

Listen, talk, **connect**

Communicating with
people living with dementia



**A guide for carers,
relatives and friends**

Welcome



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Foreword from Dr Nori Graham



Care UK has produced 'Listen, talk, connect' as a guide to support anyone who wants to communicate effectively with someone living with dementia. If you are

already in this situation, you will know that communication can be challenging at times. A heart-breaking consequence is that healthy, strong relationships become ever harder to maintain.

In my view, 'Listen, talk, connect' provides an excellent set of guiding principles and practical tips to get the most out of visiting someone living with dementia. The advice given here will help to keep the flow of communication going – ensuring interactions remain positive and meaningful.

I would also like to offer some thoughts of my own. When it comes to good communication, it's important to remember that the care of the person living with dementia is a team game. You, along with the professional carers and the person living with dementia, are all key members of the same team. However, your knowledge of your relative or friend is likely to be greater than that of any professional carer.

When you visit, you would probably assume that all your time should be spent with the person living with dementia. Of course, the team at the care home are likely to be very busy, but you should still try to spend some time with them, listening to them and hearing about observations they might have. Information you are able to provide, and experiences you have had with your relative, will prove very helpful to the professional carers.



There is also an indirect benefit from communication with the care home team. It is a most rewarding experience to feel listened to and appreciated by people such as you – those who know and love the person who is receiving their care.

Perhaps, given that the person living with dementia may not be able to express their feelings clearly, your feedback might be the most gratifying part of their work.

Happy and appreciated carers create a warm and welcoming environment and contribute inevitably to happy care home residents. In turn, it is much more likely everyone will have a happier time together when you visit.

Dr Nori Graham
Non-Executive Director
Care UK

About this book

by Maizie Mears-Owen



When I meet friends and family members who have loved ones living with dementia, I am frequently asked questions along the lines of "What do I do when...?", "What can

I say to...?", "How do I act if...?"

There is no easy answer to any of these questions but there is one simple fact to bear in mind: as people, we are all social beings with a basic need to communicate and, above all, a need to know that what we have said has been heard - and understood. Dementia changes many things about a person, but not this fundamental fact.

Listening is key when it comes to communicating with someone living with dementia. Not feeling listened to, or heard, can be a source of great anxiety and frustration to us all - and dementia will only amplify this. As carers and visitors, we have to listen carefully when we are talking to someone with dementia - and look for clues when the meaning isn't immediately clear.

I also know that, whatever I tell the people who ask me, communicating with loved ones can be hard at times. I tell them to always remember this: they are not alone. There are some behaviours associated with dementia that means communication will be very challenging some days - no matter how hard they try and no matter how much they know about the disease.

I tell people that they will need to be much more considered and concrete in their language, to avoid any confusion or upsetting misunderstandings. I say that visits generally flow much better when they become more aware of non-verbal communication. I help them to make sure that their body language tallies with their spoken word and I explain how someone living with dementia will read their face for clues, and watch how they act and sit to find a meaning behind their voice.

I talk them through some of the more complex aspects of dementia - that people living with the disease often express themselves in a more metaphorical way; that emotionally loaded words such as 'mum', 'dad' and 'home' actually communicates a plethora of meanings, experiences and feelings.

From here on in though, I will also suggest that they read this booklet.

'Listen, talk, connect' has been put together by colleagues and those with personal experience of caring for loved ones, with one goal: to assist relatives, friends and carers to continue having meaningful conversations and shared moments with anyone living with dementia.

My colleagues at Care UK, and I, hope you find this guide useful - and that the hints and tips are easily incorporated into your visits, enabling you to continue to connect with the people who are important to you.

Maizie Mears-Owen
Head of Dementia
Care UK

Spare a thought

I know who I am

"I am Nancy"

You know who I am

But

I may have forgotten who you are

So please introduce yourself

It is so easy and really polite

"Hello Nancy I am <your name>"

Remember that is how we did it

In the old days

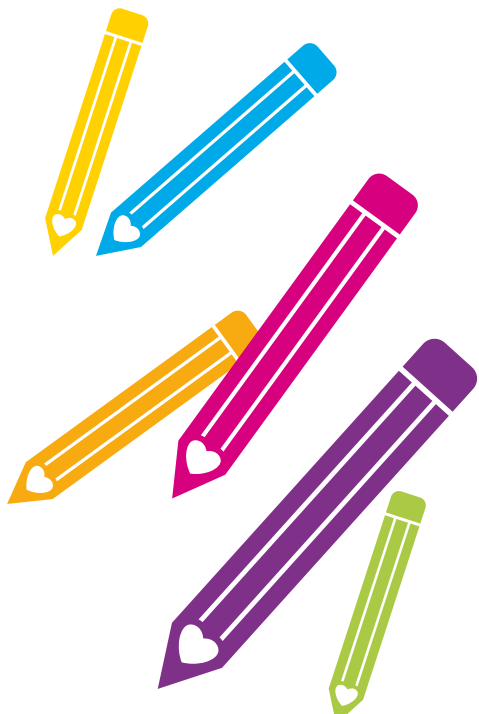
As easy as knocking on the door

Before entering

And calling "Anyone there?"

