

WHAT'S NOT SAID IN DEMENTIA CARE?

A SUPPORT
RESOURCE FOR
CARERS



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https://www.qualtrics.manchester.ac.uk/jfe/form/SV_elhZcxmrOc4lk3Q



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Extracts from carer interviews have been edited for readability, but the sense and emphasis has not been changed. The Simon Fellowship project and the PhD CASE Scholarship were approved by the University of Manchester Research Ethics Committee Project IDs: 14057 and 7297. All participants are informal carers, either caring for a parent, family member or a partner. All but two participants were White British (one man and one woman were British African-Caribbean). Participants ranged in age from 39 to 82, though roughly half were in their late 50s or 60s.

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What's not said in dementia care?

We all lie. It's a part of everyday life. We tend to think of honesty and openness as the 'default setting' for all interactions. But is this really the case? Most people tell small or 'white' lies on a daily basis. How many times have you responded to the question 'how are you?' by simply saying "I'm fine," when, in fact, you might be having a rough day or feeling under the weather?

And the lies we tell change over the course of our lives. When dementia is involved in our experiences, many of us find the ways we tell lies and keep secrets begins to change.

Carers often struggle with complex moral questions in relation to concealment in care practice. Is it ever appropriate to hide things from a person living with dementia? If so, when is it appropriate to do so? Why might some lies be considered 'bad' whilst others are considered 'good'?



In this booklet we explore lies, fibs and fabrications of all kinds in the context of caring for someone living with dementia. Based on a sociological project exploring this issue, we provide some guidance and share stories from carers' experiences to help you think about your own life and caring.

The booklet is quite lengthy and includes lots of examples. It could be good to read it in portions if you find you are struggling to get headspace or the time to engage with it. After all, your wellbeing comes first.

Let's talk about lying

The role of concealment in dementia care is a controversial topic. And one of the first big issues is the word 'lying'. The word itself can make people feel uncomfortable, because in our everyday life the idea that we lie is frowned on. And we are not supposed to say that we lie. But in our project exploring people's everyday lives we found that everyone lied.

And lots of other psychological and sociological research projects have found that lying is a normal part of day-to-day interactions.

So in this booklet we won't be judging lying, secrecy and concealment through a moral lens. It isn't our responsibility to tell you whether lies are good or bad, or whether to use them or not. And we also use concealment as an umbrella term covering various everyday behaviours, including lies, fabrications, secrets, misdirection, playing along, and so forth.

We hope to help you reflect on these issues for your own purposes and in your own situation. After all, one of the most important things we found in carers' experiences over and over again was that everyone's situation was different. Which means you're the expert on your care role.



We have seen over the past decade or two a change in how care professionals, like nurses, doctors and social workers, offer advice about lies and secrets. It is becoming more common to acknowledge the possible positive uses that fibs and falsehoods might have when caring for someone living with dementia.

Usually in these recommendations the potential for harm associated with concealing things from people living with dementia is weighed against the possibility of physical and emotional harm that might come from honesty. You may have come across phrases such as Therapeutic Lies, Compassionate Communication, or the Best Interests Decision Framework in your conversations with others on this topic. These policies can be helpful to some but attempts to create a universal framework for whether concealment is 'good' or 'bad' in any given situation is a difficult task.

Often, there is a tension between the person living with dementia's right to be properly informed and the challenges of navigating everyday life for carers.

It can be hard to make sense of these formal frameworks in the context of your day-to-day life.

