DREAMS: START

Dementia Related Manual for Sleep:

Strategies for Relatives

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UCL Division of Psychiatry
6th Floor Maple House
149 Tottenham Court Road
London W1T 7NF
United Kingdom

Introduction

- This is your manual to use.
- These sessions are about you, your relative and how sleep problems affect you both.
- They are based on **what has been shown to work**, and **what we know about people with dementia and with sleep problems**.
- Over the next few weeks we will work together to:
    - Understand your relative's sleep pattern
    - Try out new strategies to help
    - Use information about sleep problems in dementia
    - Develop a regular sleep pattern for your relative and help you sleep too
- You may feel **'I have tried it all before'** and you are probably already using some of the strategies. We hope to build on what you do now and introduce new ideas, doing more of what works and less of what does not.

Key Point:

Although not all difficulties will change. Putting what you learn in DREAMS: START into practice should make things better.

What to expect

- Our discussions will be based on **you and your relative's experiences**.
- We will make a plan together to improve sleep **based on** the particular challenges you and your relative face, as with sleep, it is not 'one size fits all'.
- You will **put strategies into practice** during, and between sessions.

There will be six sessions each lasting **one hour and each will include:**

- A new topic to discuss.
- Making a plan for you to try out between sessions.
- A new way of reducing stress for you and your relative.
- Ways to monitor progress between sessions.

DREAMS: START

Session 1: Understanding sleep and dementia
Session 2: Making a plan
Session 3: Daytime activity and routine
Session 4: Difficult night-time behaviours
Session 5: Taking care of your own sleep
Session 6: What works? Using strategies in the future

DREAMS: START

Session 1:

Understanding sleep and dementia

Plan for today

Sleep and dementia	p. 7
What is sleep?	p. 8
What causes sleep problems in dementia?	p. 12
Making changes to improve sleep	p. 13
The impact of sleep problems on you and your relative	p. 20
Managing the stress that sleep problems can bring	p. 21
Managing stress: The signal breath	p. 22
Summary	p. 24
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Sleep and dementia

Talking point:

Tell me about your relative's sleep problems?

- Sleep disturbance is very common in dementia. 50-90% of people with dementia have disturbed sleep at some point.
- Sleep difficulties can often start several years before being diagnosed with dementia and worsen as dementia becomes more severe.
- Some of the difficulties that you may see happening include:

☐ Waking up several times during the night, often confused

☐ Waking up too early

☐ Being very sleepy or falling asleep during the day

☐ Having a disturbed sleep pattern e.g. asleep during the day and awake at night

☐ Agitation or restlessness in the evening or at night

☐ Difficulty falling asleep

☐ Pacing or wandering

☐ Other_____

My father, he couldn't, he didn't seem to settle very well at all.

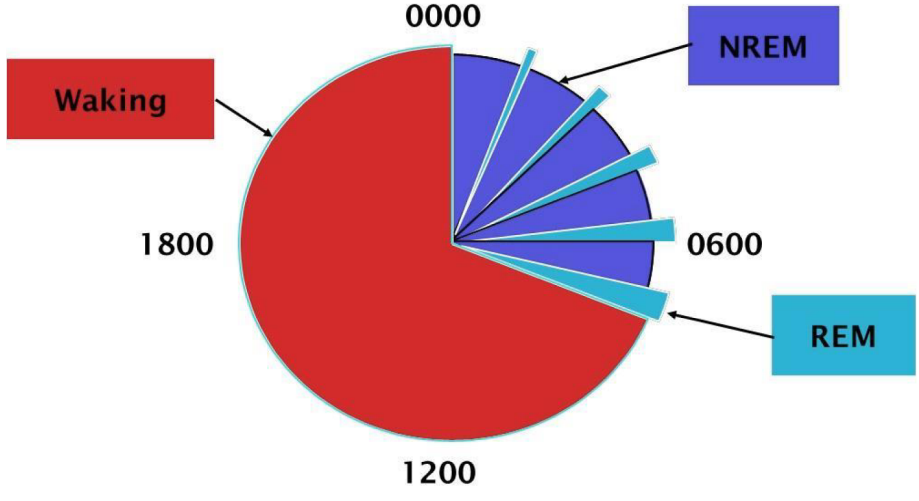
She's gone off to sleep and then I would notice that she's awake and realise that she was out on the landing again.