As you open the door

**By Jean Shaw, written while
her mother was living at home.
Her mother was a resident at
Kings Court in County Durham.**



“No one knows what they think or do not think, but we have to make life as ‘normal’ as possible for them, even if it is hurting us inside.

The day mum said that she did not know who I was will stay with me forever. The child she had borne and loved had become someone that visited her lots so I must be someone she knew.”

Jean Shaw

Chapter one

I wish I had known



Almost every day, somewhere in the UK somebody will say to us: "I wish I had known that before". And no wonder. Dementia, of any form, is an incredibly complex disease that doctors are still struggling to fully understand.

We know that when someone you love is diagnosed with dementia, the future seems so uncertain – so unpredictable. More than anything, people worry about how they will talk to someone struggling with the disease and wonder what sort of relationship they will be able to maintain as the illness progresses.

The truth is that communicating with someone with dementia can be very rewarding – for both of you. It can change a bad day into a good day; turn tears of frustration into tears of joy; transform fear to calm. It can make living with the illness more bearable and it can bring you close, once more, to someone you thought you had lost.

However, it can be hard at times too. The person's mind is working differently to the way we know.

It can live in moments of time far removed from the present; it can process sights and sounds in ways others can't imagine; it can forget things that were once unforgettable, yet somehow recall abstract information stored decades ago.

It is by understanding a few aspects of this disease that connecting with people living with dementia starts to become easier – and you start to help them evolve through the illness to become happier.

"...communicating with someone with dementia can be very rewarding for both of you"



Nothing is black and white

“For me, the single most important piece of information to bear in mind when talking to a person with dementia is that their perception of reality is the only one that counts. They will see things differently to you and I for a whole host of reasons – impaired vision, hallucinations and hearing problems, to name but a few. If you contradict them or argue with their statements, you may cause distress or anger.

To put it simply, if they say the wall is black when it is white, you need to accept that it is black. Try to imagine that you thought the wall was black but everyone around you was saying it was white.

You would be terrified – assuming there was some awful conspiracy, that people around you were trying to wind you up, or that you were desperately ill in some way. You would lash out in frustration or sob in fear.

This is no different for someone living with dementia. What they say they are seeing is usually what they are actually seeing. So, don't argue the point. Instead, talk to them. If they seem distressed, ask if what they are seeing bothers them - if they want to move position, if having some music on would soothe them, for example.

I have to say, that of all the things that people have told me they wish they had known before – it is this.”

Simon Jones, Head of Behavioural Services, Care UK





Living for the moment

“In my view, talking to someone with dementia is all about acknowledging who the person is –today.

A mind affected by dementia travels back in time – occasionally at first, and more often as the illness progresses. It might be the 21st century to you – but it could be 1956 to the person you are trying to talk to. So, you need to establish where the person is when you are talking to them.

If, for example, they say they want to go home, ask where home is and what it looks like. It might not be the one they have just

left; it might be the one they lived in as a small child. Talk to them about what they like about their home and what memories they have of it.

This can have the most incredible results. Rather than the person with dementia getting upset ‘because they can’t go home’, they relive some of their most happy childhood memories or the honeymoon period of married life.”

Allison Kennie, Home Manager of Paisley Court in Liverpool



“I would encourage anyone with a relative in a care home to remember that talking to their loved one is only part of the conversation.

Do everything you can to help us, the care team, to get to know our new resident. Tell us what was important to the person before they were living with dementia – what they valued, what they desired, what made them special.

Share their likes and dislikes, their favourite foods, their hobbies, jobs, interests and dreams.

This will help us to connect with your relative in a much more meaningful way.”

Esther Enwezor
Home Manager of Cherry Orchard in Dagenham





Top Tips

from Care UK colleagues
across the UK

People tell us they wish they had known that:

- **Every person living with dementia is an individual with individual needs.**
It may take time to find the best ways to connect with your loved one, but persevere and don't be hard on yourself if nothing seems to be working. There will be good days and bad days but, by following the tips in this book, you will find topics of conversation and activities that you can do together – and really enjoy.
- **Changes in behaviour are all part of the disease.** Dementia can cause people to lash out, to lose their inhibitions, to forget someone they have known for 50 years or more. It can be hard at times – but don't be offended, don't get cross and don't apologise for them in front of others. It's the dementia doing the talking – not the person you thought you knew so well before.
- **Communication isn't just about the conversation.** We can all appreciate the simple pleasures in life, whatever our state of health - such as good food, hot baths and fresh air. Sometimes, the best way to communicate with someone is to simply do something they love doing – and you like doing with them.
- **Closed questions work better.**
So, rather than ask “what do you want to wear today?” say “would you like to wear the red cardigan or the blue one?” It's little things like this that can make all the difference when communicating with someone living with dementia.

