

# LIVING BETTER WITH DEMENTIA



## LET'S TELL THE TRUTH ABOUT DEMENTIA!

Things you need to know



© Norrms McNamara, founder, Partner Elaine and co-founder Jane Moore

[www.purpleangel-global.com](http://www.purpleangel-global.com)

**Progressive Dementia:** Severe, emotional and mental disruption and deterioration; symptoms of crippling diseases of the brain. Progressive, meaning it will lead to death. Mostly seen in the elderly but also young onset (under 65years), which can be difficult for the person and their family to come to terms with. As brain neurons die, mental processes are altered, causing the person to experience loss of cherished memories, subtle or severe personality changes, disorientation, and reduced ability to make reasoned judgements affecting every day function.

**Age-related memory loss** is not the same as progressive dementia. Going upstairs and forgetting what you went up there for, forgetting someone's name, losing your keys or not immediately being able to remember where you parked the car in a car park, are signs of normal aging. With normal aging, the brain becomes weary, as with other organs, and slows down as the years pass. We all forget things as we get older but if you find you can't remember where you live, or that you even drove your car to town at all, then you should seek advice. Stress, depression and other illnesses can also cloud the memory.

Norman McNamara and his wife Elaine



**Welcome to Living Better with Dementia,—a 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 and Mixed Dementia, Frontotemporal dementia and many more.**

**It is important to receive the correct diagnosis as dementia can also be due to a few reversible causes such as a urinary tract infection, deficiency of vitamin B12, thyroid problems, brain injury and very rarely, a brain tumour.**

**We hope this free booklet will give you an insight into the signs, symptoms and other things that you need to know about but perhaps were too frightened to ask.**

*Norman McNamara, Elaine Waddington and Jane Moore*

# Questions to be asked at the point of Diagnosis?

ALWAYS, ALWAYS make a second appointment at the diagnosis for TWO weeks after as you will go home that night and think of a THOUSAND MORE questions to ask.

Always write down the questions you want to ask before you go in, go through them methodically and do not be hurried.

When diagnosed with a type of dementia, always ask :  
"How do they know it's that type of dementia, how has the conclusion been arrived at and how does it differ from other types of dementia?"

This is so INCREDIBLY IMPORTANT WHEN IT COMES TO MEDICATION. A variety of drugs, including anticholinergics and some antiparkinsonian medications, can worsen LBD symptoms.

Every person is different and will therefore have different symptoms but the following pages list some symptoms which you may find difficult to cope with and may need support. It is important that you think about the future—most importantly to make a Lasting Power of Attorney which covers both finances and health, update your Will and write down end of life wishes with your loved one. Solicitors, doctors, and dementia practitioners can help. Norrms

**Do you have any questions or concerns about dementia? Speak to a specialist dementia nurse on the Admiral Nurse Dementia Helpline – open seven days a week.  
0800 888 6678**



<https://www.dementiauk.org/>

Email: [helpline@dementiauk.org](mailto:helpline@dementiauk.org)

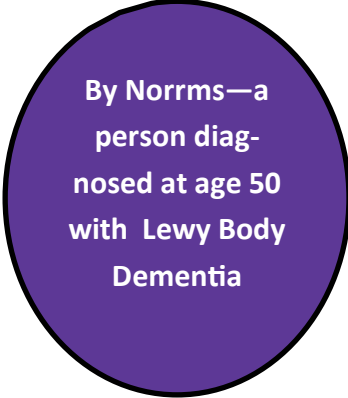
### Hallucinations

are not dreams or night terrors. Let's get that out of the way first.

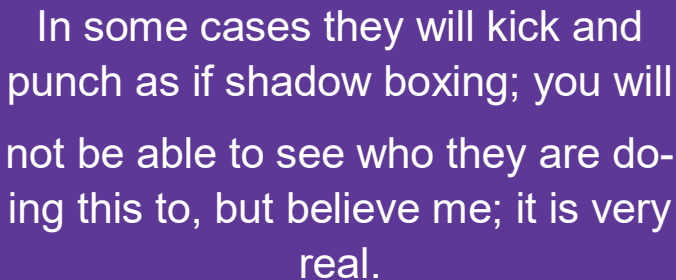
Hallucinations are usually connected with those who have Lewy Body dementia but also

those suffering from Alzheimer's and Vascular dementia due to lack of oxygen to the brain.

