Managing dementia:
Read both the professionals and the carers tips.
Carer’s Wise Words from a professional and from a daughter.

Norman McNamara says “Please Don’t”
CARER’S GUIDE

Tips from Jane Moore, carer to her mum with dementia and co-founder of The Purple Angel campaign.

12 PROMISES TO YOURSELF

1. Always Agree – Don’t Ever Argue
2. Don’t Try to Reason
3. Redirect Attention to Avert Crisis
4. Never Ask “Do you Remember”, it stresses
5. Never Say “I Already Told You That” Or “You Just Did That”
6. Never Say “You Can’t”
7. Don’t Tell – Ask Instead
8. Do Chat Say: “Tell Me About It”
9. Encourage and Praise
10. Smile- Even if you don’t feel Like it!
11. Reminisce With The Person Not For The Person
12. Focus On The Good Things and Enjoy The Moment

Memory Cafes are great places to relax and enjoy the company of others and it is vital to keep socialising. There are also carers groups for support and many areas have Dementia Care Practitioners (via your GP) who can help.

Cognitive Stimulation and challenging the brain with new activities can be a way to stay healthy, together with a good diet and plenty of exercise.

Memory Cafes in Cornwall: http://www.cmcnetworkforum.btck.co.uk/
For all other areas: http://www.memorycafes.org.uk/

PURPLE ANGEL-GLOBAL.COM
Welcome to Living with Dementia a free publication for anyone living with dementia, their family and carers.

Dementia is a term which covers the symptoms of several diseases, such as Alzheimer’s; Lewy Body Disease; Vascular Dementia and many more. It is important to receive a proper diagnosis.

Dementia can also be caused by B12 deficiency; Urine infection; thyroid; brain injury and less common a tumour. These are hopefully reversible causes and you would not forgive yourself if you ignored the signs.

It is important to put a Lasting Power of Attorney in place as soon as possible. Make sure your Will is up to date too and know where to get advice when needed.

We enjoyed putting together our first edition, and now we’re aiming to try and have an updated version every few months with much more focus on you and how you cope and featuring your tips and ideas, coping strategies and more from the experts.

So if you’ve got a story to share an experience of value or something you’ve come across that has helped you cope, then use this as your platform to share that info with us - just email us in your updates.

We’re looking forward to hearing from you all!

Norms McNamara and Jane Moore,
Founder and Co Founder of Purple Angel www.purpleangel-global.com
BRAIN HEALTH

Try a new hobby or take up a sport! This is proven to be of benefit and helps to keep the brain active.

Eat a good diet with plenty of fresh fruit and vegetables – the more colour there is on your plate the better for you!

Getting plenty of fresh air and sleep is also important to your health.

Your GP can advise about Cognitive Stimulation Sessions and Memory Cafes in your area – it is vital to keep socialising.

Make sure you look after yourself and get some respite if needed.
PURPLE ANGEL SUPPORT PROJECTS

For independent living, please take a look at our anti-scam ringtone to download for around 99p plus our doorbell and MP3 Player

http://www.purpleangel-global.com/support-projects.html

Purple Angel Music Door Bell
Purple Angel Music have been working closely with trading standards after they asked us to help fight door step phone scammers, targeting the elderly and the vulnerable. We have created two products designed specifically to help deter these people. It is not a cure but we feel that it is the best thing on the market right now.

Door Bell: we can supply and install a fully working door bell with one of our specially written MP3s that suggests that the house is in no need of any home repairs or improvements. This is something that hopefully would create concern from the canvasser that the house has additional protection and cause them to move on.

Purple Angel Music Ring Tones
Phone ringtone: most phones will ask for donations for bogus charities, inform the person that they have won the lottery and just require a few details from them to release the money. Our song, which is an old nursery rhyme or hymn emphasises mainly “don’t give out your bank details!” and also “don’t give out your card details. It is also possible to have a motion sensor installed next to the phone which maintains the tune playing even after the phone has been picked up, all gentle into music and familiar tunes designed specifically not to scare the person living on their own but hopefully put off the caller and make them move on. This product is available now for mobile phones, the motion sensor is ready now and we will be sourcing a MP3 uploadable hand set mid 2016.

Website: www.purpleangelmusic.co.uk

THE SWEETIE QUIZ
all answers chocolate or sweets!

1. Definitely not before 20.00 hours
2. Voodoo in a box
3. Cow juice container
4. Floral items, could be climbing or hybrid tea
5. Single snowy deposit (messy chocolate bar)
6. This becomes you according to the song
7. This pub only sells cow juice
8. Sounds like bloomers
9. Clever little individuals (colourful round sweets!)
10. Beautiful lady from Istanbul
11. Superman, Spiderman and Batman are all these
12. Shh! Talk quietly!
13. A star cluster
14. Another star cluster
15. A planet
16. A very posh road
17. Extra terrestrials (sherbet)

Answers:
Communicating

Greetings. Do they know who you are? They may not recognise you - even though you know them well – they may only recall you as a younger person! Think about whether you need to say your name or whether a warm hello will suffice. Approach with a smile.