- **Do what you say you will.** To someone living with dementia “see you later” means just that. If you don’t return “later” they can get very upset – especially if they are lonely. Think about how your words could be interpreted and try to be as literal with your choice of phrases as possible.
- **Sometimes it’s best to let go.** One of the toughest things for families to cope with is the extent to which their loved one can change. However, life will become easier for everyone when it is accepted that things once so important to the relative, may no longer matter. Acknowledge and love them for who they are today.



In their shoes...

- **It helps to try to see the world through the eyes of the person living with dementia.** It’s a hard disease to understand but it’s important to know that living with dementia can make the everyday world unfamiliar, scary and unpredictable. As a visitor or a carer, you can provide reassurance not just through your words, but your tone of voice and touch. Again, communication is not just about the spoken word.

Chapter two

Making sense of it all



Many healthcare professionals are already familiar with a concept in dementia care known as ‘being in the moment’. However, for new carers, occasional visitors and relatives, this approach is not only new, it can radically change the way they communicate with their patient or loved one forever - and always for the better.

To understand ‘being in the moment’, it is important to consider how dementia affects the human brain – as it’s the opposite of what many people expect.

In the main, the dementia takes away recent memories. People living with dementia might forget what they had for breakfast, but they can remember the name of the Prime Minister. They may not recall anything about your last visit – yet they may be able to tell you the registration number of their first car, the name of their headmaster or what the weather was like on the day of their wedding.

Just understanding and ‘going with’ this can have the most incredible impact on your conversations. Remember, just because they don’t recognise you, it doesn’t mean they don’t need you. The fact that your face isn’t as they expected, doesn’t mean that they love you any less.

The fact that they are living in a different place today, doesn’t mean you can’t go there with them or that you are both alone, living in separate worlds now.

You don’t need to talk about what you did yesterday to laugh together today. You just need to find out where your loved one is, in their time, to connect once again.





In their shoes...

"Imagine being abroad - without a map and no idea where you are. You can't read the road signs and you can't ask a stranger for help as you won't understand the reply.

I'm sure that most of us have been in a situation like this at some point - and many of us would readily admit to getting angry or upset as we drove around in circles trying to find our way out of the strange city that had entrapped us.

This is how someone living with dementia can feel. They have no

reference points to go to any more and no previous memories to draw on. This is why they have started to act in a different way. They are lost, confused and anxious. It's a normal reaction to an abnormal situation.

It's also why you need to talk to them about where they are. This way, you can understand the reasons for their behaviour and reassure them - when reassurance is often all they need."

Maizie Mears-Owen
Head of Dementia
Care UK

"...talk about the period of time they are living in, right there and then"

"As short-term memories disappear, the human brain will look to fill the voids created by offering up other memories. These memories are always from time gone by so, as the disease progresses, your loved one will probably begin to live in their own past more and more.

Sometimes, people may think that they are actually the person they were 20 years ago – or more. Not many people realise that the effect of dementia can be this pronounced. This explains why they may not recognise you, that they may not understand why the petite blonde they married 50 years ago looks so different now. They may not understand modern gadgets and not like the contemporary food that is put in front of them for dinner.

Think of it like this: they probably feel just as you would if you woke up tomorrow to find it was the year 2040 – frightened, confused, lost.



So, always reassure and never challenge; always stay calm and never panic. Join them in 'their moment' and talk about the period of time they are living in, right there and then. If they are talking about their mum, ask questions about her – what she loved to do, what she wore and what made her special.

Hold their hands if you want (and if they want too) and, above all, try to enjoy that moment with them. "

Simon Jones, Head of Behavioural Services, Care UK



Top Tips

from Care UK colleagues
across the UK

'Be in the moment' with your loved one;

- **Understand that this disease is, in many ways, like all others.**

Trying to reason with the symptoms will not make them go away. So, never try to bring the person back to the present. This may cause distress, confusion and frustration when you could instead instigate hope, joy and laughter.

- **Listen and don't fear silence.**

By hanging on the every word of the person living with dementia, you will be able to get a real sense of where they are at that moment in time. Incredibly, words that once seemed nonsense to you, will make some sense now.



- **Help your loved one to be happy in the time that they are living in.** If they are talking to you about their brother and how he fell off his bike, chat about their childhood, or if they are describing their wife on their wedding day, ask them more about that special moment.
- **Try to avoid saying “do you remember?” or “you remember me, don’t you?”** This is many people’s natural first reaction. Instead, ask simple questions to understand where they are at that moment, and what they are comfortable talking about.
- **Go with their mood and don’t try too hard to change it.** If your loved one is having a good day, take full advantage - suggesting a trip out or a walk in the garden. If they are not having such a good day, don’t blame them – or indeed yourself. Allow the person living with dementia to set the agenda.