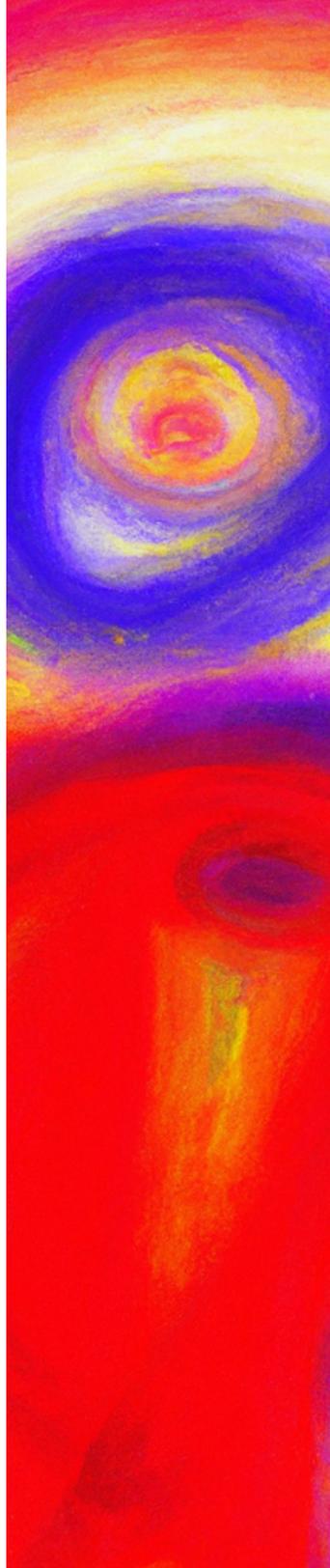
In this resource we aim to rethink concealment in care along more neutral lines, encouraging reflection upon the specifics of your own relationship and how this might help with the shifting role of concealment in your experiences. Various real-world examples are used to highlight familiar situations, and we encourage you to reflect on how these carers engaged in practices of concealment. Do you feel the same way as these carers? Do you recognise their struggles and empathise with their choices? Would you have done the same thing, or done anything differently? Do the explanations these carers provide make sense to you? If not, are you able to get to grips with why you might disagree with them? How can you plan for future situations like these yourself?

Concealing grief

A situation familiar to many carers is when a person living with dementia believes that a friend or relative who has passed away is still alive. Here is a story from Amber, talking about her mother who has dementia, believing she had received a call from her mother (Amber's grandmother):

She told me her mother had phoned and I said "Mum, grandma phoned?" and she said "Yes," and I asked her again and she repeated that her mother had phoned her. And I said "But mum, your mother's, uh, grandma's dead." And from the reaction from her I'd never ever say it again: "No she's not! No she's not!" From that reaction I have never mentioned it. Never said a word because it would upset her and she just doesn't understand it. She's back there. There was a stage where she wanted to go back to Jamaica. She wanted to go and visit her friends and go out with her friends when she was younger, and I just let her talk it through without saying anything about how they've died, because she'd gone back to her younger days. You just have to find ways of dealing with it without stressing her and getting her upset. But that's how it is. That's dementia.

**QUOTATION FROM AMBER, A
CARER FOR HER MOTHER**



Carers often feel that it's important to protect the people they care for from the grief of loss that they might feel if they were regularly remembering and forgetting that people they love have passed away. This was the most common example carers gave of their experiences of concealment. These issues are not without their own challenges for carers, however. Take John, for example, who struggled with a similar situation with his wife and had learnt to conceal from her that her mother had died.

After years of this kind of topic coming up again and again, John was tired and felt that his ability to communicate with his wife had changed completely:

You start to feel the strain. But after time it's like that disappeared, too. You're in a different world. Something just completely changed. What I find I have to do, you have to stop trying to reason with her. I couldn't reason with her anymore.

Do you find yourself having to conceal this kind of grief and pain? Do you feel a strain in doing so? Is it like living in a different world, like John felt?

It is common in healthcare guidance to suggest that carers conceal the death of loved ones from people living with dementia when they repeatedly experience that loss. Whilst this approach often seems gentler for the person living with dementia, maintaining these concealments can be very hard for carers to engage in. In carers' experiences in our project, it can lead over time to a feeling of disconnection from the person living with dementia, and to tiredness, strain and exhaustion.

**QUOTATION FROM
JOHN, A CARER FOR HIS
WIFE**

Perhaps it could be helpful in your own caring to remember to take care of yourself, too, when you're using concealments.

Even though they are unavoidable in many carers' experience, it could be important to acknowledge your own wellbeing, and sense of your world, life and relationships.

If you don't have personal experience of this, do you think you would conceal this kind of information from the person for whom you are providing care?

WHAT'S IT LIKE FOR YOU IN YOUR CARING?