What is sleep?

Talking point:

What do you notice happening to you and your relative when you don't get a good night's sleep?

- Sleep is an important time for us to refresh our brain and body.
- The sleeping brain is not simply in "off-mode", but instead goes through various stages of sleep. Throughout the night we move between two types of sleep:
    - Non-REM (NREM) sleep happens more at the beginning of the night consisting of phases of light and deep sleep. When in the deepest sleep, we are harder to wake up.
    - REM (rapid-eye movement) sleep happens later in the night; here we experience brief bursts of eye movements and dream.
- The brain's 'sleep cycles' each last about 90 minutes, and move from NREM to REM sleep. Good sleepers typically have 4-5 sleep cycles each night.



A typical sleep-wake cycle for someone going to bed at midnight and getting up at 7am

How does sleep work?

- Sleep is automatic and controlled by two processes which work together so that we sleep well at night. These are:

    1. The Circadian Rhythm or ‘the body clock’
    2. ‘Sleep pressure’

Circadian rhythm

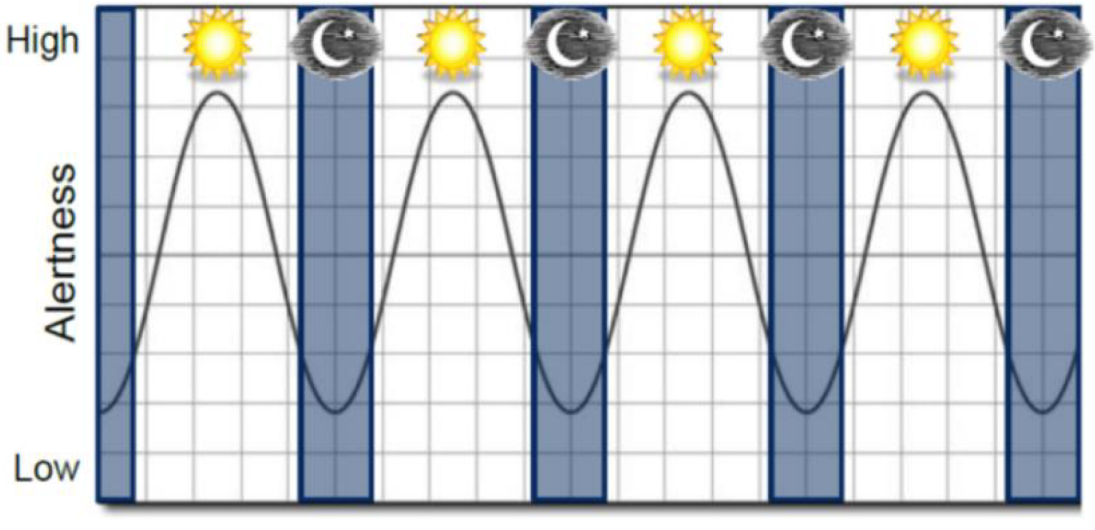
- Circadian rhythm is our body clock which helps us to make sense of our environment, for example when it will be light or dark. This shows our brains and bodies *when* and *how much to sleep*.

- The brain controls the body clock.

- When we sleep well at night, our body clock creates a balance and we feel refreshed and alert in the day.

- There are times when our body clock gets ‘out of sync’, for example, when jet-lagged.

- A good sleeper with a regular pattern will get up early in the morning feeling wide awake. This peaks around midday. After a ‘post lunch dip’ our wakefulness continues to fall until bedtime and sleep.