Chapter three

Starting a conversation



People tell us that, from time to time, they just don't know how to start a conversation with someone living with dementia. Sometimes, it's a son who misses talking to his able, active father about their shared hobbies. Sometimes, it's a former colleague who makes occasional visits to see an old friend for a catch up, yet can be lost for words.

We promise you this: that in almost every instance, it is possible for the son to shout about a football match with his father on a Sunday and for two old friends to catch up

about the old times on Thursday evenings, just like they used to, over a pint at the pub. It just comes down to knowing how to strike up those longed-for conversations.





“To help families to reconnect, we encourage staff and visitors to use themed (memory) boxes to prompt comfortable discussion and activity. These are so simple yet have some truly amazing results.

In the case of the son mentioned, he could go through the loft, trawl eBay, call in favours from friends and family (even clubs themselves) and create a football-themed box.

Anything from yesteryear would go down well. If the son could get his hands

on old match programmes, a team scarf from the 70s, photographs of key players from his dad’s ‘era’ - they would soon have plenty to talk about. Each week, he could download or buy a DVD of a key match and they could watch it together over a cup of hot Bovril.

I can’t tell you how much joy this would bring to both of them. Dad could be in ‘his moment’ while the son would have an incredible trip down memory lane.”

Esther Enwezor, Home Manager of Cherry Orchard in Dagenham



“In the case of the former colleague, he can make a bigger impact on his friend’s wellbeing than he could ever imagine.

To give an example, I helped to care for a wonderful gentleman who was living with dementia. His main carer was his wife and he came to us for day care, but really struggled to settle at first.

Desperate to find ways to connect with him, I contacted the firm he worked for as an engineer and asked if they could send us any old brochures and photographs.

As it happened, the company remembered the gentleman well and went the extra mile. Within a week, a big envelope arrived at the day centre, packed full of brochures, posters, photographs - even memos he would have received over the years.

Better still, a former colleague then started to visit him, taking him for drives to places they had once visited together in a work capacity.

As a colleague you could do what I did - contacting their old work place, searching the internet for archive images and going to the library for old books and newspaper articles. The list is endless.

The subsequent themed box or book would help them to strike up conversations easily. They could talk about who else they worked with and for, their greatest triumphs at work and their happiest memories.”

Paulette Scott,
Day Club Manager in Suffolk





Top Tips

from Care UK colleagues
across the UK

Unlocking memories

- Remember, the three most important themes to focus on when preparing a life book or themed box are home, work and family.
- Don't spend a fortune on leather bound books and beautiful boxes – get a shoe box and cover it with images that are meaningful to your loved one.
- “Often, a person living with dementia will find it easier to remember and talk about things if they are shown an image or object. However, the pictures or objects don't have to be directly related to people or events in your loved one's life. If they were once a fireman, a picture of a fire engine will be enough to bring memories flooding back and to get the conversation flowing.”

Pam Purnell, Home Manager in Suffolk



"There are endless things that can spark conversations..."

- Think about using pictures from when the person was younger.
- Never send in original pictures to a care home. They might get lost or damaged. Send in copies and laminate them too – if you are able.
- As important as images are, think wider than just pictures for memory boxes. There are endless things that can spark conversations such as:-
 - badges and medals from youth groups, military services or professional bodies
 - tickets and programmes from sporting or theatrical events
 - trinkets from family holidays
 - items from hobbies such as fishing floats, golf balls and stamps.
- Memory books and themed boxes needn't cost a fortune. Use YouTube to find old TV adverts, go to the library and find history books of the local area, the cars they once drove, the places they once visited, the clothes they once wore.
- Use your imagination and you can have as much fun compiling a memory box as you will have talking about it.

- "Talking photo albums, available on Amazon, are incredible. You can record a message from the people in the photographs – perfect if you want to maintain a conversation with a loved one but live too far away to visit every week."

**Mitch Lloyd,
Home Manager
of Kings Court
in County
Durham**



Chapter four

Having a conversation



Not every conversation with someone living with dementia can end with a trip down memory lane. Sometimes, there isn't time to pore over a memory book because there are meals to cook, clothes to sort through, shopping to put away, or an important appointment to get to.

By following a few simple tips, it is still possible to hold meaningful conversations with your loved one – and to avoid a rushed exchange ending in tears of frustration or disappointment.

We asked our colleagues to share their years of experience with us and give practical tips for carers who need to make themselves understood when their loved one is easily confused; for nervous visitors who want to communicate confidently with their friends and for anyone who wants to make a positive difference with their words and deeds.





"it gives the person a real sense of purpose and direction"



In their shoes...

