I thought Dad’s increasing confusion was just part of getting older?

Dad's been living here about twelve months now, but lately he's been getting quite confused about where he is. A staff member the other day mentioned this could be dementia. I thought his confusion was him just getting older?

Yes, we have been noticing these changes. But memory loss and confusion aren't always due to dementia. It's important that we rule out things that could be causing this.

So there could be another reason he's forgetful and confused?

There could be any number of reasons. Some vitamin and hormone deficiencies can cause this. Or depression, or medication clashes. Maybe over-medication. Dehydration and infection in the body can also bring about confusion.

Look, He's always been a little forgetful but the confusion worries me.

Yes so it's really important that we get a medical diagnosis as soon as possible so that if he does have a treatable condition, it can be treated in the right way.

And what if it is dementia...what then?

Well, early signs of dementia are very subtle, May (carer) not be immediately obvious and also vary a lot from person to person. So finding out if he does have dementia, or not, is an important first step and will help us determine how care and support can be provided. We can then work as a team to give your father the best care. There's also support available for you if your father does have dementia. A care plan meeting with the doctor would be a good idea.
(VIDEO 02) Isn't dementia just a normal part of ageing?

(DAUGHTER)
As you know, Dad has dementia. But I didn't think it was that serious, isn't it just a normal part of ageing?

(CARER)
A lot of people think that. But in fact it's a group of symptoms caused by a brain disease, most commonly Alzheimer's. These diseases attack and eventually kill off brain cells. So the person finds it harder and harder to do the things that they could easily do before.

(DAUGHTER)
So it's true he won't get better? Maybe he just isn't getting the right care?"

(CARER)
Because we don't know what causes dementia, we don't know how to effectively stop it from getting worse. But there are a lot of things we can do to make life easier for people living with dementia.

(DAUGHTER)
Like what...what kind of things can I do for him?

(CARER)
Things that enable him and improve the quality of his life. One of the ways you can help him is to understand and accept that your Dad may not be able to do some things as well as he could before. And we'll provide him with as much support as we can to help him continue to be the best that he can be, in light of these changes.

(VIDEO 03) I was told that dementia is a terminal disease. Will mum die from dementia?

(DAUGHTER)
My brother-in-law told me that dementia is a terminal disease - Mum has had it for five years. Will she die from dementia?

(CARER)
Hearing that from your brother-in-law, must have been a real shock?
Yes it was, I wasn't aware it was terminal?

Many people are unaware that dementia is a terminal illness and that people do die from it. And until recently there hasn't been much information on this topic. One of the reasons for this is that the person's health can decline so gradually, that people don't link their eventual death with the dementia. As people with dementia decline, they're likely to have episodes of illness caused by infections. Then they only partially recover. So each time they get ill, there's a further decline in their ability.

So she is ... She's only going to get worse?

Sadly, yes. As it progresses, she may not be able to recognise you or your family. She may sleep a lot more, eat less, or even stop eating altogether and get really frail.

That's such an awful thing to hear you know, Mums always been a strong person. So unfair.

Look, it might help to talk to the staff about how your mum will be cared for as she gets sicker and is less able to do things for herself. If she can no longer tell you what she wants to happen, then you, or another family member, should make decisions on her behalf. So that your mum gets the best care she can right to the end of her life.

That's what we all want for her.

And it might be important for you and other family members, if you needed to talk to someone, to consider seeing a counsellor, or psychologist, about how you're dealing with what's happening to her too.
Why can I have a great conversation with dad some days and other days he doesn’t seem to understand me?

Some days I can have a great conversation with dad and other days he doesn't seem to understand me and I find it really hard to communicate with him. Why is that?

Losing the ability to communicate can be one of the most frustrating and difficult problems for people with dementia and their families. As the illness progresses, your father may experience a gradual lessening of his ability to communicate. He'll find it more and more difficult to find the right words and understand what others are saying to him.

Yeah, that's how he gets. Yet other times he's fine.

If you think he doesn't seem to understand what you're saying, we need to first rule out other reasons.

Like?

Well, it could be his hearing, so it's worth having this checked in case it's changed. Generally when talking to your father, it's helpful if you remain calm and talk in a gentle way. Try not to show him you're having trouble understanding him. If you do get frustrated then don't let him see it, as he may misinterpret this and become frustrated and upset himself. Your behaviour can trigger his behaviour.

Yeah, I see what you mean. Okay, so what else can I do?

