

Aged Care

Communicating and connecting

Creating meaningful engagement
with people living with dementia



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About dementia

There are currently more than 320,000 Australians living with dementia and this number is expected to increase to almost 900,000 by 2050.¹

Dementia is a broad term which describes a set of symptoms that develop as a result of damage to the brain. The symptoms typically include memory loss, difficulty communicating, confusion and loss of reasoning abilities; all of which change a person's ability to cope with such disabilities. Dementia is a progressive condition, where the symptoms gradually get worse over time. There are many different forms of dementia including, Alzheimer's disease, Vascular dementia, Frontotemporal Lobar dementia, and dementia with Lewy bodies. Dementia is more likely to affect people over 65, but can also affect younger people too. Later in their journey of living with dementia, the person may become unable to do everyday tasks and will need increasing amounts of care and support. Early diagnosis of dementia is important. It can help you and the person with dementia have access to medication that slows down the progression of the condition; receive counseling, advice and support; and give you the time to plan and make important decisions about the future. If you're worried about someone and their memory loss, it's important to see a GP as soon as possible.

Bupa Aged Care is one of Australia's leading providers of dementia care. Combining experience and expertise to provide safe, comfortable and stimulating environments for more than 6,000 residents, approximately 70% of whom are living with dementia.

Bupa's expertise in dementia care includes an innovative 'Person-First' approach, where care revolves around each person's own needs, not fixed rules and routines.

¹ Source - <https://fightdementia.org.au/news/g8-summit-increasing-dementia-research-funding-to-find-a-cure>

Introduction

Communication is vital to our lives and our relationships. It is so much more than just a way to deliver factual information – it is the way we express what we think and how we feel. Losing the ability to communicate is one of the most debilitating and isolating things that can happen to a person. Watching someone lose the ability to communicate can be just as distressing.

For people living with dementia and for their carers or those close to them, communication can be a daily struggle. Dementia is a progressive condition, and as it progresses, it increasingly affects a person's ability to convey their thoughts and feelings. The inability to communicate can leave families, friends and carers feeling that there is a great emotional distance between themselves and that person. As the changes they see in that person become more acute, carers of people living with dementia need to be adaptable. It is one of the hardest things to accept that what worked for Mum five years, five months, or five days ago, may now be met with a blank expression or a lack of understanding. But to give people with dementia quality of life, it's very important that we can recognise when change is needed to better support the person we care for; this includes the way we communicate.

There is no 'silver bullet' to cure people with dementia, but it is a condition where if support is provided in a sensitive way, it is possible for people with dementia to live well. It is vitally important that as a carer, you have a sense of what to expect. You are then best placed to feel that you are doing all you can.



**Professor
Graham Stokes**
Director of Dementia
Care, Bupa

Using this guide

This guide has been designed for the families, friends and carers of people living with dementia. Whether the person is at home or in a care home, each section of this guide will provide practical tips on how to communicate with the person throughout their journey of living with dementia, advising you on steps you can take to connect with them, and to help them have a good quality of life.

For ease of use and to help you navigate the dementia journey, we have divided this guide into four sections; giving examples of how the condition changes as it progresses. It's important to realise that the speed at which people progress can vary considerably and that the condition will manifest itself in different ways for each individual.

A person's journey of living with dementia commonly includes:

Memory loss and confusion: Usually happens early in the person's journey. This is when they will become anxious about what's happening to them.

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Changes in how the person is acting or behaving: Their confusion will increasingly manifest itself in 'different' or 'odd' actions or reactions, this can be challenging to respond to.

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Changes in the person's ability to understand the here and now: As the condition progresses, the person with dementia will begin to retreat into the safety of their established memories and have trouble understanding and comprehending what is happening in the here and now.

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Physical frailty and dependency: As the person reaches the end of their journey of living with dementia, the person becomes frail and increasingly dependent on others for care and support both emotionally and physically.

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Memory loss and confusion

Memory loss, and the subsequent ‘not knowing’ and confusion it causes, is usually one of the first signs of dementia. At this time in their journey, forgetfulness and disorientation can often lead to anxiety and frustration, where the person with dementia is aware something is wrong, causing them to begin to feel they are no longer in control of their own lives.