"It may help carers, relatives and friends to think of the disease as being like stuck in traffic. You know exactly where you want to go but you just can't get there. This is frustrating at the best of times, but imagine if this is what you faced – every day.

It's no wonder that people living with dementia feel disorientated and adrift – and it's no wonder they tend to follow their carers around. They need someone to show them the way.

The good news is that carers and visitors can put things in place to

ease those feelings of being lost and helpless.

They can give the person living with dementia a meaningful task to focus on such as doing a crossword, polishing the brass or watering the plants. This gives carers time to make a cup of tea, do some online shopping or make an important phone call. Equally, it gives the person a real sense of purpose and direction when they would otherwise feel quite lost."

Maizie Mears-Owen
Head of Dementia
Care UK

Practical pointers

"It's important to understand that we have to change our communication style to meet the needs of someone living with dementia as they are unable to change theirs.

The language you use should be clear and straightforward without being patronising.

Practically, this means avoiding irony and sarcasm. For example, don't say "lovely weather isn't it" when it's pouring with rain. The irony will be lost on someone living with dementia. Say it like it is instead.

It also means avoiding terms that have crept into our language over recent years. Telling your loved one that you "just googled TV ads on your iPad" to find the Pears advert from the 60s will be utterly meaningless and horribly confusing for them. Just say that you asked friends for help.

Finally, try to encourage people living with dementia to retain some independence. It would be better, for example, to say "would you like a cup of tea?" instead of "let's have a cup of tea". It is a small point but then small things can make a big difference to people with dementia."

**Angela Marshall, Dementia Specialist
Care UK**

"...small things can make a big difference to people living with dementia."



"Many carers feel guilt when spending time away from their loved one, but it's important to make time for yourself. For example, for a husband whose passion is rugby you could play their favourite match over and over again; it might be the only thing that keeps him occupied. There is absolutely nothing wrong with that.

Each half would give you time to make dinner and at half time you can enjoy a cup of tea together while he delights in telling you about the match he just watched. I can't think of a better way to enjoy a couple of hours – each doing what you need to while creating a positive conversation to share."

Maizie Mears-Owen



Angela Marshall: "One of the most important tips I can share is this – don't talk about a person in front of them, however innocent your intentions.

I have worked with hundreds of people living with dementia and while many of them have struggled to talk to me, most have understood me very well indeed."

"It is very hard for people living with dementia to communicate as well as they once did. It's one of the symptoms of this disease, unfortunately.

What many people don't realise is that what sounds unintelligible to you makes perfect sense to your loved one. This is another effect of the disease.

Always bear this in mind and don't admit that you don't understand what the person is saying. Make it clear that you are listening; that they have your full attention. It can be hard, but be patient, retain eye contact, don't fidget, but nod in agreement when it is suitable. Put yourself in their shoes if you can and understand that it is the disease doing the talking, not your loved one."

**Gráinne Wokes, Home Manager
of Jubilee House in Godalming**

*"it is the disease
doing the talking
not your loved one"*





Six suggestions for comfortable conversations

1 **Avoid talking across people which can happen at larger family gatherings or when several people visit at once.**

Try really hard to involve those living with dementia in all conversations, encouraging them to make the critical decisions such as where you should all sit, what you should drink or eat, or what you should do together.



2 **Be aware that you may have to listen to the same stories, questions or concerns over and over again.**

As tough as it can be to accept, this is how dementia affects the brain. For your part, always react as though you are hearing the subject for the first time. You might find that your familiarity with the topic makes it easier to think of helpful responses in advance.



3 **Express one idea at a time.**

Bombarding someone living with dementia with several questions at once, or reeling off a list of all the things you have done since your last visit, is just too much for a mind affected with dementia to absorb. Tell stories in bite-sized pieces and the conversation will be much more rewarding all round.

4 Give the person living with dementia plenty of time to get their message across and judge from their reactions if they would like you to help them make their point.

If your loved one seems comfortable talking, then let them carry on for as long as they want but, if they seem distressed, it might be a good idea to lend a hand.



5 If their words make no sense, try to look for a meaning behind them. For example, if they are talking about their father a lot at the visit, talk about their childhood and the memories they can draw on at that time.

6 Keep questions simple and straightforward.

For example, rather than saying “what would you like for breakfast?” ask “would you prefer some toast or some porridge this morning?”. Even better, hold the options up too as this will make choosing even easier.



Chapter five

Making the most of your visit



Whether you are visiting a loved one in a care home every day, or visiting an old friend once in a while because you miss seeing them over the garden fence, making the most of that time together is vital.

Maybe you are wondering how to fill the hours you spend together every week, or maybe you don't know what to expect when you arrive at the home as it has been so long since you last met.

Whatever your worries, there are simple steps that you can follow to make the most out of every visit.



1

It's all in the timing.

Try and visit in the middle of the day. Evenings can be quite difficult for residents in care homes as they often become tired and agitated. Neither of you will get the most out of a visit at the end of a day, so avoid that slot if you possibly can.