Health and wellbeing

Our research highlighted another common experience involving food and nutrition, health and medication. Here there is a more ongoing, pervasive use of concealment in the day-to-day when food, health or medication is involved. In the example below, Andrew talks about the challenge of getting his wife to eat food he would prepare for her. He explains his use of concealment as a response to this challenge:

She won't have much food. She'll say, "Oh I'm not having one. Are you having one?" I say, "You're kidding? I love those, I'm gonna have one," and she'll say, "Oh, go on then. I'll have one." I don't eat it, whatever it is, but she'll have something if I have something. She'll often say to me, "I don't want to have any cheese. Are you having one?" I'll say, "I'm not having one if you're not having one!" "Alright, then I'll have one." So, I take her a cheese and she'll say, "Well, where's yours?" I'll say, "Here, it's on the table. I'm going to have it in a minute when I finish this cup of tea." "Oh, right. Okay, then." It's all sorts of 'kidology.' It's a shame really, you feel you should'nae be tricking her, but I'm tricking her to get her to eat. I don't trick her into anything else, just to get her to eat.



What do you think about Andrew's 'kidology'? Or what he called a 'playful approach' to concealments. Is this something you've ever done with friends and family with dementia? Do you feel it can help to try to be playful in concealments? Or does that not work for you?

**QUOTATION FROM ANDREW,
CARER FOR HIS WIFE**

Carers describe lots of different ways of managing concealments and lots of different ways of feeling about concealment. A key factor that shapes carers' feelings is usually what the subject matter of concealments is.

In Andrew's example, concealing things in order to help his wife eat enough food to be healthy seemed sensible to him. He felt he was doing a good thing and he did it in a way that he felt was 'playful'.

Carers often feel they have to justify their actions to others, and that it can be hard when people don't understand the pressures of the situation. This was especially true when carers talked to medical or care professionals who might be unfamiliar with the dynamics of their pre-existing relationships.

Some carers found it helpful to keep a list of the kinds of things that they have to know about the person with dementia. And things they have to conceal from them. And this was important for sharing with health professionals, formal carers, social workers and so forth, to ensure they understood how best to help the health and wellbeing of the person they care for.

Others didn't want to write anything down and found it easier to try to develop good relationships with specific care professionals whenever possible.

- **Do you feel you have to conceal things to help maintain the health and wellbeing of the person you care for?**
- **How do you find it when you're interacting with healthcare professionals? Do they understand?**
- **What would work for you, in terms of helping get them to understand what is happening?**
- **How does it feel for you having to try to get people to understand what's happening in your care situation?**

Restricting freedoms

Issues relating to cars and driving are also common in carers experiences. These are a good example of situations where carers feel they have to restrict the freedom and choice of the person they care for, for their own good or for the safety of others. Consider the experience of Ellie, who was caring for her husband with Alzheimer's. She felt she had to collude with the DVLA to get his driving licence revoked:

I thought he was unsafe on the road. I was thinking if he had an accident and I hadn't said he had Alzheimer's and something bad came out of it, where would we be? He tried his hardest to get his driving licence back. He even went to the place we used to live, and he tried to contact the DVLA assessment centre for people with disabilities.

They wouldn't give it to him. He goes wild with them for two hours. So, that was a very big contention between us to begin with, because he couldn't understand why he wasn't allowed to drive. I didn't tell him that I had been in contact with them because that would have made things far worse. I couldn't have told him that I had rung the DVLA, because he kept fighting for his licence and I knew the only thing he had on his mind at one stage was that driving licence.

**QUOTATION FROM ELLIE,
CARER FOR HER HUSBAND**



Carers in our project often found themselves having to judge between competing moral obligations. Should they avoid lying, or protect people against potential harms by restricting the freedom of the person they care for? Ellie's example shows how carers are often the ones who carry the burden of concealments and it can be a heavy load.

We found this to be a complex situation for many carers, compounded by a strong sense that there is still something wrong with concealing things from a loved one. When asked about the role of concealment in Ellie's care practice, she responded as follows:

No, I just didn't lie. I just didn't tell him if you see what I mean. I didn't tell him lies, but I just didn't tell him what I've done. Is that another way of lying?