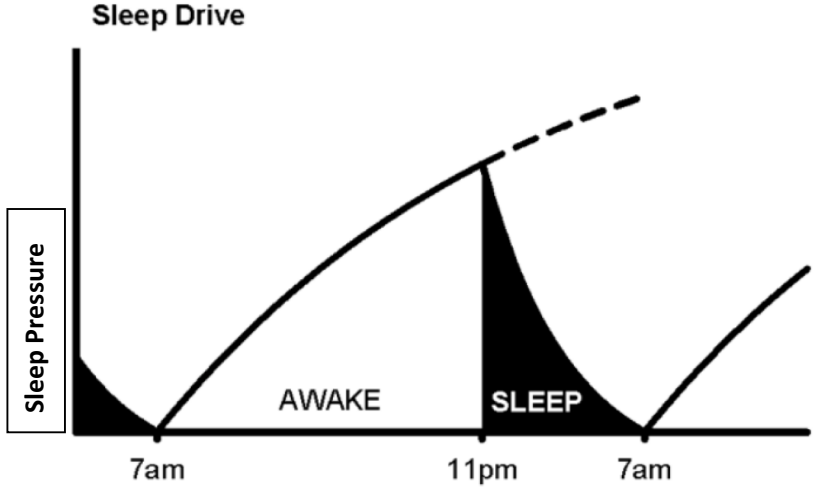
- Dementia can affect the part of the brain that controls our ‘body clock’.
- This can make people more alert or active at night and less alert or active during the day.
- Reduced physical activity, irregular meal times, and reduced exposure to natural sunlight can disrupt the “body clock” so that they wake more at night.
- Light, exercise and food all play a role in helping the brain and body to understand what time of day it is, allowing the brain to work out when it should be awake or asleep.

Key Point:

People with dementia often have a disrupted body clock which makes it harder to know when it is day or night

Sleep pressure

- 'Sleep pressure' is the brain's need for sleep. It increases the longer you are awake.
- When we wake up in the morning after a good night's sleep, we will have a very low sleep pressure. Sleep pressure will increase during the day until bedtime.
- By going to bed and having a good night's sleep, then sleep pressure will be reset for the start of the next day.
- So, at bed time, the 'sleep pressure' is at its highest, creating the perfect opportunity for sleep.



Why is sleep important?

- When we do not get enough sleep, our concentration, mood and memory is affected.
- We also know that people who have poor sleep over long periods of time are more likely to get health problems like cardiovascular disease and diabetes.
- Going to bed and getting up at the same times each day, makes us more likely to experience good quality sleep and therefore be awake, active and healthy during the day.

Talking point:

Did your relative have problems sleeping before the diagnosis, if so, what helped then?

What causes sleep problems in dementia?

Talking point:

People often have thoughts about what could be causing sleep problems in their relatives, is this something that you have thought about? What ideas have you had?

There are many reasons why sleep patterns are disturbed in dementia. Some changes occur as we become older and may affect you and your relative:

- ☐ Having more physical health problems, including pain
- ☐ Spending less time in deep restorative sleep and more time in lighter sleep
- ☐ Needing to go to the toilet more in the night
- ☐ Side effects of medication
- ☐ Not being active / napping during the day
- ☐ Not being in daylight
- ☐ Being confused about night and day
- ☐ Being frightened at night
- ☐ Going to bed very early and then waking up early

Making changes to improve sleep

- In our next session we will develop a plan to help you manage your relative's sleep difficulties based on the Actigraph information (wrist watch they wore), sleep diaries and our discussions today.

- In the meantime we will look at changes to your relative's lifestyle that can improve sleep.

Lifestyle factors that can impact on sleep:

Caffeine

- Caffeine perks you up and it can be good to have in the morning to help wake up!
- Most people know caffeine is in coffee and tea, but it's also in chocolate, some soft drinks (i.e. coke), and also in some medicines. Check labels if you are not sure.
- If someone naps during the day or goes to bed early in the evening, having caffeine up until 6pm may help them to stay awake during early evening.
- However caffeine's effects can last for many hours so it is a good idea not to give your relative any caffeine for 4 to 6 hours before bedtime, or even the middle of night. Try decaffeinated drinks.

Alcohol

- Alcohol can disrupt sleep and may make your relative more confused or likely to fall.
- Alcohol may help people fall into a deep sleep at the beginning of the night, but it will then lead to disturbed sleep later in the night.
- Limit it to one small glass of wine or half a pint of beer. Do not drink a lot of alcohol in the evening.