It is important to note the difference between common moments of forgetfulness which happen to everyone, and more concerning signs of ‘extraordinary forgetfulness’, which could be indicative of early dementia. For example, while it is common for someone to mislay their keys, it is more concerning if someone begins to forget meaningful information, such as the names of close friends. Common characteristics of people who are experiencing this early memory loss include confusing everyday tasks, such as storing food in the cooker instead of in the fridge, as well as muddled language, such as using the wrong word at the wrong time. While you may find that conversations still flow relatively well at this time, there are some simple things you can do to help the person with dementia feel that they are in control and to reduce any anxiety they may feel when they confuse words or forget simple things.



“ While it is common for someone to mislay their keys, it is more concerning if someone begins to forget meaningful information, such as the names of close friends. ”

Here are some tips on communicating, which you may find helpful:

Keep it simple and focused on what's important

Dementia isn't just about memory. It can also affect a person's ability to reason, to process information, and to learn. This means the person with dementia may not only have problems recalling words, they may also take longer to understand.

- Try to speak slowly and distinctly, using clear and simple words.
- Where possible, keep conversation brief, as it's very easy for people with dementia to lose the thread of the discussion if you talk for too long, and this can lead to frustration for both of you.
- Try not to ask open questions, as this can be confusing for someone with dementia. All questions should have a direct yes or no answer, or lead them to the answer. For example, instead of asking "What would you like for lunch?" ask "Would you like a cheese sandwich?"
- Speak as clearly as possible and use 'real names' for people and objects rather than words like 'it', 'she' or 'them'. This will help the person with dementia to keep a hold of the thread of conversation. For example, instead of asking "Do you like it?" ask "Do you like the cake?"

Try not to ask open questions, as this can be confusing for someone with dementia.

Be patient

- Try not to finish the person's sentences for them. If you can sense they are struggling to find a word, you could ask a question which might provide a helpful prompt. For example, if they are saying "I want to go... I want to go...", you could ask "Do you want to buy something?" The prompt should always take into account the context. Has the person put their coat on, or are they hovering by a door? Is it a time of day when they usually do something?
- Never say "I've told you this before." It's important to remember that if the person starts repeating themselves or asking you the same question, it's likely they have simply forgotten they have asked you before, due to the memory issues associated with their condition.
- Give the person time to respond, and while it may be hard at times, try not to get angry or frustrated if they don't understand.

Even simple things can make a big difference

- Try to remove distractions such as TV or radio when you are trying to communicate.
- Face the person and use their name, to ensure you have their attention.
- One-to-one conversations will be easier, but if you can't avoid a group situation, try to ensure only one person speaks at a time.



Reduce anxiety

- Remember that as the person with dementia's short term memory worsens, they are likely to feel anxious, confused and self-conscious. If they get muddled, or begin to say things you know to be incorrect, try not to directly contradict them or correct what they say – this will only increase their feelings of confusion. Instead, it is more productive to accept what they say as their idea of the truth, and move the conversation along.

For example, if your mother is convinced she has passed on a message or given you a letter to post, but you know she has definitely not, don't make a big issue of this. Instead, make light of it and move the conversation on:


“Do you know I'm so scatter brained nowadays I can't remember. I must be doing too much. Do you know, only yesterday...”

“ If they get muddled, or begin to say things you know to be incorrect, try not to directly contradict them. ”

Changes in how the person is acting or behaving

As dementia progresses, difficulties for the person living with the condition increases and becomes more marked. This may manifest itself in obvious physical signs, such as an unkempt appearance or weight loss (people with dementia often forget to eat). It could also become evident in changes to the way the person acts and reacts to people and situations; they may become distressed easily or appear angry, which is often as a result of feeling frightened or frustrated. The person with dementia may need more support to help them manage their day-to-day living, for example, needing reminders to eat or wash.