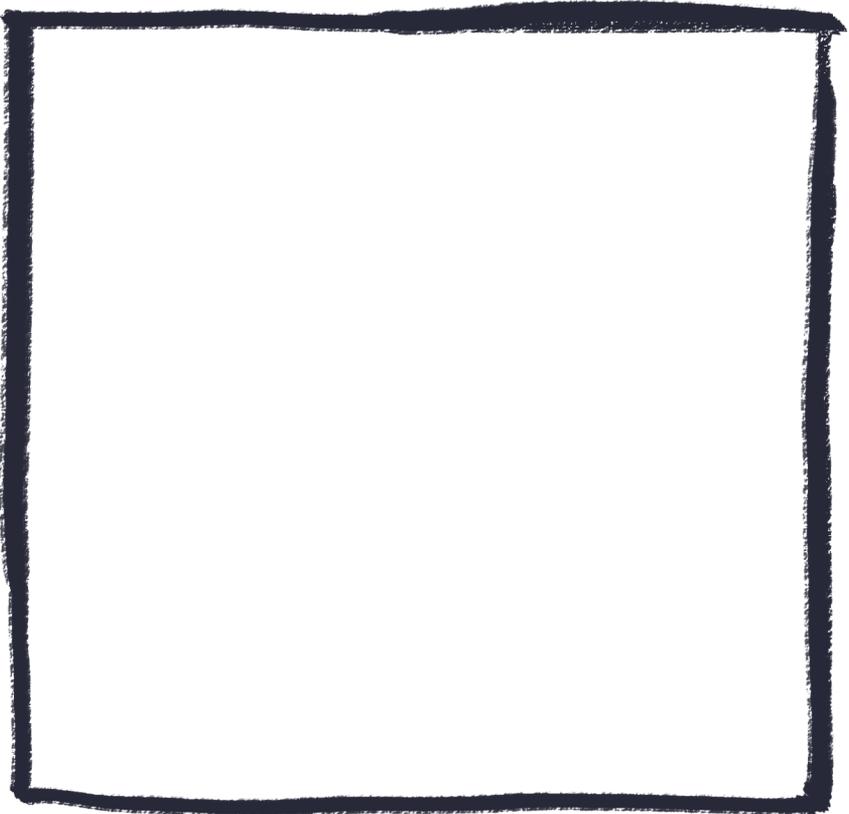
This dilemma is clearly a struggle for Ellie, perhaps one that feels familiar to you? Have you made decisions that impact upon the autonomy of the person for whom you are providing care? Did you 'lie' as part of this process and did that result in tensions in your relationship? If you have not yet made this kind of decision, what do you think about Ellie's use of concealment? Would you do the same?

Despite the clear safety concerns in this situation, Ellie still feels the need to minimise or explain away her concealments. It seems clear to carers that it is more important to protect their loved ones and others from potential harm and accidents. But carers still often harbour a powerful sense of discomfort over withholding these kinds of significant details from a loved one.

Here are some questions to help you reflect on how this difficult situation impacts your life:

- **How does it feel juggling different kinds of moral obligations?**
- **What are the costs to you of concealing things from your loved ones to protect them and others from potential harm?**
- **How can you protect and care for yourself in this situation?**

You can use this space to make some notes if you like.





It's different for everyone

Here we have a story, similar to Ellie's, from Sheila who describes an incident involving her husband with dementia and her friend. This incident follows a six-month hiatus from driving due to a serious incident that put people's lives at risk:

A friend of mine, he'd taken her into the village and there is a long stretch of road that dips down into another road crossing along the bottom. It's only in the village but it's quite a fast road to cut through. He came down the hill at quite a quick speed and my friend was clutching at his sleeve saying, "You need to stop." But he said, "No, no, no." She's screaming at him, "Stop the car, stop the car, there's a crossroads!" "No, no, no!" he said, but eventually stopped on the other side. She said, "Why did you do that?" He said, "There's never anything coming". It was at that point we both realised there's something not quite right here. I managed to get the car off him, I think it was about six weeks later. Fortunately, the car broke down, we sent it to the garage and I said to the garage man, "Can you tell him please that it's just not repairable?" and that's it.

**QUOTATION FROM SHEILA, A
CARER FOR HER HUSBAND.**

When later asked directly whether she felt the need to lie to or keep things from her husband she agrees, and further states:

Yeah I do have to manipulate things, yeah. I do tell quite a few lies about things to pacify him really. If he's stressed then it makes my life difficult.

Sheila expresses this need for the smooth running of day-to-day life and her associated need to conceal things from her husband.