Nicotine

- Nicotine in cigarettes has effects like caffeine on sleep, making it harder to fall asleep and to stay asleep.
- If you or your relative smoke, try to cut down in the evening before you go to bed, and try not to smoke at all during the night.

Diet

- Hunger can wake people, so a light snack a little before bedtime can help sleep, but going to bed too full can disturb sleep.

- It may be true that milk and other dairy products help to promote sleep and, usually, makes people less hungry.

- Try to avoid giving your relative snacks during the middle of the night as the body may come to expect food at this time and it will get in the way of having a good day and night pattern.

Exercise

- People who are physically active have a better quality of sleep, so a good way to promote sleep is to get active, by exercising three times a week for 20-30 minutes!

- The type of exercise you and your relative do really depends on what you enjoy and your ability. We will be talking more about activities in future sessions.

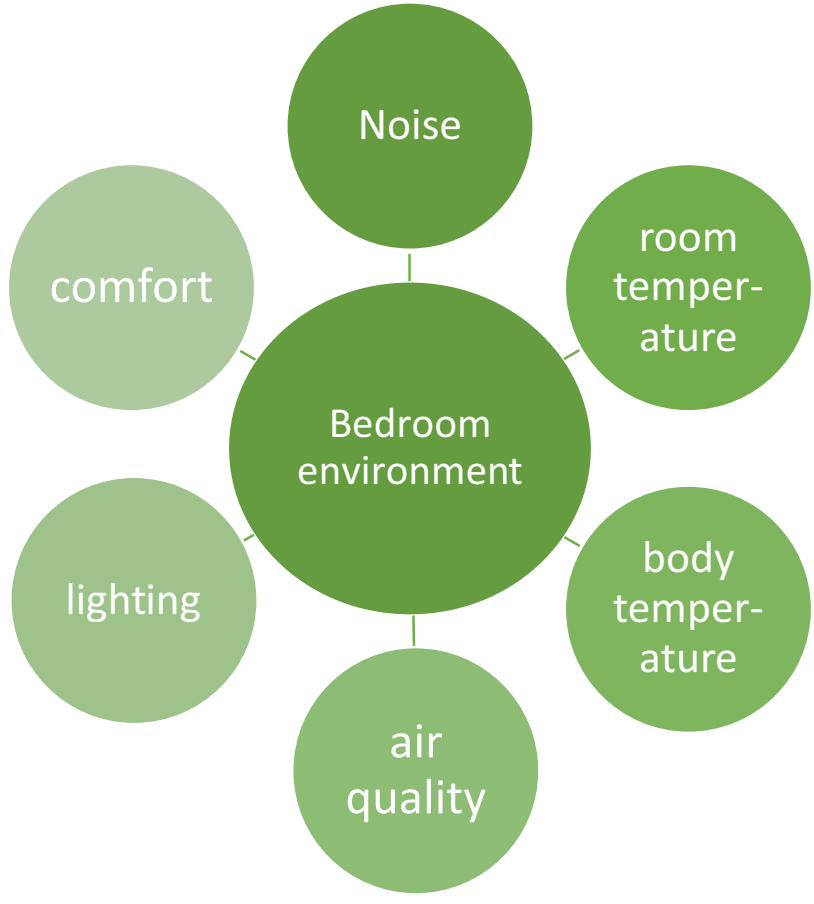
Pain

- Although pain is not a lifestyle factor it can interfere with sleep, and your relative may not be able to tell you if they are in pain.

- Do you feel your relative is in pain? If so, what do you do to manage the pain? And does it help?

The bedroom environment

Being in relaxed surroundings is important for everyone, however people with dementia are particularly sensitive and discomfort makes it harder to sleep.



Noise

- Unexpected, sudden, loud noises will stop most people sleeping. It may also be difficult to fall back asleep having woken up. However, people can get used to noise after a while.

- Nonetheless sleep may be lighter if there is noise, so try and make sure the bedroom is as quiet as possible.

Room Temperature

- The recommended room temperature for most people is around **18° C**.