Well, keeping your sentences short and simple, and focusing on one idea at a time might help. Make sure you give him plenty of time. It may take him longer to process what you've said, and come up with a response. You may need to prompt him now and then. Also give him plenty of visual cues along with the
words. If you're talking about a flower, point out a flower. Where do you usually see him?

(DAUGHTER)
Usually we're in the lounge room.

(CARER)
Hmm, it sometimes gets a little noisy in there. He may be having some difficulty blocking out other sounds or activities, to concentrate on your conversation. May be a good idea to find a quiet place, or go to his room. This way there'll be fewer distractions.

(DAUGHTER)
Yeah, that would help a lot I'd think.

(CARER)
Yeah, you know most communication with others doesn't involve the use of words. So your touch, tone of voice, facial expression and laughter... they're all important. So think about other ways that you could communicate with him. You may need to learn some different ways of communication, so you can understand your father. Might have to be creative!

(DAUGHTER)
Yes, I guess so.

(CARER)
And think about the way he's communicating with you too. What's his tone or facial expression telling you?

(DAUGHTER)
Yeah, true.

(CARER)
Above all, people living with dementia want to feel connected, particularly with their family members. So even a gentle touch on his hand or arm, and good eye contact, can let him know that you're enjoying your visit. Maybe you could also find an activity to do with your dad. One that you know he enjoys. Remember, being together can often matter more than the words. The important thing for him is you're with him.
How will the staff know if mum is in pain or not, if she has dementia and doesn’t talk much?

Mum’s got a bad wound on her hip and doesn't talk much. How will the staff know if she's in pain or not? I've heard that with dementia she may not be able to tell others she has pain.

Yes, it’s true. People with dementia who feel pain may have trouble explaining it in words to others. So it's really important that we look for non-verbal signs. You can help staff to recognise pain.

In what way? I'm not here all the time.

Of course, staff who support her will look for the usual clues that your mum is experiencing pain. But because you know your mum, it would be helpful for the staff if you could share what you know about her with them.

What kinds of things would you need to know?

Well, how could you tell if she was in pain? What might she do, or not do? Would she go really quiet and just want to lie, or sit around, and not do things that she loves, like going for walks? Would she respond out of character? Is she normally a very placid person?

Usually, yes.

Well, she may get a bit irritable if people do try to talk to her, or do things with her? It will be really helpful for others to know this about your mum to tell if she is in pain. Staff can use this knowledge when they check on how she's going, and if her hip wound is still troubling her. It's very important that family members share information with the staff to help them with her daily care.
(DAUGHTER)
Yes, I can see that it would help.

(CARER)
Your knowledge of your mum can also really help when discussing with the medical doctor about how the pain could best be treated. Would you like to arrange for a medical assessment and a review of her current treatment?

(DAUGHTER)
Yes, I will, thankyou.

(VIDEO 06) The staff are always cutting up dad’s food at meal time. Why can’t he be allowed to do this himself?

(DAUGHTER)
When I come to visit Dad at dinner time the staff are always cutting up his food. He's always cut up his own food. Why can't he be allowed to do this himself?

(CARER)
Well, let's ask the staff why they're doing this. The process of cutting up food and eating, is really quite complex. It's often the case that as dementia progresses, people find these seemingly simple tasks quite difficult. There are many fine movements of the hands involved requiring intricate brain connections. People living with dementia can sometimes forget what knives, forks and spoons are used for. Does your dad have arthritis? That could also be a reason why he's having trouble.

(DAUGHTER)
Yeah, he does have arthritis.

(CARER)
Ok, so maybe have a conversation with the staff who are supporting him at meal times about what changes in his abilities, has led them to cut up his food.

(DAUGHTER)
Yeah, I guess I'm just wanting him to maintain as much independence as he can, for as long as he can.

(CARER)
Yes, independence is important for his sense of dignity and self-worth, so it would be good if we could work together
to establish what's most important to your dad and how we can help him maintain that independence.

(DAUGHTER)
And dignity

(CARER)
Yes, exactly. So for instance we could try serving food that doesn't need cutting up, or cutting up his food before it's served. Or perhaps 'finger food'. We could also try modified cutlery and other utensils that you father could use. This way, he might be able to cut up his own food. Would you like to put in a request to the occupational therapist to do an assessment for this?

(DAUGHTER)
Yes I would, thankyou.

(VIDEO 07) My husband was always very level headed, but he seems to get upset for no obvious reason.