I will NOT apologise for using the word "suffering" because if anybody has hallucinations, as I do, they are suffering! Day or night these can happen. It may appear that people who suffer hallucinations are talking to themselves or want to chase people.



By Norrms—a  
person diag-  
nosed at age 50  
with Lewy Body  
Dementia



In some cases they will kick and punch as if shadow boxing; you will not be able to see who they are doing this to, but believe me; it is very real.

I have seen the hurt it brings when you visit a loved one and they are holding hands, or have arms wrapped around a complete stranger in a care setting and don't recognize you. You may well have been with this person a lifetime but please be aware, this happens more regularly than you think.

### **Spatial awareness:**

**Is the person stumbling? Staggering like they are drunk for no apparent reason?**

**Do they fall going upstairs as well as downstairs banging their toes on doors, beds and so on. Are they missing the step down on the pavement, or more importantly walking into the road with no fear of oncoming traffic?? The signal from the eyes to the brain is distorted and this can cause the person with dementia to see things very differently and miss the most important things.**

**Night Terrors:** Imagine your worst fear being played out right in front of your eyes. Imagine the horror unfolding in front of you, piercing screams, grotesque faces and beings, clawing at you, biting you, then multiply this by 100,000 and you have a night terror. Also, imagine not being able to wake from this as it seems never ending. Imagine this every 30 minutes of each night

**Dementia is progressive which means symptoms will gradually get worse over time but everyone is unique and therefore it is impossible to give a time span for the progression.**

**Loss of appetite:** because of that signal to the brain from the stomach and eyes not working properly, people with dementia may want to eat more than usual as they have forgotten they have just had their meal. “What if they eat a lot?” I hear you cry? “They must feel full” I hear you say but how can they feel full if the signals are not working and they still feel starving? So you see, it’s not their fault, they are not at fault at all because of this awful disease. Then there is the quandary of those not eating or drinking enough. This can be caused by many things but sometimes it is just a case of putting water into a yellow cup or container, placing a small meal on a yellow plate instead of white and doing the same with tea and coffee.

People with dementia can sometimes see right through clear glass and don’t see what’s in front of them.





### NEXT STEPS

Ask what are your next steps. Ask what support groups are out there, advice groups, memory cafes, memory groups, lunch clubs, anything going on where you can sit down with others and share your experiences.

Ask where is the nearest Carers' club, how do you join, is there a carers magazine you can be sent, or is there a dementia lead.

What happens if the carer is ill - who looks after the carer? Ask about short respite breaks and assessments for your loved one.

Find out who is the dementia lead at your nearest hospital, do you have dementia-friendly wards?

Barton Surgery  
Devon, UK



For your nearest memory café ask at your GP surgery or visit

<http://www.memorycafes.org.uk>

### *Being a carer* Elaine's Story

Working as a carer is a hard job and usually low pay. It's long hours and can be very demanding both physically and mentally. It can also be very rewarding. Carers are very special people and so often don't get the recognition they deserve, although the JOB is your choice. Becoming a Carer for a loved one is very differ-

It isn't a choice, but a set of circumstances which mean you become a carer. Many people don't even recognise themselves as carers. It took me 8 years !! It doesn't mean we don't do our best but it can be very difficult. You can become lonely and isolated. Friends stop asking you out because they know you cant go unless you find a carer for your loved one. This isn't always possible and can become more difficult and you feel it's too much hassle for the little time you get.

As a carer, you become responsible for the loved one. You may have to make decisions about the home and financial decisions. Your finances can become a problem, especially if you have to finish work to look after your loved one. Your day and night may have to revolve around them and your life has to go on hold. If you want to go out and have time to yourself you have to put carers in place to make sure your loved one is safe. When you are at work as a carer there is always someone there who can give you a break if the situation is becoming too much. You only work so many hours and then you go home. When you care for a loved one, quite often you are the only person there. During the day, if the loved one becomes agitated and upset, it's usually aimed at you.

*Some people care too much. I think it's called love.*

*-Winnie the Pooh.*

Don't take it personally, they don't mean it, its the illness. they would be mortified at some of the things if they understood. In the middle of the night when they won't sleep or are having night terrors or hallucinations when there is only you and you are tired and agitated yourself, just try and walk away (as long as they are safe) if only for 5 mins. I have locked myself in my bathroom many a time for a little space. I have been shouted at and the door banged, but don't feel guilty, we are all still only human and lack of sleep, etc. causes stress

A health professional once said to me .....

