

Chapter 1 part 1

1.1 Chapter 1

1.2 Personal circumstances elements

At the start of this chapter, we showed you how dementia is a personal experience which is different for each individual. We will now show you the different aspects which can make up that experience.

Tom Kitwood, one of the major researchers in dementia, first introduced these personal circumstances as a sum:

Dementia Process = Neurological impairment + Physical Health + Social Psychology + Personality + Biography.

This sum helps to understand that the dementia process is complex and includes many different elements, not all related to the medical field.

1.3 Personality and biography

Consider the person's lifelong interests and hobbies. For example, Ted always loved football, so he will probably still enjoy it. Anne enjoyed cooking, so she will still enjoy it, she might just need a little support.

1.4 values and achievements

When you are with the person in your care, why don't you ask some questions that can remind you of their values and achievements?

1.5 Coping

Another aspect of personality is the way we cope with events. Throughout their lives, people with dementia met many challenges and coped in different ways: maybe they managed to find a job during a time of financial struggle, or the way they grieved the loss of a loved one.

People with dementia may use different ways of coping with the condition and the challenges that come with it. The way people cope is usually divided into 2 categories: self-maintaining, or self-adjusting. We will now look at both of them.

1.6 Self-maintaining

With self-maintaining coping, people try to maintain their level of functioning without taking into account the difficulties that dementia may cause. They continue to live life in their usual way, without including the notion of having dementia in their identity. In this case, people might be reluctant to show difficulties to others. Some of the coping mechanisms could be denial, or masking forgetfulness, an effort in having memory aids.

Example:

A woman with dementia who lives with her husband and her daughter's family has always cooked for everyone. One day, as she prepared a big meal, she placed the electric kettle on the gas cooker to boil water. When she noticed the burning smell, she realized her error, and hid the kettle in its box. When her husband noticed, she denied having difficulties preparing meals. The family noticed other difficulties, like potatoes served uncooked. On discussion, she refused to accept any help, as there was nothing wrong with her ability to cook. After further discussions, she accepted that the family don't need her to cook any more as they like different types of food.

1.7 Self-adjusting

With self-adjusting coping, people are aware that having dementia may cause some difficulties, and they may be more willing to take part in open discussions about their difficulties, and to accept help and support. Their coping mechanisms can include using a diary, relying on their carers' memory, keeping a routine.

Example:

A woman with dementia who lives with her husband and her daughter's family has always cooked for everyone. One day, as she prepared a big meal, she placed the electric kettle on the gas cooker to boil water. She realized that she couldn't achieve multitasking as it is needed when you cook big meals. After discussing the issue with her family, she agreed to cook meals for her husband with his help, and to let her daughter cook for her own family.

1.8 Coping, the view of the person with dementia

It is important to consider these coping mechanisms when we think about individualized care. A person coping with dementia by self-adjusting to the condition is usually more willing and more likely to accept help and change their lifelong routines. A person coping with dementia by self-maintaining their previous level of being might be more reluctant to accept help and change their way of being.

Click on the video to hear someone with dementia talk about how they cope.

1.9 Social context

Another important factor to consider is the social network of the person with dementia. The primary question is whether there is such a social network, and if there is, how positive is it?

Social networks are different for each individual. Ted's social network is built around the pub, and the Men's shed. Ann's social network includes the hairdresser's and art galleries.

1.10 Positive social environment

It is important that we provide a positive and stimulating social environment to the person with dementia. However, life events sometimes make us to act in a way that we mightn't be very proud of. Everyone does act that way at times, but we should all try to

avoid these behaviours. Tom Kitwood has called them "malignant social psychology".

For him, they include

- Treachery - using some form of deception to distract or manipulate the person with dementia
- Disempowerment - not allowing them to use the abilities they may have
- Infantilization - treating the person with dementia as if they were a child
- Intimidation - inducing fear in the person, by threats or physical power
- Labelling - categorizing people as demented or mad
- Stigmatization - treating the person as if they were an alien or an object
- Outpacing - interacting at a rate which is too fast for the person with dementia
- Invalidation - failing to take into account the reality and feelings of the person with dementia
- Banishment - excluding the person, treating them like an object
- Disparagement - telling a person they are useless.

1.11 Physical health

The physical health of the person with dementia is an important factor to consider when planning care and support. Physical health includes everything from physical fitness to overall wellbeing.

It is very common for people with dementia to have another co-existing health problem. Think of how physically active the person with dementia is. Do they have any of these conditions?

- Diabetes
- Hypertension
- Depression
- Undernutrition and weight loss
- Urinary incontinence
- Urinary tract infection
- Hearing and visual impairment
- Pain
- Falls
- Dizziness

It is important to keep an eye on their state of health, and to look out for signs that the person may be in pain or discomfort.

1.12 Neurological impairment

Two main factors need to be considered when thinking of the suitability of care and support: they are the level of impairment, and the awareness of having dementia.

Neurological impairment refers to the level of difficulties caused by dementia. Depending on how severe the impairment is, the person might display more difficulties.

Awareness is how the person with dementia understands and judges that these difficulties are caused by dementia.

People with dementia are often diagnosed with different stages of dementia, including early, moderate and late dementia. While this may give some indication of the level of impairment and awareness, it is important to note that the level of impairment and the awareness of dementia vary from person to person, regardless of the stage of dementia. We should not assume that all people in the early or moderate stages will have the same level of functioning and will respond equally well to the same care or support.

1.13 conclusion

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1.14 For more information

The Elevator logo is repeated at the top left of the teal box.

Coping Skills for Families and Carers

**You have finished: Personal Circumstances
in Chapter 1: Focusing on the Person.**

**You can now go to
Part 2: How to focus on the person**

**for more information, go to
[Dementia Elevator](#)**