Physical approach Think about where the person is sitting. Are there any sight or hearing problems that will have a bearing on how you should approach them? Try to make sure that the light is on your face rather than behind you. Eye-level, if the person is seated, will be less intimidating. If the person isbe less intimidating. If the person is quite withdrawn, sitting alongside them making some minimal movement and sound may be a gentler way to strike up a conversation straight away.

Touch aware Alight touch on the back of the hand can often feel reassuring and non-threatening. If the person moves their hand away from you, take your cue from them. If the person takes the opportunity to clasp your hand this may indicate that they need more physical reassurance and support. With people who are quite withdrawn, a gentle touch on the cheek can be a way of getting them to look at you. Again be sensitive to their reaction.

It may feel like the first time the person has seen you. How will this impact on your conversation? How is this person feeling? If they have been able to speak, what do the words convey? What does the tone
of voice convey? What does their facial expression tell you? What does their body position tell you? What does their respiration rate tell you? Is there any indication that the person is in physical discomfort or pain? In dementia care - you need to listen with your eyes and your ears.

Take your lead from the person with dementia. Don’t try to switch topic too soon - or your serve won’t get back over the net. Work on what is in the foreground for them.

Consciously relax. You are likely to be moving at a much faster pace than the person with dementia. You need to be relaxed and slowing your pace. Become aware of your breathing; exhale fully, relax any bodily tension that you are carrying; drop your shoulders, unclench your jaws and stretch out.

Minimize background noise. If there is a lot of background noise; TV, music, vacuuming, or chatting then your chances of good communication are less. Close your eyes for a few minutes and listen. Can you lessen any of them?

Be open to a range of possibilities
We often go into situations with set ideas of what we want to speak about - or what we expect to hear and we try to switch the conversation quickly to the topic we have in mind. At the beginning of a communication

Think how the person may be feeling. What is their
emotional state likely to be? Are they relaxed and happy - or anxious and distressed? Are they calm or frightened? Are they likely to respond to humour or are they angry and frustrated?

When the person speaks. As word finding becomes more difficult for the person with dementia the content of speech becomes more limited. So for example a female name such as Julie may come to represent every female rather than referring to Julie in person. References to Mother, Father and home attached to a ‘feeling’ and not a literal question may help the person to feel safe, secure or belonging.

Say what you think the other feels. You have listened with your eyes and your ears to how the person is feeling. A simple statement of what you have observed will let the person know that you care how they feel. For example, ‘You sound sad right now’ or ‘You look really relaxed sitting there’. Keep it simple.

Put present and past together to understand the other’s reality. The more that you know about the key stories, people and themes of a person’s life the better you become at interpreting meaning. If you are puzzled by a response, think what the person has just been experiencing before your conversation, think about what you know about the person’s past and see if you can make a connection.
Communicating

you think they have said. If you are not sure then just feedback the key words to see if any more are forthcoming.

Don’t correct ‘mistakes’
It is often tricky to know whether to correct errors, for example when someone has got the wrong time of day or got muddled up. Be wary of your tone if you feel you need to correct the person.

Don’t shy away from tears or laughter People with dementia often lead very emotional lives. Anxiety and grief may be quite near to the surface. You may not be able to fix the cause of the anxiety or grief but seeing this through with them will help them enormously. Having a belly laugh together is a great stress reliever.

Confrontation is pointless Sometimes people will accept your point of view or explanation, other times they won’t. If they won’t, then graciously agree with them and move the topic of conversation on to something less troubling.

Little and often is usually better Finding words for things and communicating can be particularly tiring for some people with dementia. Take a break but come back again soon. Communication should be there until the end. Never assume the person cannot understand. Use repetition, gentle touch and eye contact. Use warmth, friendliness and a smile.
“PLEASE DON´T”
By Norrms McNamara
Diagnosed with dementia at just 50 years of age and Founder of Purple Angel

Please Don’t
"Mock my Dementia, I was once like you, I once worked full time to keep and provide for my family. I had so many hopes and dreams, I STILL DO!! You don’t even know me, you have no idea what I have achieved in the past and what I hope to still achieve now, please don’t mock me just for being ill, I wouldn’t if roles were reversed, you don’t even know me, please don’t mock me just because I have dementia.

Please Don’t
"Stare at me, let’s stare together at the changes that are now being made within the world of dementia, let us stare together in wonderment at how the stigma of this disease is being disassembled before our very eyes, brick by brick the wall of Stigma is coming down.

Please Don’t
"Ignore Me" I have so much to say, I have early stages of dementia, have you even heard of that? Dementia doesn’t just suddenly "Happen" it creeps up on you slowly, in stages, but if you LISTEN to me I can help you recognise the signs of early dementia so you can help your loved ones to carry on living a full life.

Please Don’t
"Tell THAT Joke” about dementia, I have heard them all, and they are not funny!! When you forget something, why do you think it's funny to say "Ha ha, I must have dementia” If you got a pain in the back or abdomen would you say "Ha ha, I think I may have Cancer”?? Dementia is a terminal disease with no cure at the moment, nothing much funny about that!!

