in setting or clearing the dinner table
 - is comforting in that
 - it is a task that we learn from early childhood.
- To someone with dementia it is a skill,
 - like riding a bike,
 - that stays in the long-term memory ...
- so encourage them to continue to help as long as possible.
- **Do things together ...**

Remember, although the person has dementia,
they still have a lot to give ...

and it is up to us to give them the opportunity to do these things ...

Challenging Behaviour

And while we might regard our client's behaviour as 'challenging', try to put **yourself in their place ... both that of the person with dementia as well as the family caregiver.**

- How would you like it if you were suddenly told
- you needed support to stay in your home
 - but you truly believed
 - you were doing a good job at looking after yourself
- and you did not understand why someone else had to do this?
- Imagine being confronted by a stranger
 - who insisted on staying and
 - worse, went around your home
 - as if it were theirs.
- So how would you feel if strangers suddenly came into your house?
- How would you behave
 - if suddenly a young woman wanted to dress or undress you
 - and worse toilet you
 - Or shower you?
- How would you feel?
- How would you behave?
- Would you tell that person in no uncertain terms to get out of your house?
- And how would you feel if you were then labelled 'difficult'???
 - I visited a lady who had good and bad days
 - and on bad days she'd call the police
 - to come and evict this burglar (me!)

- And think too of the relatives
- i.e. the wife or husband or child who has been looking after their loved one,
 - but now finds it too difficult to cope
 - and has to admit they need help.
- Calling for help by a caregiver
 - **is usually the very final last resort ...**
- By putting yourself in their shoes you may be able to understand
 - the anguish and

- the embarrassment and
- even the shame that the caregiver feels
- **when they can no longer 'do their duty' ...**
- and by putting yourself in their shoes, you may be able to understand relatives' behaviour and,
- through understanding, be more confident in getting to know them and
- dealing with any questions or concerns they may have.

Remember that some of the **difficulties** may be:

- confusing days of the week
- forgetting to turn up for appointments
- being unable to handle money
- constantly using the phone
- neglecting personal care and hygiene
- becoming isolated
- being frightened in their own home
- becoming increasingly vulnerable
- being unable to go out on their own
- forgetting the time of day and night
- showing changes in behaviour.

Story of Jeanette and her husband Ken ... 108 different carers over a year ...

So what **practical things** can we do to help?

I'm going to give you a list of things you should **try to do** ...

- but don't feel guilty
- if you can't do them all the time ...
- and when you're giving this same advice to the caregiver
- be very careful not to make him/her feel guilty
- because they **can't do these things** 168 hours/week ...

Speak

- clearly,
- calmly and
- slowly
- to allow the person time to understand information.
- Use simple short sentences and
- avoid direct questions.
- Keep choices to a minimum and
- **don't raise your voice**

Body language

People with dementia may be finding it difficult to understand what is being said but may still be aware of body language.

- Smile warmly,
- make eye contact,
- **make sure you are at the person's level,**
- use a friendly tone and
- respect personal space

Listen

Listen carefully to what the person has to say,

- giving plenty of encouragement,
- whilst looking out for other clues of what they might be trying to communicate

Show respect and patience

Adapt what you are saying

- if the person with dementia does not understand
- what you have said.
- Allow them time to find a way to express themselves;
- they may find it hard to find the words #to tell you what you they want.

Noise

A person with dementia

- may have difficulty listening
- if there are a lot of different noises around them.
- Reduce unnecessary noise or
- move to a quieter area

Lighting

Make sure the lighting is sufficient

- so the person with dementia can see you
- and everything around them clearly.
- Turn up the lights or
- move to a well-lit area.

Finding the way

People with dementia may have forgotten where things are.

- Colours,
- textures or
- busy environments
 - may also cause **confusion** and
- They may not recognise **everyday objects**.
- They may need you to help them to **find their way around**.
- They may not be able to **follow simple directions** and
- need you to **guide them** to where they want to go.

Remember, this can happen one day and then be fine the next ... **be vigilant and don't be surprised ...**

Whose reality

The person may be confused and say something that does not make sense to you,

- avoid making the person feel foolish
- by contradicting them.
- Try to find a way around the situation

Predictable

The person with dementia may be confused

- if things have been rearranged or
- by new people they meet.

Try to keep things the same or

offer additional assistance if things have changed.

Try and arrange that the same person supports the person each time or
have a team they know ...

but above all **remember**

- they might not remember you or
- what you talked about the last time you met.

Every day can be different

For some people with dementia

- what they can do changes from day to day
- so how you help them
- may need to be different every time they visit.
- Look out for signs and
- offer help when needed.

Above all else though remember

- although we are carers,
 - **we are also human ...**
 - we can't be these paragons of virtue all the time
 - doing all these marvellous, perfect things ...
- **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 confront
 - when they are being aggressive
- 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 ...