

## **Activity: Dementia is only part of my life**

### **A case study on avoidable difficulties**

This learning exercise is adapted from the SCIE Open Dementia Programme e-learning module, 'Common difficulties and how to help'.

Read the story below and consider the questions that follow.

Cynthia has Alzheimer's disease. She lives alone, following the death of her husband last year. Cynthia has two home care visits a day. Over the course of a week, these visits are undertaken by a large number of different staff. Cynthia has arthritis in her hips, and often finds it quite difficult to rise from her low armchair.

The home care staff only have short periods of time allocated for their visits, so they wash and dress Cynthia rather than helping her do it for herself. They choose her clothes because this is quicker. They rarely talk to her.

On the evening visit, Cynthia is given a sleeping pill. However, she wakes and rises very early and sometimes, when the morning home carer arrives, she finds that Cynthia has been up for some time and has already attempted to dress herself. However, since Cynthia has invariably forgotten to wash, the home carer tells her off and insists on undressing and washing her.

- What factors can you pinpoint in this short case study that could be creating avoidable difficulties for Cynthia?
- What specific difficulties could Cynthia experience as a result?
- What might help?

### **Trainer's notes**

If running this as a group activity, pair up participants first and ask them to complete the activity with their partner. Then, ask pairs to come back and share answers in a wider group discussion.

There are at least 10 problematic factors here – we've listed them below – and identified the difficulties that are likely to result.

#### **1. 'death of Cynthia's husband'**

Cynthia's recent bereavement could easily have led to depression which, in older people, can often cause confusion. Cynthia may need bereavement counselling and/or empathic support from her care staff to help her talk and express feelings about her husband's death.

#### **2. 'a large number of different staff'**

Cynthia is likely to experience problems recognising faces and remembering names because so many people are involved in her care. If she does not know her carers she is unlikely to feel safe with them, which could lead her to being resistant to care. Having a small, consistent team of staff who are known and trusted by an individual will avoid these difficulties.

3. 'arthritis'

If Cynthia is in pain, she may be withdrawn, restless or bad-tempered. She may even be aggressive, particularly if the painful area is touched by care staff. It is important to ensure that Cynthia has the appropriate medication and/or physiotherapy to help alleviate her pain.

4. 'low armchair'

With her arthritis, Cynthia clearly finds it difficult to rise from the low armchair. She may become agitated. She may not be able to get out of the chair in time to get to the toilet, and so may appear to be incontinent. Cynthia urgently needs an assessment by an occupational therapist to raise or replace the armchair.

5. 'short periods of time allocated for their visits, so they wash and dress Cynthia'

Those who commission care packages need to be aware that short visits will often create extra problems for people with dementia. If there is insufficient time available for staff to enable Cynthia to do things for herself, she will begin to experience difficulty carrying out everyday tasks for herself, and may eventually lose the capacity for self-care. The staff themselves also need to recognise that 'doing for' rather than enabling someone can often take longer, because the person may resist this disempowering approach.

6. 'They choose her clothes'

Making choices for Cynthia, rather than enabling her to do so herself, could lead to Cynthia experiencing decision-making difficulties.

7. 'They rarely talk to her'

This lack of communication could well make Cynthia withdrawn. She lives alone and her visits by home carers are her primary source of contact with the outside world. Cynthia will gradually lose communication skills because these skills are not being used. It does not take any extra time to explain tasks that are being undertaken, and to chat with someone while attending to their care needs. There is no excuse for failing to communicate with Cynthia.

8. 'sleeping pill'

Sedative medication will often create hangover effects, including increased confusion, impairment of memory and impaired performance of motor tasks. Sedatives can also be responsible for falls. Cynthia may not need this medication at all and it should be reviewed by her doctor.

9. 'tells her off'

Being told off for trying to maintain her own independence will be a very demoralising experience for Cynthia. She may become withdrawn. She may stick up for her rights and appear to be aggressive. Or she may simply give up trying, and eventually lose the capacity for self-care. Cynthia should be encouraged to do things for herself and validated for her efforts. It is also important for staff to focus on what's really important, and maybe it isn't essential for Cynthia to wash every day.

10. 'home carer insists'

Staff need to remember that Cynthia has the right to be in charge of her own life. Taking over and making Cynthia to conform to their own expectations is not appropriate. If Cynthia is having her rights denied, she may need to be aggressive in attempting to stick up for herself. Or she may feel so disempowered that she gives up, in which case she will lose the capacity for self-care

Remind learners that this list of difficulties looks like a list of symptoms of advanced dementia:

1. confusion
2. problems recognising faces and remembering names
3. resistant to care
4. withdrawn
5. restless
6. bad-tempered
7. aggressive
8. agitated
9. incontinent
10. difficulty carrying out everyday tasks
11. lose the capacity for self-care
12. decision-making difficulties
13. lose communication skills
14. impairment of memory
15. impaired performance of motor tasks
16. falls.

And yet, as we have seen, every single one of these difficulties had an avoidable cause. It is likely that Cynthia's dementia will appear to be much more severe than it actually is. Living with dementia is undoubtedly a challenge. People are faced with increasing difficulties in many aspects of their day-to-day lives. It is so important, therefore, to ensure that they are not also faced with additional difficulties that could have been avoided.

With a little extra planning, sensitivity and insight, we can ensure that people with dementia have the best possible chance of maintaining their abilities for as long as possible.