People living with someone with dementia, may also notice more subtle changes, such as walking about in the middle of the night or erratic eating habits. It can be distressing to see such changes in that person, and feelings of frustration are not uncommon for those caring for someone with dementia. It can be very hard, but understanding that their actions may be the result of upset, feelings of insecurity or an attempt to tell you what they need or want, is the key to understanding and communication.



“ Many people living with dementia have no concept of time. If they don’t appear to be willing to communicate with you at that moment, or want to do something different, don’t push them. ”

Here are some tips that may help to deal with communication when a person is at this time in their journey of living with dementia:

- **Help the person retain control**

Think about tasks and activities they could do which will help them feel valuable, such as everyday jobs they used to do and enjoy. Are there jobs they could help with around the house? Peeling vegetables before dinner, or perhaps some dusting?

- **Give clear and helpful instructions**

When a person with dementia is becoming more deeply affected by the condition, consider how you can help them to maintain control through simple, effective communication. You may find that seemingly straightforward requests, such as “Please make me a cup of tea” can cause significant frustration for the person with dementia, whereas making the tea together, with clear instructions, can give them back a sense of control. For example, “Fill the kettle with water”, “Boil the kettle”, “Get a tea bag from the cupboard” etc.

- **Be flexible to their world**

Many people living with dementia have no concept of time. If they don't appear to be willing to communicate with you at that moment, consider whether they have just woken up, or have been awake all night. Perhaps they are simply tired, and not in the mood to talk, or want to do something different such as rest or watch TV. It's also worth remembering that even if you get no response from the person with dementia, it's important not to speak as though they weren't there as this can make them feel frustrated, devalued and ignored.

“ Seemingly straight forward requests, such as “Please make me a cup of tea”, can cause significant frustration for the person. ”



- **Know when to walk away**

If someone becomes angry or threatening, take a deep breath and walk away. Remember it isn't easy to live with dementia. You can always go back and try again in a moment's time.

- **Have someone to support you**

As the condition of the person with dementia starts to change, it's important to have someone to share your concerns with. Having someone to share the caring experience and give you a break from time to time is incredibly valuable.

Make sure you have a family member or friend who you can confide in. You need to look after yourself.

- **Don't hide dementia**

You may find it helps to keep friends, colleagues or other family members regularly updated about the condition of the person with dementia, so they make allowances and are more accepting of them even when they act in ways that appears to be unusual or strange.

“ Supporting a person living with dementia means we see how they are acting, reacting or behaving as a form of communication. If we listen with our eyes as well as our ears, understanding will follow. ”

Margaret Ryan

Head of Dementia Services
Bupa Aged Care



Changes in the person's ability to understand the here and now

At this time in their journey, the person living with dementia may start to lose their ability to understand the here and now, or even on reality as you know it. As they become more confused in their day-to-day lives, the person with dementia may begin to retreat into the safety of established memories. They may also become confused by familiar faces or places, mistaking their daughter for their wife, or thinking they are in another place or time.

This can be particularly hard for carers as the person with dementia becomes more dependent, and loses awareness of the world, people around them, as well as any understanding of their condition. As the person becomes increasingly reliant on you, it's common to feel isolated; communication at this time is more important than ever. Family, friends and carers of people living with dementia can also feel distressed when the person asks difficult questions such as, wanting to see their mother who has passed away; believing they need to go to work; or go and collect children from school.

“Remember that no solution is a permanent solution, so while one approach might work one day, a different approach may be required the next time.”

Dealing with such issues or situations can be difficult, so here are some tips you may find helpful.

Join their world

- Try not to contradict the person with dementia as this could increase their anxiety. Remember, at that moment in time, what they are saying, they believe to be true.
- Focus on how you can put them at ease and reduce their anxiety. For example, if they constantly ask for their mother who you know has passed away, rather than correcting them, you could simply respond "Tell me about your mum". Recognising what the person is feeling at this time may give you the opportunity to give them reassurance, comfort and a sense of self. It might also be an opportunity to reminisce about people or times in their life.
- Do not feel guilty that you are avoiding the question. If you can make the person with dementia feel content, relaxed and at ease rather than anxious, sad or distressed, you are simply doing the best thing for them. This is a way to give someone what they do not possess, peace of mind.