(WIFE)
My husband was always very level headed, but he seems to get upset for no obvious reason. Maybe he is unhappy being here?

(CARER)
It's very common for people living with dementia to appear to change their personality, and it can be quite upsetting to think that your husband appears different and unhappy.

(WIFE)
Oh, it’s very upsetting. He's had his moments like anyone, but this is not like him at all!

(CARER)
There can be many reasons why his behaviour may be changing. Because dementia is the result of changes that take place in the brain, it can affect a person's memory, their mood and their behaviour. Sometimes the person's behaviour may be related to these changes taking place in the brain.

(WIFE)
But what if he’s just unhappy being here?

(CARER)
Well, Sometimes there may also be changes occurring in the person's environment. Their health, how they're feeling or
the medication they're taking. Any of these things can trigger changes in behaviour. Dementia affects people in different ways. It's good to discuss your concerns with the care staff.

(WIFE)
Maybe I'll also discuss it with his doctor, to see if it’s a physical illness

(CARER)
Yes, or whether he's feeling down or depressed, or if he's experiencing some other discomfort. Any of these things could be causing the changes you're seeing.

(WIFE)
It’s so hard to deal with him when he gets upset like this. I feel terrible for him.

(CARER)
Always remember that the behaviour is not deliberate. It's out of his control. What your father might need is comfort and support, even though it may not appear that way.

(VIDEO 08) I was told that dad is having ‘sundowning’. What does this mean?

(GRANDAUGHTER)
One of the staff told me that Grandad is having 'sundowning'. What does Sundowning mean?

(CARER)
The term 'sundowning' is sometimes used to describe certain behaviour which occurs in the later part of the day. Sometimes people who have dementia appear to get a bit upset or become restless and more agitated in the late afternoon, or early evening. It can be worse after a change in the environment or usual routine.

(GRANDAUGHTER)
Is it serious? What causes it?

(CARER)
No one is sure what causes it, although it seems to result from changes that are occurring in the brain. People living with dementia tend to tire more easily and find it harder to settle when tired. It could be that your dad was used to doing some particular activity at this time of the day, and
has a sense that he should be doing something, but doesn't know what. Long established behaviour patterns may be triggering his restlessness at this time of the day. It could be connected to the type of work he used to do. What did he do for work?

(GRANDAUGHTER)
He worked for a bank most of his life.

(CARER)
Well he might have been closing up, making sure things were balanced, locking the safe, making sure documents were secured, and all those sorts of things.

(GRANDAUGHTER)
Do you have any ideas how we can help him with this?

(CARER)
Perhaps he needs some simple, but interesting activity he can do with you or family members when you visit. Something that links with his past life experiences and interest, to help him feel connected and engaged, but also to help calm him. Have a chat with the activities coordinator that might give you some ideas of what you could do with him on your visits.

(VIDEO 09) Whenever I visit dad he wants me to take him home. He doesn’t seem to remember why he is living here. It's really upsetting and I feel bad leaving him.

(SON)
Every time I visit Dad he wants me to take him home. He doesn't seem to remember why he is living here. It’s really upsetting for me when I come to visit him. I feel so bad leaving him here.

(CARER)
The decision to move someone to an aged care facility is often a really difficult one. And there's often a nagging sense of guilt about it.

(CARER)
But, because your Dad has dementia, he probably can't logically work out why he's here, and he probably can't remember, even if you tell him each time he asks. The changes in his brain are making it too hard for him. People can also mean different things by 'home'? The idea of home can mean much more than an actual place. It can mean somewhere we feel
safe and comfortable; where everything is familiar, and we know what to expect and can relax. Maybe your Dad's telling you that at this moment, he's not feeling any of these things. You do take him back home sometimes though. How does that usually go?

(SON)
Yes sometimes he comes home with us and that's good. But then when I do take him home he asks me to take him home!

(CARER)
Well he might be saying "bring me back to the facility". Remember though, it's important you acknowledge what he's saying. "Yes I know Dad. I know you want to go home, and that it's hard for you. But there's no one at home to be with you right now"...something along those lines.

(SON)
Yeah, I said to him the other day "Dad, I'm here with you now, and we're together, and that's what's important isn't it?"

(CARER)
Yes, that's good. And also, maybe have a few ideas about how to distract him saying "Dad, I need your help with something - or let's do such and such together." It might be helpful to take an activity you can do with him each time you visit, something that he can do with you and enjoy. You being with him can give him a feeling of home. Talking with your dad about the memories connected with some of the familiar things he has in his room, like photos, or other objects, can also help.