2

Call ahead. The last thing you want to do is turn up to a home with a jigsaw puzzle to do together when your loved one doesn't want to get out of bed. Ask the staff what to expect and you can come prepared.

3

Think about how best to greet your loved one.

As dementia progresses, and the person spends more time living in the past, they will probably respond better if you use their most familiar name. Being called Dad or Grandad might confuse them so you may have to get used to using their first name if that puts them at ease.



4

Let the person living with dementia lead the way at the visit.

Ask them if they would like to sit in the lounge or their room; if they would like tea or coffee; if they would prefer to have a stroll around the inside of the home or the outside. They need to feel valued and independent.



5

Try to turn off background noise.

Loud environments can be disorientating at the best of times but for someone living with dementia, being confronted with a blaring radio in one room and a loud television in the other can be especially confusing.





6

Take along a four-legged friend. The positive benefits of stroking a dog cannot be over-estimated – and are even more beneficial for someone who has perhaps lost some of their communication skills.

7 **Go outside.** “Outdoor and nature-based experiences form some of our strongest emotional memories. Older people will have spent a large part of their childhood and early lives outdoors, whether through play or as part of travelling to school and work. Dementia leads to a loss of factual recall but emotional memories stay intact for much longer.

By providing experiences that are outdoors or nature-based, there are many opportunities for reminiscence. Exploring this part of a person’s life history can provide new information about likes and dislikes and, in turn, promote wellbeing by finding meaningful experiences.”

Neil Mapes, Dementia Adventure



8

Have a duvet day.

Snuggle down to an old film with popcorn and a choc ice.



10

Bring some jobs that need doing.

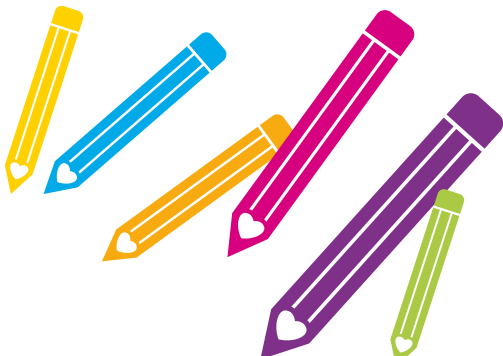
Maybe you have got some peas that need shelling or some flowers that need arranging. This will give them a real sense of purpose and give you both something to talk about.



9

Bring someone along to your visit - even if they can't make it in person.

Get them to record a video message, write a letter, send some pictures or speak over Skype.



11

Do a project together

that you can pick up on every visit - like knitting a scarf, following a tapestry project or making a collage. You will both have something to look forward to then.



12

If you both used to read the papers over breakfast or on lazy Sunday mornings, carry on doing just that.

Take two copies of the same newspaper so that you can talk about the articles that interest you both.



13

Play a game. It's easy to think that just because someone isn't communicating well that they can't play Scrabble, or bridge or whist. You might just be surprised!



14

Take some time out.

"We believe in 'Hush-No Rush' when it comes to

visits and encourage our visitors to have 'quiet time' – looking at letters and photos, reminiscing about times gone by. These create some wonderful moments."

**Esther Enwezor,
Home Manager of
Cherry Orchard in
Dagenham**





15

Just be there.

“Even when there is no verbal communication, just sharing a moment as husband and wife is so important. We have many partners visiting us every day and sometimes they just sit together in the garden or help their loved one to take a bath or shave.

Other times, they plan something special – like asking the chef to cook a special anniversary meal. The point is, they are there for each other and that’s what counts.”

**Katherine Foley, Home Manager
of Tall Trees in Colchester**



Visiting with children

People living with dementia respond very well to children, so never feel that you should leave your child at home when planning a trip to a care home.

Here are five things you can do with children to make a visit especially rewarding for young and old alike.

1

Call ahead and see if there is going to be a particularly good day to visit with your child. Maybe they have animals visiting or have a baking class the child could join in with. It's definitely worth asking.



2 **Whenever you visit, pack plenty of toys – but leave the noisy ones at home.** Search out any toys that the child and the resident can enjoy together like completing a jigsaw or sharing a book. The traditional fairy tales like Jack and the Beanstalk and Cinderella would be particularly worth bringing along.



3 **Take some sweets** for the resident to give to their youngest visitor. Who doesn't like grandma's sweetie tin?



4 **Ask the child to make something** for the person they are visiting – a picture, a cake or model all go down well.



5 **Get out in the garden.** Have a look at what the gardening club has been up to and see if the family can help with any dead-heading, weeding or tasting!



Chapter six

The unspoken word



As language becomes less useful to people living with dementia, so other means of communication become more important. That can be touch, sight, taste or sound.