“ I knew an 84 year old woman who thought her son was seven years old. She reacted with fury when she was told that he was much older. Instead, the carer could have said 'Have you any photographs of him? I'd like to see. I bet he was a handful' or simply, 'Your son. You must be really proud of him.' These are feelings which are untainted by the passage of time. ”

Professor Graham Stokes

Director of Dementia Care
Bupa

- Always try to focus on the emotion or feelings, rather than the actual communication. If they say they need to go to work, why could this be? Is it that they are remembering a time when they felt useful?
- Try to put the person at ease by looking at some familiar photographs or talking about something you know they love.

When you understand the meaning behind their actions or reactions, you'll be able to find solutions to help them cope.

“ There's a gentleman we currently care for who wakes up at 4 o'clock in the morning and walks up and down the corridors. We realised that this was because he was a baker for forty years and he thought he was going to work. Rather than distressing him by asking him to go back to his room, we bought chef hats, a bread machine and ingredients to make the dough. Now when he wakes, he can put on his chef's hat and teach the staff how to make bread! ”

Colleen Worbs

General Manager
Bupa Bendigo

Creating connections

It is a common misconception that when someone has dementia they lose their personality. This is not true. Living with dementia affects the person's ability to recall memories, process and language, or differentiate between past and present. The result is that the way they behave and how they express their emotions changes. This may give the impression their personality has changed but the essential features of who they are as a person will remain throughout their journey of living with dementia.

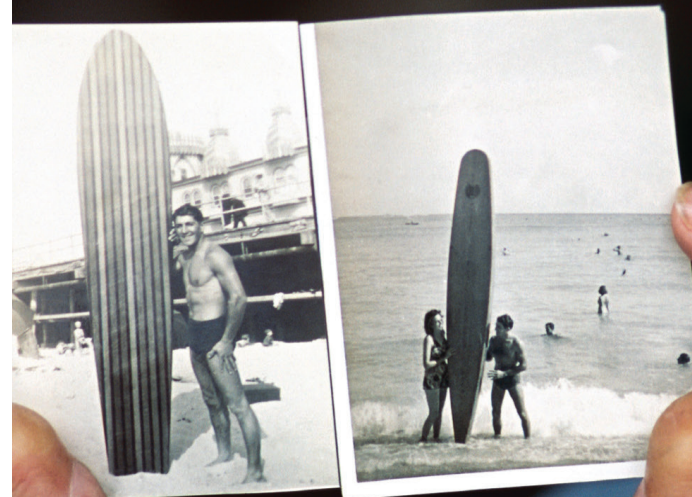
The most successful connections are the ones that carry deep-seated meaning for the person with dementia. If you have reached a point where you feel your relationship with someone is diminishing, or you feel you are struggling to communicate or make a connection, here are some tips that might help strengthen your relationship.

- If you engage in a conversation with someone with dementia, make sure it is meaningful to them. Talk about things they like talking about, whether this is sport, their family or another hobby or pastime. Flippant conversations and statements can confuse them and increase their anxiety.

Increase comfort, reduce anxiety

Anxiety can increase as the journey of living with dementia progresses. The person with dementia begins to have difficulty understanding the present, and they no longer have the knowledge of what is happening, where they are or who is around them. At this stage in the journey, it's vitally important to focus on how you can reduce that anxiety.

“ If you can make the person smile, even for a moment, the contact will have been worthwhile. ”



- While recent memories can be a struggle for people with dementia, they can often recollect times from their youth and early adulthood. Use these memories to connect and strengthen your relationship with them.
- Another common misconception about dementia is that if the person no longer appears to respond, then there is no point in engaging. In fact, it is even more important to support that person and engage with them at this time, and give them enjoyment of life in the here and now. If you can make the person smile, even for a moment, the contact will have been worthwhile. Think about what would make them 'come alive'. This could be playing a meaningful piece of music that triggers happy memories, or watching an old film from decades ago.
- We all have bad days when we don't feel like talking, or feel irritable. Do remember that this is also true for people living with dementia, so sometimes communication may not be a success. If this happens, try again in a moment's time.