~

"Don't let *this* illness become *your* illness"

I know what he meant but its very difficult not to

The upside is, if you have to finish work, that you can spend more time together, going out and about and making each day special whilst you can. Inclusion and engagement make life easier and a good sense of humour always helps . Laugh together at things whilst doing different things but never laugh at them, always with them.

Always join groups, memory cafes, etc. and you will still be able to get the support you need. One phone call a year from professionals is not ENOUGH !! All carers need to help each other, one size does not FIT ALL

*Caring matters – YOU matter!*



*Elaine*

Ask if the FAB team (Financial assessments and benefits team – UK only) can come around and see you to help you sort out your finances.

Ask about direct payments so you and you alone decide on which carers/care company to use. Ask what OUT OF HOURS team there is and their PHONE NUMBER, you may very well need them at some point.



### **And last, but not least, REQUEST THE TRUTH ABOUT DEMENTIA**

Ask the Dr's, community psychiatrists or Consultants what will happen (unless a cure is found) during the later stages. DO NOT BE PUT OFF with "Oh we don't really know" or "Everybody is different". Ask them to tell you the WORST CASE SCENARIO, but only if you wish to. Remember you don't have too, but it's there if you want it and you have a right to know!

## Care at end of life

**Notes from Carolyn and Jenny (Guest contributors)**

**Although there are wonderful community specialist palliative care nurses there are none specifically for dementia (as Macmillan are to cancer).**

**Dementia at end of life can be frightening and very lonely. It is the carer who is often left with feelings of guilt and the death of a loved one you have cared for over many years leaves it's mark long afterwards.**

**Financially it can be devastating and hard to find professional advice. Many carers say professional care staff, despite the wonderful job they do, fail to listen to family members who usually know their loved one the best. Carolyn.**

**I think that any leaflet about the end stages of dementia needs to talk about where people might end their lives and whether quality or quantity is important. I remain convinced that staying in ones own environment with support is the best outcome. Life may not appear perfect to the outsider but life prolonged in an alien environment, as has happened to two different friend's parents, is imperfect, as is being moved against ones will into a home and dying prematurely from unhappiness.**

**I know this is very personal and not very objective but hope it's a useful thought. Jenny.**

### QUIZ—GIVE THE TITLES OF THE SONGS!

- 1) When you're weary, feeling small
- 2) Home again across the sea
- 3) Give me your answer do
- 4) Down Paradise Row
- 5) Where it began—I can't begin to tell you
- 6) Are you sorry we drifted apart?
- 7) There's an old mill by the stream
- 8) I beg your pardon
- 9) Don't know when I'll be back again
- 10) One for the money, two for the show
- 11) I want the world to know how happy I can be
- 12) Ding Dong the bells are gonna chime
- 13) You make me happy when skies are grey
- 14) Two lonely people together
- 15) Till we meet tomorrow
- 16) Silver buckles on his knee
- 17) You are lost and gone forever
- 18) I once was lost but now I'm found
- 19) Far have I travelled, much have I seen, vast painted deserts..
- 20) In Dublin's fair city

Answers on Page 17

Imagine being an "OUTDOORSY" person all your life, always out and about, walking up hills and down dales, never catching a bus, or driving unless necessary - keeping fit most of your life - then.....Dementia comes along and takes all that away.



Then imagine getting to the stage where you are in a care home, sitting in a wing-backed chair making it difficult even to see the person seated next to you. (Don't even get me going on them!!) - for hours on end, and left with only your thoughts of days when you were breathing fresh air, getting out there, seeing the sights, smelling cut grass and feeling so happy to have the wind on your face??

WOULD YOU BE FRUSTRATED????

I KNOW I WOULD!!

So much can be done to help all elderly care home residents, with little changes such as sitting someone outside when it's warm enough and making sure chairs are positioned away from the draught of open windows but bringing the fresh air in. We know there are staffing problems and as much as we would like it, we would all love care homes to take people out into the fresh air but we know many don't have sufficient staff to do this. However, a few small changes could provide a better quality of life.