(VIDEO 10) I bring in all my wife’s favourite foods but she has lost interest in things she used to love.

(HUSBAND)
My wife doesn't seem interested in food any more. I bring in all her favourites - she used to love Ritter Sport chocolates and now she won't touch them. I really try.

(CARER)
There could be a number of reasons why your wife has changed her interest in food. She may be having trouble recognising things as food to eat. Or her sense of smell or taste could be affected. Or possibly the part of her brain that triggers hunger, or a desire to eat, may be affected.
(HUSBAND)
Could there be other reasons?

(CARER)
Has she had any health problems or a change in medication which may have reduced her appetite?

(HUSBAND)
I don't think so but I'll check that.

(CARER)
She could be feeling down, which is affecting her desire to eat. Or another factor could be that your wife may need to increase her exercise. We all feel hungrier after physical activity, so going for even short walks with her may help simulate her desire to eat.

(HUSBAND)
I hope so, she really needs to eat.

(CARER)
Some high calorie drinks might help as a backup. You could try telling her that drinking more water or juice will keep her skin healthy and beautiful or that the doctor has advised her to eat a banana for good digestion, or carrots for better eyesight.

(HUSBAND)
Can't the staff make her eat?

(CARER)
The staff can try different strategies to keep your wife's nutrition and fluid levels up, but they can't force her to eat. They may be able to present meals to her in a different way. If she's having trouble with cutlery, she might prefer finger food or, if she's having difficulty swallowing, she may need her food pureed. It could be perhaps her dentures or teeth are causing discomfort when she eats.

(HUSBAND)
What if we still can't get her to eat, what then?

(CARER)
I know this is a really difficult thing to deal with, but your wife may stop eating and drinking altogether as she nears the end of life. Do you know what her wishes are with respect to the care she would like to receive during this time?
(HUSBAND)
"I'm not sure. It's hard for me to even think about it"

(CARER)
At some point, do you think it might be a good idea to review her advance care plan?

(VIDEO 11) Mum never used to flirt, but now she follows a man around all the time. It’s totally out of character and I find it really embarrassing.

(SON)
I find it really embarrassing. My mum never used to flirt, but now she seems to follow one of the male residents around all the time. It's totally out of character. Can't the staff stop her?

(CARER)
When trying to understand your mother's behaviour, we need to think about why your mother might be behaving this way. Your mother could be looking for companionship, human touch, or comfort. Maybe she's met someone she really likes. Some beautiful friendships have been formed in aged care facilities. It's important to remember that sexuality is a normal human need that continues throughout life and that the need to express our sexuality continues as we grow older.

(SON)
Oh please this is my Mum you're talking about!

(CARER)
Well, people with dementia still experience this need.

(CARER)
Sometimes behaviours like the one you're concerned about, may be related to changes taking place in the brain. In other instances, there may be events or factors in the environment triggering the behaviour. She might be feeling a bit restless, bored or lonely. If this is the case, doing something with your mother may distract her. Giving your mother a hug, or holding her hand, may also give her the human touch she might be seeking.

(SON)
So could it be the dementia?

(CARER)
There can be many reasons why behaviours change. Every person with dementia is an individual who will react to circumstances in their own way. It's important that you not over-react in front of her even though you may find the behaviour embarrassing. You should try and speak to a staff member who is knowledgeable about sexuality and dementia to discuss this further.

(VIDEO 12) Is dad the same person now as before he had dementia?

(SON)
I told the staff that my father has always hated bananas but when I came in to visit him last week he was eating one. I got a bit angry at first but he seemed to enjoy it. It made me think "Is he the same person now as before he had dementia?"

(CARER)
Changes in personality, preferences and behaviours that accompany dementia can be very upsetting when you've known someone all your life. But deep down he's still your father even though little by little many of the familiar things about him may change, or become lost.

(SON)
Yes, it seems I'm losing the old dad in some ways.

(CARER)
Even with small things like his dislike for bananas, it can seem a big loss. Let's not forget though that people do also change their minds. What someone enjoyed before, they may not like now and things they didn't like before, they may now enjoy.

(SON)
Well at least I know he enjoys bananas now!

(CARER)
Haha, yes. Look, you may think that your father is changing so much and he's not the father he was before...the father that you used to know, but what is important, is that he is happy, relaxed and enjoying things.