Reminisce together

Reminiscing can bring back happy memories for our residents and create a sense of wellbeing. So in Bupa care homes we encourage family, friends and carers to help residents put together a Life Board filled with meaningful items such as photographs to represent what is important to them.

“ We had a gentleman who was very unsettled in the evening. We found out from his family that around this time every day, he busied himself by sorting and putting things in order for the night around the home. So we involved him in our home's evening duties including taking down the flag, feeding the chooks in the backyard, and locking up the home. After he felt all was in order, he would relax and settle by the other residents watching the evening news on TV. ”

Heather McKibbin
General Manager
Bupa Bellarine

“ I realised that it was no longer about supporting, caring, doing, it was about being. Not even talking. Just being close, sitting there, sharing a view, holding hands. ”

Physical frailty and dependency

At this time in their journey, the person living with dementia will now have lost the physical capacity to care for themselves. They may appear to be completely disconnected from the world, people around them, and may be almost unable to verbally communicate. Because of their physical frailty and dependency, the person may require more care and support than is possible to provide single-handedly at home, and may therefore, live in a care home.

At this time, dependency and communication may be possible only through physical contact. However, this alone can make a huge difference to the person living with dementia. This section provides some advice on maintaining that important connection with someone, without the use of language.

- Remember, even if the person with dementia is no longer able to communicate with you by talking, your physical presence alone may be enough to reassure them and put them at ease.
- If they cannot respond with words, show them how you feel. Sometimes holding hands, gently touching or hugging will get the person with dementia to respond.
- Maintaining eye contact with the person you are communicating with is a simple, yet effective way to show you are engaged and trying to connect with them.

Use the Senses - meaningful engagement is still possible

Engage the person with dementia by using sensory cues and stimulation to create meaningful moments.

Visual	use a variety of bold colours, shapes and pictures.
Touch	feeling materials with varied textures, soft, rough , ruffled warm or cool.
Taste	providing favourite flavours that are significant to the person, like ice cream or chutney.
Smell	pick flowers and bring scents and perfumes the person has always loved.
Hearing	providing preferred music and don't be afraid to sing a song, music is often retained long after other memories have faded.

Visual clues

- Try to observe visual clues from the person with dementia. They may use facial expressions to either show that they understood or misunderstood something - smiling, looks of confusion and distress, or looks of contentment are just some visual clues.
- Also observe their breathing to gauge emotional effect – faster breathing may indicate distress, while slower breathing may show you that they are calm.
- Remember, they may also be looking for clues. If you look angry, frustrated or confused, they are just as likely to read this as you would. So a smile can really go a long way!

A picture can paint a thousand words

“A picture can paint a thousand words”; never so true a saying as for people with dementia. Where words fail or you are struggling to get your message across, think about how you could communicate using gestures, drawings, photos or facial expressions. Remember that you're speaking in an attempt to communicate, and there are many different ways to do that. Be creative!

- If you're trying to get a response from the person with dementia, show them what you mean rather than asking them a question repeatedly. For example, if you are asking if they would like a sandwich or a bowl of pasta, show them the food to reinforce the question.
- Many of us use gestures in our day-to-day lives to make communication easier. Think about how you use hand signals in a restaurant to demonstrate that you would like the bill, or signal that you'd like someone to call you? This is a simple way to make communication clearer and easier for the person with dementia. For example, asking whether they are cold or hungry could be coupled with the appropriate actions to emphasise the question.
- If you are struggling to engage with the person with dementia and feel at a loss as to how to make a connection, you could use prompts such as drawings or old photographs.

The simple action of sharing a moment together or reminiscing over family photographs may help you to maintain your relationship.

Frequently asked questions

Communicating with someone with dementia can be frustrating, tiring, and at times you may wonder whether your efforts are worthwhile. However, you are not alone and many of the questions you may want to ask are likely to have been asked before.

Here are some of the common questions our Bupa dementia care experts encounter on a regular basis with answers by Professor Graham Stokes, Director of Dementia Care at Bupa.

Q: I feel I don't know how to talk to my husband/wife/mother anymore. How can I reconnect?

