How can we best understand dementia?

Dementia causes a set of problems that are related to each other. These include memory loss, trouble communicating, confusion and difficulty with walking around. There might be difficulty with recognising people they know, even if they are close friends and family members. Although it is a medical issue, it is better to think in terms of a change in how the person experiences the world. The aim is to try to understand what the person is experiencing. Then the physical and social environment can be adjusted to be safe and not distress them. Since no two people have dementia in the exact same way, what needs to be done will also not be the same for any two people with dementia.

How is sleep different for people with dementia?

Up to half the people with dementia will have a sleep pattern that is not normal. They are often sleepy during the day and have difficulty with sleeping for long periods at night. They may have less deep, restful sleep and a lighter sleep. This could be due to dementia directly or due to changes in how they perceive the world. Some forms of dementia can disrupt the Body Clock. See also Ageing and Sleep.

What are the causes of these changes in sleep?

There are many possible causes of these sleep changes. The way that the brain controls sleep may be changed. The person may have unmet needs or problems such as pain.

Important Things to Know About Dementia and Sleep

- Up to half the people with dementia have difficulty with sleeping.
- Good sleep is important for people with dementia to improve daytime function.
- Patients with dementia might be tired during the day, but not be able to sleep well at night.
- It is best to keep the same sleep/wake times and routine as before the dementia began.
- Some drugs used to treat dementia may also affect sleep.
- It is good to nap during the day and the best time for this is before lunchtime.
- A person with dementia might wander at night, but there are ways to reduce this.

They may have had sleep problems in the past, or they might be living in a place where it is hard to sleep well. It is also possible that their poor sleep may be linked to breathing or other sleep related problems such as Obstructive Sleep Apnoea, Snoring or Periodic Limb Movements.

Some medications may affect sleep, including those that are used in dementia. These include pain relievers, drugs to treat Parkinson’s disease and antidepressants.

What do these sleep problems lead to?

Not getting enough sleep will lead to a lower quality of life and greater difficulty with functioning during the day. The person may be tense, sleepy, have problems focusing, fall over or have mood problems such as depression. They may talk in their sleep, wake up often and may wander around during the night.

Wandering is of great concern for carers. It disturbs the carer’s sleep and may be a danger for the person with dementia. This means that the at-home carer also has trouble getting enough sleep.

What can be done to make sure a person with dementia gets enough rest?

As a rule -

- Try to get them to have sleep and wake patterns that reflect their sleep habits from the past that they found helpful. For example, if they used to fall asleep to music,
then they should be allowed music. Or, if they typically
got up early, then they should still keep getting up at the
same time.

- The use of Melatonin has been tried with people living
with dementia and did not help.
- Massage has been found to help for some people.
- Keep the same getting-ready-for-bed routine from the past.
- See also Good Sleep Habits.

**During the day**
- It is important to stay active.
- Being exposed to bright light or sunlight controls
Melatonin levels and sends the brain a message to be
awake. Outdoor light in the morning and in the evening
helps keep the Body Clock on a stable routine.
- Older people need fluids but these should be reduced in
the afternoon and evening.
- About 4 in 10 older people have naps. Short naps may be
helpful if there is inadequate sleep at night. It is better if
the naps are before lunch so the person is more tired
when they go to bed.

**During the night**
- The sleep room should be dark and quiet at night. Often
people with dementia wake up and think it is morning if
there is light.

For safety and finding the way at night, use red or amber
lighting. Lights of these colours are less alerting.
Try acting out a “going to bed” routine for them to copy.
If a person really wants to be up at night, do not force them
to be in bed or to sleep. They need an accepting
environment that helps them feel safe.

**How can we help people who wander at night?**

When people living with dementia wander at night they
don’t get as much good sleep. This lowers their quality of
life. Don’t just assume that wandering is a result of
dementia. Often things can be done to help. You could try
the following:
First think about the history of the person. If they have had
different sleep patterns in the past, they may be trying to
get back to that routine.

- It could be that there is a ‘cause’ that makes them wander.
  There might be something around them that disturbs them.
- Some experts believe that people with dementia get
disturbed by things around them more easily. This could be
  the case if they wander at the same time every night. It is
  also likely if others in the same room or house are having
trouble sleeping.
- Finally, wandering may stem from a problem or unmet
need. The person may not be able to express what is wrong
using words. They may be moving due to pain, lack of
comfort, feeling lonely, fear, not being familiar with what is
around them, or many other things. The behaviour can be
aiming to meet the need. For example, they might be pacing
because they are bored. If they are saying the same thing
over and over, it may be that they are trying to tell you
about an unmet need. Finally, abnormal behaviour may be
the result of an unmet need e.g. screaming from frustration
or pain.

**What are the effects on the family carers
of people with dementia?**

There are six main things that disrupt the sleep of family
carers:
- Having to provide physical care
- Being ready to give care
- Keeping an watch over them
- Disruptions because of what the person with dementia
does
- Worry
- Continued sleep disruption even after care duties end

It helps if carers know about these concerns and understand
they are not unusual. They can start to deal with them with
support from helpers or health care providers.

**Where can I find more information?**