The differences between Ellie's and Sheila's attitudes highlight the broad range of attitudes we found about the role of concealment in care practice. Do you find yourself identifying more with Ellie or Sheila, both, or neither?

Some carers found it straightforward to acknowledge and accept the need to conceal and framed it as a pragmatic approach to care. Often they would make sense of this by seeing how dangerous things could get for others, or by reflecting on the sheer exhaustion that everyday life would present if they tried to be honest all the time.





WHAT OTHER FACTORS DO YOU THINK AFFECT YOUR OWN EXPERIENCES?

In our project we found lots of factors affected how people felt about concealments in their care. Here are some of them:

- The experience of concealment in their own lives so far, growing up, during relationships in the past and in the present. Some carers had to lie a lot to keep themselves safe in previous experiences, for example during childhood, and so dementia fit a pattern of things they had learnt to cope with. Others felt they had been a very honest person their whole life until dementia came along, making it hard to accept the need they felt now to conceal things from a loved one.
- The cultural perspective they have. Some people's religious beliefs, or cultural background, ethnicity or profession sometimes shaped their views on concealments.
- Who they care for. Some carers were concealing things from a parent with dementia and some from a partner with dementia. Some were concealing things from a friend, whilst others were concealing things from a much older relative. Who you care for, what your relationship is like, and what the expectations are of such a relationship might be factors shaping your feelings about concealment.

Aggression and violence



Managing powerful emotions and associated physical outbursts is an experience some carers navigate. Jennifer's story is a good example of this. Whilst describing changes to her husband's behaviour, Jennifer reveals having to hide her emotions from her husband:

**QUOTATION FROM JENNIFER,
CARER FOR HER HUSBAND.**

I said to him, "Now I want to watch this program on TV." And he said to me, "Well piss off then," which was alien really. He started to shout very hard, and it used to upset me, and I used to go off into the kitchen and have a little cry. And I'd come back, and he'd say, "Oh, are you alright?" You know, as if it hadn't happened? I do suffer from a bad back, so I said, "Oh yes, my back's a bit bad." "Oh," he'd say "well you give me a love." No recollection that he'd shouted at me. And then just a couple of times, he pushed me. It didn't hurt me or anything, but he just gave me a little push.

Not only do carers often need to protect people with dementia from physical and emotional harm, but some carers describe practices of concealment that protect their own physical and emotional safety. Carers often expressed how dementia had not only changed the person who they care for, sometimes making them dangerous or frightening, but also robbed them of the very person they would go to for help with those fears.

It is never right for anyone to harm you, and carers shouldn't have to use concealment to protect them from aggression and violence. It could be very important for your safety and wellbeing to reflect on how concealments you're using might be coping strategies that you're using to help yourself through dangerous situations.

Have you ever had to manage these kinds of situations? Does the sense of shock, fear or loss that comes through in Jennifer's story feel familiar to you? Do you feel that using concealments in this way might contribute to a sense of isolation? Perhaps concealments we use point towards a need for help and support.

If you do have personal experience of aggression and violence, don't forget there are many support resources available to you and you shouldn't be alone in your situation. The Alzheimer's Society provides a list of organisations that can help: <https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/aggression-other-resources>

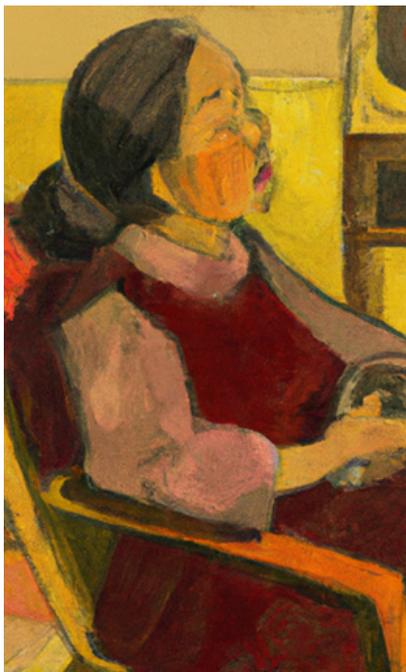
Talking about aggression and violence also shows us that things are not the same for everyone in dementia care. The burdens are often not spread equally. The costs are often not shared justly. And it can be especially hard if there are other factors affecting your caring experience. It could be helpful to reflect on the factors that shape the caring life you experience. Here are a few possibilities that came up regularly in our interviews with carers:

Gender: your gender, and the gender of the person you care for, can shape the kind of experience that you have. It isn't the same for women caring for men, and men caring for women, because gender shapes our relationships, everyday lives and social expectations. Do you think your gender influences your experience of care and concealment?