A: It's normal to feel afraid that you no longer know how to connect with your loved one, particularly if they have reached a stage with their dementia where they no longer appear to understand or seem incoherent. The most important thing to remember is that they are still the same person. Although they may seem to have little understanding or ability to communicate, they may respond to affection and enjoy interests that have always been a part of their life. Think about the things they used to enjoy, whether that was music, sport, watching TV or gardening, and try to engage on that subject. You could also use visual or other sensory stimuli to engage with them, such as sitting in the garden where smells, colours and sounds come alive. Making a happy meaningful moment, even if it is just for a short period of time, is hugely beneficial to the person – even if minutes later it is forgotten.

Q: My mum, who has dementia, keeps asking for my dad. Should we tell her that he has died?

A: This is not an uncommon question asked by people with dementia and it can be very distressing to have to answer again and again. If a loved one has died recently, you could remind the person with dementia of this fact a few times to see if they remember; however, it is important to use your judgment to avoid causing unnecessary upset.

Consider each response you give as a way to reduce the person's anxiety. If the person genuinely can't remember, repeatedly having to break the news that someone has died can be as painful as the first time they heard it because, to them, it is the first time. Causing such distress and grief isn't necessary, so instead, try to put them at ease. You can avoid the direct question by engaging them with conversation. In this instance you could say, for example "You and dad used to go walking together didn't you? Where was your favourite place? Let's see if we can find some photos."

Don't feel bad that you have not given the whole truth, as you have the person's best interest at heart and are focusing on what's important – reducing their anxiety.

Q: I feel myself getting angry when I have to repeat myself for the hundredth time and this makes me feel guilty. What can I do?

A: Caring for someone with dementia can be frustrating and tiring, so it's no wonder people feel angry and irritable from time to time. No one should sacrifice themselves entirely for someone else, nor should you feel guilty if you want some space for yourself, or a day off to do something fun. It's so important to make time for you.

Having time away from caring doesn't necessarily have to be physical – it can simply be having some time alone at home to read, relax or even sleep. Many people find that sharing the load of caring for someone with dementia is valuable.

If you don't have friends or relatives available to support you, look for a care home near you which offers short term or day care to support the carers of people living with dementia. If the person with dementia is already in a care home, don't feel that you need to visit every day. Take some time out, do something for yourself, and you'll feel all the better for it. It's also important that you have someone to talk to, so you can share your thoughts and concerns.

A few hours off now and then is the least you deserve; feeling guilty is common, but your health and wellbeing needs to be a priority.

Q: My partner won't let me hug them anymore. I feel as though they don't love me anymore. Why have they changed?

A: It can, understandably, be distressing to see a loved one distance themselves physically and emotionally from you. However it's important to remember that this is not a personal attack on you – it is the dementia affecting their memory. It could be that they are confused about who you are – and it's only natural that you wouldn't welcome affection from someone you don't know well. Or perhaps they are mistaking you for another relative, who they wouldn't usually hug?

It doesn't mean they will never want affection from you, but you may need to judge carefully what is appropriate – depending on how they are, and the stage of their dementia. It's also important to remember that people with dementia have good and bad days, and sometimes they might just feel tired, frustrated or confused.

Q: My dad won't answer to the name dad anymore, why is this?

A: If your dad doesn't recall that he is a father, or believes you are someone else, such as his wife or mother, it may seem strange that you are addressing him by the name dad. Instead, try using his first name, or a nickname that he is used to others using.

Summary




Caring for someone with dementia can be an emotional roller coaster. The distress felt by many when the person they know and love is no longer able to communicate and connect as they once did should not be underestimated.

You can make a difference by understanding more about how dementia affects how the person acts and behaves, and also holding onto the knowledge that they are still the same person. There surely will be good days, bad days, and days where you feel like giving up. Though remember, communication is vitally important to help maintain and strengthen your relationship with someone living with dementia.

I hope that this guide has provided some helpful advice and support, wherever you are in the journey.

Professor Graham Stokes, Director of Dementia Care, Bupa.

For more information:

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-  bupa.com.au/aged-care/dementia-hub
-  Contact your local Bupa care home

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