

Understanding My Dementia



I have had the privilege of being surrounded by marvellous people all my life. I know Stanley loves me dearly but I do not expect him or any other family member to care for me when I am permanently 'adrift'. I expect to be cared for in an appropriate place and my end of life directive is 'No Resuscitation'. I know to 'depart' is far better.

In 2011 We moved to a 'Retirement Village' which has on site Dementia Care

I have also removed half the pages of my original booklet and most of the photographs to simplify things for this website version



This Booklet was put together in 2010 a year after I had been diagnosed with Alzheimer's Dementia at a time when I was able to anticipate the problems I and my supporters are likely to experience in the future when my condition deteriorates.

I have had the privilege of looking after others with Dementia while working as a GP. I read extensively around the subject once I realised I had such problems myself and I passionately believe that care can be more proactive than is usually the case and that the person with Dementia is still there, trapped inside the disease.

So when the front door is shut and the key is lost there is usually a back door or a ladder with which to climb in the window. Those who care about the trapped person might like a few tools to help in the construction of 'escape routes'!

LISTEN TO THE MEANING BEHIND THE WORDS

Is it getting dark yet ?
How long does it take to get back?
Are you cold?

Is she really saying

I am not really enjoying this.



Stories A woman at a day centre who repeatedly told of her first day at school when she wet herself and felt humiliated by the teacher and everyone laughing, might in fact have been saying that was how she was feeling now

REPETITION REPETITION REPETITION

‘I must go home now’ might mean
I am feeling lost or uncomfortable

Asking what time it is, might just mean ‘I
have no idea what I am meant to be doing’

A repeated phrase might be saying “can we talk?”, or an attempt to get your attention or an introduction to enable the next thing to be said.

A person with Alzheimer’s can behave in new ways

Most taken from Alzheimer’s Society leaflets

Behaviour may be related to:

- *Physical discomfort, illness, or medication side effects*
- *Overstimulation such as loud noise or a too busy environment*
- *Unfamiliar surroundings such as a new place or inability to recognise an old one.*
- *A too complicated task or difficulty with tasks or activities*
- *Frustrating interactions such as Inability to communicate effectively*

Anxiety or agitation

They may become restless and need to move around or pace, or may become upset in certain places or focused on specific details. He or she may also become over-reliant on a certain caregiver for attention and direction.

How to respond:

Listen to the frustration

Find out what may be causing the anxiety, and try to understand.

Provide reassurance

Use calming phrases. Let the individual know you’re there for him or her.

Involve the person in activities

Try using art, music or other activities to help the person relax.

Modify the environment

Decrease noise and distractions, or move to another place.

Find outlets for the person’s energy

They may be looking for something to do. Take a walk, or go for a car ride.

Confusion

They may not recognize familiar people, places or things, may forget relationships, call family members by other names or become confused as to where home is. The person may also forget the purpose of common items, such as a pen or a fork.

How to respond:

Stay calm

Although being called by a different name or not being recognised can be painful, try not to show your hurt.

Respond with a brief explanation

Don’t overwhelm the person with lengthy statements and reasons. Clarify with a simple explanation.

Show photos and other reminders

Use photographs and other items to remind of important people & places.

Offer corrections as suggestions

Avoid explanations that sound like scolding. Try “A pen so you can write,”

Try not to take it personally

Other Tips

Don’t stop them doing something because they aren’t doing it ‘properly’.
Don’t exclude them from conversations they understand more than you realise.
Controlling is not the same as caring.
Ask, is this a problem for them or for me, and, who can adapt more easily?
Limit Choices to preferably one item!

A person with Alzheimer's can behave in new ways

Most taken from Alzheimer's Society leaflets

Aggression

Verbal (shouting) or physical (throwing, pushing) may occur suddenly, with no apparent reason, or follow a frustration.

How to respond:

Try to identify the cause. Think about what happened just before the reaction that may have triggered the behaviour.

Focus on feelings, not facts. Try not to dwell on specific details; rather the feelings behind the words.

Don't get angry or upset. Be positive, reassuring, speak slowly in a soft tone.

Limit distractions. Try to adapt the surroundings, to avoid a repetition.

Shift the focus to another activity as the immediate situation or activity may have unintentionally caused the aggressive response. Try music, or exercise to help soothe the person.

Repetition

A person with Alzheimer's may do or say something over and over again – a word, question or activity, probably looking for comfort, security or some familiarity. They may also pace or undo a recently completed task. These actions can be stressful for others.

How to respond:

Look for a reason behind the repetition. Try to find a specific cause.

Focus on the emotion,

Rather than react to what the person is *doing*, think about how they are *feeling*.

Turn the action into an activity

If moving their hand up and down the table, provide a cloth & suggest they do some polishing.

Stay calm, and be patient

Reassure the person with a calm voice and gentle touch.

Provide an answer

Give the person the answer again if unable to distract.

Suspicion

Memory loss and confusion may cause things to be perceived in new, unusual ways. Individuals may become suspicious or accuse others of theft, or improper behaviour. The person may misinterpret what they see and hear.

How to respond:

Don't take offence. Listen to what is troubling them, try to understand.

Be reassuring, Let the person know you care and take them seriously.

Don't argue or try to convince

Allow the individual to express ideas. Acknowledge his or her opinions.

Offer a simple answer

Share your thoughts with the individual, but keep it simple. Don't overwhelm the person with explanations or reasons.

Switch the focus to another activity

Engage the individual in an activity, or ask for help with a task.

Duplicate any lost items

If the person is often searching for a specific item, have several available.

Important to Plan ahead

Feelings remain even when facts are forgotten

even a happy occasion can be 'spoilt' by a sad farewell.



"Happy exit" strategies

Rather than make a 'scene' of having to go, say 'I am just going to the loo' or 'need to make a drink' so that I am happy to 'let you go'. I might then forget you haven't returned but still feel happy rather than feel disturbed because something is not right by your departure..

It has been said, 'parachute in, evaporate out'

Explanations for Absent People

For example, if Stanley is absent, you could remind me that he used to be away when he went to Africa.

Affirming Moments

"You always were good at jigsaws"
(even if the present one has limited pieces).

Reasons to rest rather than follow around

"Why not sit down for a while, we don't want you to conk out!"

My Siblings & My Childhood



Pictures of my siblings when they were children and also as adults

Friends and Relatives



Pictures of my cousins now and as children

Pictures of my friends now and in earlier times

Our family children

Pictures of my children when they were young as well as when adults with their spouses and the grandchildren.

All well labelled of course with names.



Time Travel or what year is it?



The photos in this booklet might help you to work out which decade I believe I am in, perhaps by which house photos and/or the people I recognise.



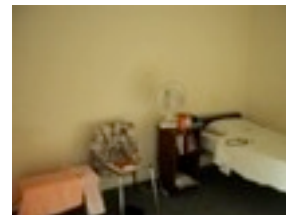
When adrift in time (perhaps I may be thinking it is 1960) do try to reorientate me but if you can't, accept it, be aware that I then might think X is not yet born or not yet married, so I assume they are someone else or perhaps I have no idea as to who they are.



If I am asking where someone is who has actually died, I may be adrift in a year when they were alive so you can say they are not here at the moment (which is true) "so let's have a cup of tea", or remind me of a reason why they might have been absent in the past "he went to Africa."

Picture of where I trained *There is no need to tell lies*

Working as a Doctor



In Zululand



In Southampton