*I am still this person you see now. I am still the person I once was.*

*I will always be the person I have always been.*

## **CALMING COMMUNICATION TECHNIQUES**

**By Jane Moore**



**YES**

**Using positive language can relieve stress for both the person with memory loss and their carer/family. Search out ways to empower and enrich.**

**Think about how many times you have used negative phrases such as: “You don’t work anymore!” and “You can’t do that!” Instead, think of a positive answer such as: “You were good at your job” or ask: “Can you help me with.....?” Activities must be appropriate and give a good feeling of accomplishment and joy.**

**When you need the person to be co-operative, *ask* for their help instead of telling them what you wish them to do!**



**Communicating in the right way with a person who has memory loss does not come naturally to most of us.**

**We are used to speaking plainly. You can, however, still be truthful without being hurtful or saying things which are unnecessary.**

**Instead of saying “Don’t do that!”  
say:**

**“Please will  
you do  
this?”**

**Just using words in the right way can make such a different to dignity and morale.**

**If you are at the doctor’s surgery and your loved one says: “There is nothing wrong with me”, simply apologise for not letting them know that it is just a regular check-up.**

**Be inventive but respectful. Dignity is important.**

**Using positive language can smooth the way towards calmer living. Don’t reason or confront, argue or remind a person with dementia of things they have forgotten unless they specifically ask you to do that! When memories *are* recalled don’t question them. Be glad of the recall even if the details may not be quite correct in your view.**

**QUIZ ANSWERS: 1) Bridge over Troubled Waters; 2) Sailing; 3) Daisy, Daisy; 4) Underneath the Arches; 5) Sweet Caroline; 6) Are You Lonesome Tonight? 7) Nellie Dean; 8) Rose Garden; 9) Leaving on a Jet Plane; 10) Blue Suede Shoes; 11) Congratulations; 12) Get me to the Church on Time; 13) You are my Sunshine; 14) The Last Waltz; 15) Goodnight Sweetheart; 16) Bobbie Shafto; 17) Oh My Darling Clementine; 18) Amazing Grace; 19) Mull of Kintyre; 20) Mollie Malone (Cockles & Mussels) .**

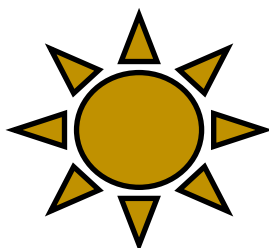
## HOME

Many people who are suffering from dementia are frightened and lonely. Many will ask to “Go home”. People with memory problems and curtailed activities of daily living experience great loss.

“Home” is the place they knew before dementia robbed them of their life skills. It is not their fault.

Talk about the things that are dear to them now – don’t push memories that have long since gone and which will simply frustrate and disappoint even more.

A touch, a smile, a reaction of empathy – not sympathy - will ease fear and worry.



Sundowning is easier to understand than you think — it does exactly what it says on the tin! As the sun goes down, the person with dementia gets worse, becomes more confused, more agitated and frustrated. Occasionally this can happen at other times during the day too. Reflections in windows as early evening falls, can appear that an intruder is trying to get into the house, so best to draw the curtains before sunset.



**You may wonder why the musical score! Music has been shown to light up more areas of the brain than most other things!**

**You can use favourite music both to calm and to stimulate. Many of our favourite songs stay with us all and words remind us of places we have been and people we have known. Happy times for many of us! Music has been widely studied across the**

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**You can use favourite music both to calm and to stimulate. Many of our favourite songs stay with us all and words remind us of places we have been and people we have known. Happy times for many of us! Music has been widely studied across the world, showing benefits which are dramatic for the care and support of people with dementia.**

**Music is the route for better communication and engagement.**

**People with memory loss seem to retain the ability to remember words of their favourite songs and music can also promote dialogue and awakening. Try an MP3 player!**



## TRUTH



I have dementia, there you go it's said,  
From when I wake in the morning until I go to bed,  
Nothing can change that, however uncouth,  
But what we can do, is tell the truth,  
Dementia is ugly, cruel, never easy,  
It enters your life it's so very sleazy,  
A silent assassin that creeps up on you,  
Without you knowing, quite what to do,  
It feeds on your memories, strength and good will,  
Eating away, making you ill,  
All that was once, real and true,  
Now so confusing, saddened and blue,  
However, you wrap it, what words you use,  
Dementia's Dementia, however, you muse,  
So let's all be honest, forthright and true,  
Let's tell the truth, it's ALL we can do

Norrms McNamara