Please Don’t
"Write us off " We have so much to give, so much to do, so many more people to meet, to laugh with, to love, to cherish. So many more grandchildren to see born and to teach the ways of the world, I am not finished, in fact I am just beginning to see life for what it really is, short, but beautiful, and so can you, if only you embrace it fully.
A useful compilation of coping tips - from a professional carer. Chantelle Merritt.

Try to avoid saying the following:

- You just asked me that.
- You don’t work anymore.
- You have forgotten again.
- Why are you doing that?
- I have already told you.
- Wait a minute.
- Stop doing that.
- You have just eaten.
- -------- is in a bad mood.
- You’re not allowed to do that.
- You can’t go out/home.
- And if all else fails try to distract!

Dementia is progressive, which means the symptoms will gradually get worse and depend on the individual and what type of dementia.

Each person is unique and will experience dementia in their own way.
It’s very important that people with dementia are treated with respect. Be kind and reassuring to the person without talking down to them.

Never talk over their head as if they are not there - especially if you’re talking about them. Include them in conversations.

Avoid scolding or criticizing them.

Look for the meaning behind their words, even if they don’t seem to be making much sense. Whatever the detail of what they are saying, the person is usually trying to communicate how they feel.

Try to imagine how you would like to be spoken to if you were in their position.

It is important to take account of abilities, interests and preferences. Dementia affects people’s thinking, reasoning and memory; but the person’s feelings remain intact. A person with dementia will probably be sad or upset at times –

A Carer must always try to explain what they are doing and why. Watch for expression and body language.

Choice can be confusing. Phrase questions so that they only need a ‘yes’ or ‘no’ answer.

Avoid situations in which the person is bound to fail. This can be humiliating.

Encourage tasks that they can still manage and activities they enjoy.

Let them do things at their own pace and in their own way.

Do things with the person, rather than for them, to retain independence.

Break activities down into small steps for a sense of achievement, even if they can only manage part of a task.

Try not to correct what the person with dementia says, the accuracy of the information is not as important as what the person is trying to express. Don’t argue!

Dementia affects each person in different ways. Some people with a dementia struggle to make sense of their feelings but can still be aware of changes in perception and experience fear.

Please share your coping tips with us, as a health professional, a relative, a carer or someone involved with those living with dementia, your tips could help someone cope that little bit better.
UNDERSTANDING BEHAVIOUR

‘There is a reason behind everything’

The person living with dementia might be feeling unheard or misunderstood - frightened, embarrassed, frustrated or annoyed because they need help to do the things they used to do independently. The person might also be in pain.

Only rarely is aggression a symptom of dementia. If aggression does occur, the most likely reason is that the person is reacting to a distressing situation or has a need that is being unmet. When we look for the message behind someone’s behaviour, we are well on the way to finding an effective response.

The important thing is to try to see things from the person’s point of view.

It might be that we can do something different straight away to respond to the person’s feelings; for example, take a walk around the garden with the person who is feeling trapped.

If we realize that a person’s aggression comes from feeling frustrated about things they can’t do now, it will be vital to discover things that the person ‘can’ still do, and encourage them to use these remaining strengths as much as possible.

We may need to face up to the fact that it was something we did – without meaning to – that brought on the person’s difficult feelings and reaction. Speaking or acting too quickly is something we can change. We shouldn’t blame ourselves - it’s important to keep learning. Think whether something early in the person’s life is affecting them now.

Understanding Emotional Needs

**Attachment/Inclusion** We all like to feel connected to someone or something, to belong to a group; to be a member and not feel left out.

**Comfort** We all need to feel comfort. We need to be warm, dry, and clean; to have a full stomach and not be thirsty; to have quiet when we want it; to have our anxiety calmed; to have a sense of tenderness, closeness, and bonding with others; Being made to wait for the toilet is not an option for us.

**Identity** We want our own identity, to be special. We want our individuality to be recognised in our food preferences, our clothing; our activities and recreation. Saying “Tell me about it” is an excellent way to reminisce together.

**Occupation** We want to help others; to occupy ourselves with ‘work’ that has meaning and purpose. (Give your loved one ‘jobs’ like folding laundry, setting the table, help with dinner, etc.)

Love Everybody needs it. To love someone; to be loved and accepted; to love an activity, a food; to love religion, self-love/self-respect.
“SUNDOWNING”

“Sundowning” is a term describing intensified agitation and confusion and usually begins late in the afternoon but can happen at other times too.

You should keep the house well-lit during late afternoon as some experts believe “Sundowning” to be a response to the change from daylight to darkness.

It is very tiring for people with dementia, coping with changes to their memory and lifestyle and dealing with a myriad of strange new thoughts and sensations. As the person becomes easily fatigued both mentally and physically this can heighten confusion and restlessness.

Being out in the fresh air, keeping active and doing meaningful activities - such as doing the daily chores together (if the person enjoys this!) can avert “Sundowning”. Singing or listening to music and the calming effect of a family pet can also be of great help. It may help to start an activity about an hour before the heightened confusion and agitation begins each day and keep the person active and engaged.

Reflections, in mirrors or dark windows may be mistaken for an intruder and cause anxiety and fear.
THE LEWY BODY SOLDIER

You can read Norman Mc Namara’s latest book:
The Lewy Body Soldier

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