Ethnicity and culture: different cultures, families, classes and generations have different views about concealment, and react to concealments in different ways. How do your values and culture shape your experiences do you think?

Age: younger and older people might experience changes in caring relationships differently. How does your age and the age of the person you're caring for shape the way that concealments work in your life?





In discussions of dementia, personality changes of people with a diagnosis are widely discussed, but our research highlights an associated shifting sense of self for those providing care.

As with lots of the examples above, people's experiences of change in the people they care for often resulted in concealments of some kind. Together, these changes can make your relationship feel very different. And this can have consequences for your own sense of self.

**QUOTATION FROM SARAH,
CARER FOR HER HUSBAND.**

Becoming a different person

You might have found yourself, over time, not being able to say and do the various things you normally would with the person for whom you are caring. Perhaps you are already experiencing a sense of change? The following example comes from Sarah:

You learn that there are some things that you don't say, because they can't possibly give you an answer, and it's upsetting for the person. It's very difficult when you've been able to say what you want, when you want and how you want. All the sharing of experiences had gone. I was choosing what I asked him so that I didn't have to lie to him, because that's not in my nature. It closes communication down as well. My husband would know when I was upset over something he'd done, and it used to break my heart 'cause he'd say, "I don't know what I've done but I'm sorry. Can we please be friends?" And I'd be like, "No, no go away." So, unhelpful! I suppose I could have done things differently but I'm human as well as he is, and I've got to let off steam as well.

There are intense and complicated emotions involved in withholding things from a person we care for, which can impact on our own wellbeing and sense of who we are. In Sarah's story, she went on to tell us that all these changes made her feel like she'd become a different person, and for a while she didn't really know who she was.

Whilst the use of concealment resolves some issues for carers we spoke to, it opens-up others, and our research highlights the importance of being attentive to these changes.

- **Do you feel like who you are is changing, or has changed? What is that like for you?**
- **What effects do concealments have for you personally? Do they make you feel differently about yourself?**
- **How do you cope with the changes you're experiencing?**
- **Who could you seek support from?**
- **Remember, other carers are often going through similar experiences, as our data show. Perhaps you could reach out to a carers organisation to talk about these experiences?**

The complexities of concealment

Hopefully, through the examples explored above, you have been able to identify some familiar concerns with respect to the role of concealment in your care practice.

In engaging with these examples, we hope you can see that there are usually no right or wrong answers. Often, what matters more are the particulars of your relationship, past, present and future. You are the expert in that sense. The purpose of this resource is not to provide tips on when to engage in concealment or not, or in whether lies are right or wrong. Instead, it is simply to help you to reflect on your own everyday experiences of the complexities of concealment in care.

Please seek out support and help if you're struggling.



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See inside front cover for contact details about this booklet. Below you can find information about sources of support (correct as of August 2023, please see websites for most up-to-date information).

If you're a carer in Manchester and you need support, please consider contacting Manchester Carers Forum:

Telephone 07415436382

Monday to Thursday 9.30am to 4.30pm, Friday 9.30am to 2pm

Email info@manchestercarersforum.org.uk

Website: <https://www.manchestercarersforum.org.uk/>

If you live elsewhere in the UK please consider contacting:

Dementia UK:

Telephone: 020 8036 5400

Email: info@dementiauk.org

Website: <https://www.dementiauk.org/get-support/>

Alzheimer's UK:

Telephone: 0333 150 3456

Monday to Wednesday: 9am – 8pm. Thursday and Friday: 9am – 5pm. Saturday and Sunday: 10am – 4pm.

Website: <https://www.alzheimers.org.uk/get-support/dementia-support-line>

We would really appreciate your feedback on this resource. Once you have finished reading, please copy the below link into your web browser search bar or scan the QR code using your smartphone camera to complete a very short online survey. It will only take 1 minute to complete:

https://www.qualtrics.manchester.ac.uk/jfe/form/SV_elhZcxmrOc4lk3Q