It's important to remember that people living with dementia will recognise the meaning in your voice long after the words have lost their meaning. They will read your facial expressions and will understand interest, respect, reassurance, humour, kindness and love – and they will also recognise frustration, impatience, fear and anger.

So, don't just choose your words carefully when communicating – watch your body language too.

Touch if they want to be touched; respect their personal space if they want to be left alone.

Remember, if your loved one doesn't speak to you, it doesn't mean they don't want to listen to you.

If they no longer go to hug you, it doesn't mean you can't go to hug them.

If your words are misunderstood, don't give up – just use cues and clues to deliver your message too.

“As a carer, communication and listening is so important, it's not just words, it's watching body language and actions. We can tell if an activity is working if our club members are taking part and most importantly are happy, smiling and laughing.”

Elaine Carruthers
Manager of the Orchard Centre
in Epsom

Sight

Try supplementing your words with pictures, diagrams, simple sign language, and facial expressions - giving visual choices whenever you can (holding up a choice of jumpers for them to wear, for example.)

Give your loved one visual clues too – if they are going on a trip, lay out their outdoor clothes and show them a photograph of the person they are going to be visiting. If you are a carer and your patient gets distressed at bed time, set out their nightwear and toiletries, close the curtains and put on your own pyjamas well before telling the person living with dementia that it's time for bed.

“Communication isn't just words. Non-verbal communication is so important to someone living with dementia. There are lots of things that visitors can do to make communicating easier – like maintaining eye contact, having a smiley face and, above all, relaxing.”

**Allison Kennie, Home Manager
of Paisley Court in Liverpool**



Sound

Just as you can give your loved one visual clues, you can give them audio clues too. Clatter the plates around when preparing dinner and they will know that food is coming; play the same piece of music at the same time every day and they will understand that it's time for a rest.

Remember that simply listening to a familiar voice can have an incredibly powerful calming effect. When the words have run out - try reading to your loved one, especially from books with rhythmic patterns like hymns and poems.

However you communicate, always keep the background noise to an absolute minimum. What is an annoying background hum to you can be an extremely distressing din to someone living with dementia.



“Singing really helps. I have worked with people who were completely confused and really struggled to make themselves understood. In many of these cases, when we encouraged them to sing, they could get their words out. We could tell if they were distressed, we could find out why and then we could do something about it. Singing is an incredibly powerful tool when it comes to communicating.”

Allison Kennie



Touch

Physical touch can be a really effective way of communicating – but never force it. A once formal man might become more tactile as his dementia progresses whereas a once affectionate person might become ever more stand-offish. Be as tactile as the person wants you to be – not just how you want them to be.

For most though, physical touch can have a very calming and reassuring effect and offering something simple like a massage or manicure can be an easy way to achieve this.

So, take along some hand cream or Moroccan oil on a visit and unleash your inner beautician!

“People living with dementia are often physically isolated, so touch is exceptionally important for most. Hug them or hold their hands when you are talking and you will significantly improve their quality of life. The effects can be that extreme.”

Esther Enwezor, Home Manager of Cherry Orchard in Dagenham

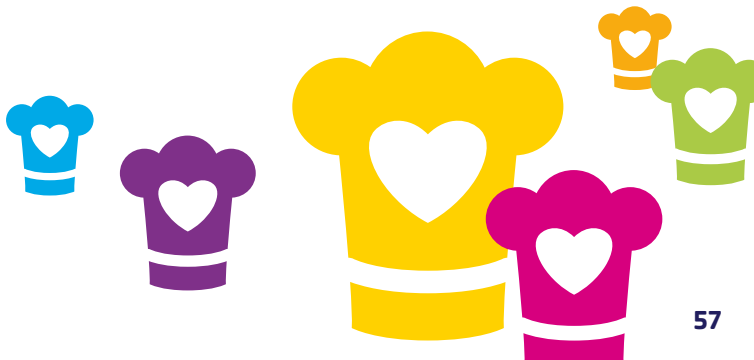
Smell and taste

Scents and tastes can have so many benefits – from evoking happy memories to having a relaxing influence. Try burning scented candles and guessing the smell together, sniffing flowers in the gardens, doing a spot of baking, tasting fruit with your eyes closed or putting on a perfume you used to wear.

"Scents and tastes can have so many benefits"

"Last year we created a sensory garden with all kinds of vegetables and herbs for residents and their families to enjoy and it has been especially beneficial for those living with dementia. For many, the scents of all the herbs and tasting of the freshly grown vegetables has had a calming effect. If in winter you are not able to get out and about, also think about bringing nature indoors to continue to evoke the senses."

Rita Matuseviciute
Activities Team at St Vincents House



Chapter seven

Coping with difficult conversations





However good you are at communicating with people living with dementia, and no matter how hard you work at retaining your relationship with your loved one, there will be times when the disease takes over.

Dementia can damage the part of the brain that affects personality. It can cause people to act in ways that aren't morally or socially responsible. It can cause hallucinations and it can wipe out memories built up over years. It is important that you are prepared for these times – and don't blame yourself or your relative when the dementia takes control for a while.

Difficult conversations, caused by dementia, usually take two forms – either your loved one becomes angry or they forget where they are in time, asking to see people who are no longer with us.

You can't stop these moments from happening altogether but you can make them easier to cope with.



1

Try not to take any changes in behaviour personally.

Your loved one can't help the way they are behaving so you certainly can't either. It's important to try to understand the cause behind the behaviour, so you can approach the situation differently next time.

2

Try not to overreact.

Anger might seem really extreme to you but it's probably just your loved one trying to make their point physically, as they can no longer express themselves easily in words. A banged table might just be a way of showing slight impatience or frustration.

3

Stay calm. This isn't the time to try and convince your loved one that you are a close relative; that

they are imagining things; that they are unwell. It's time to listen to them; to look them in the eyes; to ask them closed questions to understand their concerns; to lead them to a quiet place; to hold their hands; to speak slowly and softly; to nod as they speak; to take their complaints seriously, even if they have no logic; to give them a task to do to distract them from their worries. Do whatever you can to reassure your loved one that everything is alright.



4

Validate their feelings.

Validation techniques are something that professional carers use to cope with difficult conversations.

"If a lady in our care is looking for her husband, who died several years ago, we don't tell her that he is dead. That would just reignite the grieving process. Instead, we ask her to tell us about her husband. We ask "what was his name?", "how did you meet?", "did you have any children?", "where did you get married?" The effects are quite remarkable. It can help to distract from the anxiety of feeling alone, it can help to bring back memories and it can evoke moments of lucidity."

Denise Findley, Home Manager of Hadrian Park in Billingham

"If your loved one wants to go home and that is not possible, ask them questions about their home - "how many bedrooms did your house have?", "did you have a garden?", "who were your neighbours?" They will be able to answer these questions and, in doing so, will bring back some very happy memories. Compare this to "Don't be silly – this is your home now. You have to stay here." One causes anger and upset, the other peace and calm."

Katherine Foley, Home Manager of Tall Trees in Colchester



And finally... **look after yourself.**

Caring for someone living with dementia can be rewarding at times - but it can be hard too. Make sure you have some time for yourself, don't expect the impossible and do consider joining some support groups, calling on experts for help and asking friends and family members for their support too.

By sleeping at night, eating well, having a life outside of dementia care and having a support network, you will be able to communicate much more positively with the person you love. And that will make such a difference; a difference to you both.



Further information



For more information about Care UK and our homes and services, visit our website [careuk.com](https://www.careuk.com).

You will also find a series of free guides to download, offering advice on caring for someone living with dementia, respite care and advice on choosing a care home.

'As Easy as ABC' is a guide produced by Care UK. It gives 100 hints and tips for activity based care and is for carers, relatives of residents and visitors to our homes to help them work with residents to get the most out of each day. To download your copy visit [careuk.com/abc](https://www.careuk.com/abc) or email RCSmarketing@careuk.com with your postal address for a free copy.

Many care homes will have links with local charities that support both people living with dementia and their carers – ask your nearest home for more information and contact details.

A number of our homes hold regular support sessions for family carers through their 'Friends of' groups, dementia cafes and drop-in sessions. All are welcome at these groups – please just ask your nearest home for more information.

Nationwide we run dementia awareness events. Please visit [careuk.com/dementia-events](https://www.careuk.com/dementia-events) to find out what's on at your local Care UK care home.

For more information on funding your own care visit [careuk.com/choosing-funding-care](https://www.careuk.com/choosing-funding-care) or go directly to the Department of Health website for an explanation of personal health budgets at www.gov.uk.

Other sources of advice and support

Health and social care professionals can offer information, advice and care to people with dementia and their carers. The services available and how they are organised vary by area. For more information on what is available locally contact your local social services department or GP surgery.

Here are a few other organisations that may be able to provide help and advice;

Age UK

Age UK has been helping older people across the UK for more than 60 years.
ageuk.org.uk

Alzheimer's Society

For support, information, advice and local services for those looking after someone with dementia.
alzheimers.org.uk

Care Quality Commission

The CQC is the health and social care regulator for England.
cq.org.uk

Carers UK

Offers advice on benefits and services available to carers.
carersuk.org

Dementia Action Alliance

Supports communities and organisations to enable people to live well with dementia.
dementiaaction.org.uk

Dementia Adventure

Connecting people living with dementia with the outdoors.
dementiaadventure.co.uk

Dementia UK

Family carers and people living with dementia are at the heart of what they do.
dementiauk.org

Guide 2 Care

A resource for carers of elderly people.
guide2care.com

The Princess Royal Trust for Carers

Provides support for carers at carers' centres around the country.
carers.org

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