- Being too hot or too cold affects sleep. A hot room (more than 24° C) leads to restless and broken sleep. A cold room (less than 12° C) makes it difficult to get to sleep and can cause unpleasant and emotional dreams.

- It is a good idea to have a thermometer in the bedroom to help you get the blend of fresh air and temperature about right during different seasons.

Body Temperature

- Some people like a hot bath to relax before bed. However, poor sleepers often feel hot. We can best prepare for bed by having a bath about two hours before bedtime.

Air quality

- A stuffy room may cause an uncomfortable sleep. Fresh air promotes sleep. It may help to open a window for a bit before going to bed.

Lighting

- Too much light keeps people awake. Strong street lighting and thin curtains should be avoided! The simplest solution is to cover windows with thick curtains or blinds. Curtains in dark colours especially help to block out light.

- If you are worried about your relative getting confused or distressed when they wake up in the dark, you could try a plug-in night light that gives a little light, but is not too bright.

Comfort

- Feeling worried, frightened or upset can keep all of us awake, including when we wake in the middle of the night. This is no different for people with dementia, who may become especially agitated around bedtime.

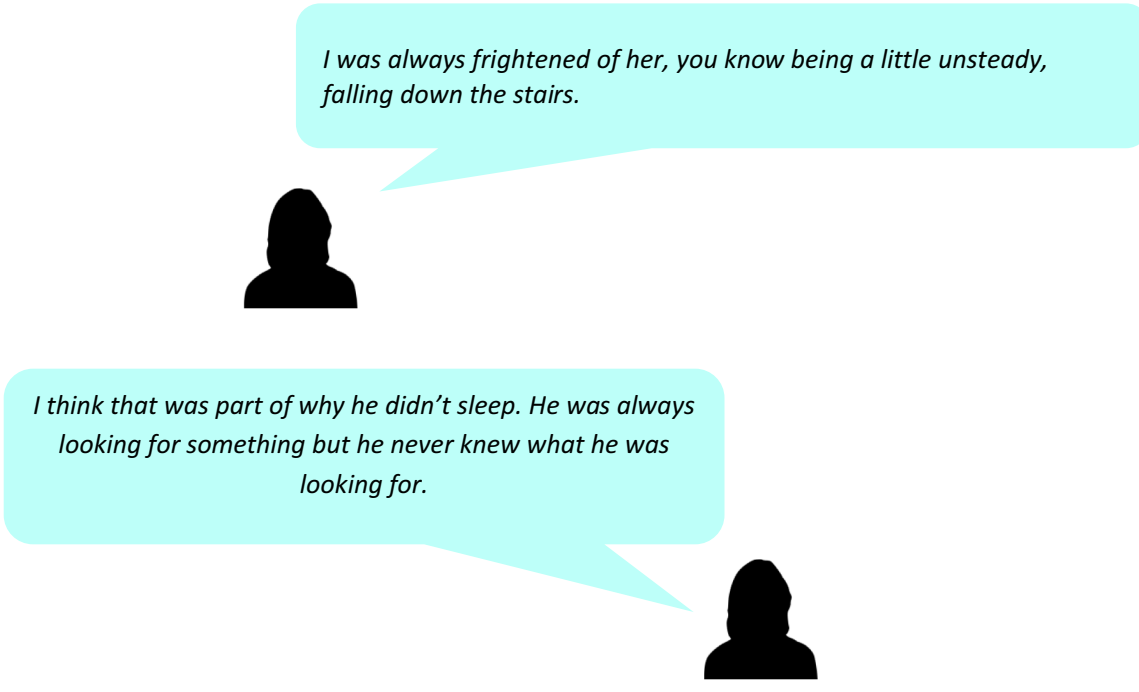
- As well as having a relaxing bedroom, have a bedtime routine, including soothing activities, like a hand massage or listening to music, may help relax your relative before bed. If it's in the middle of the night, you can reassure them it is safe.

My mother likes to have a hot water bottle or something … I think she finds comfort in that to help her sleep

You know, we sleep in single beds but for her to fall asleep I go to hold her hand and wait until she is fast asleep.

Let's fill in the changes you mentioned (on the table on page 28)…

The impact of sleep problems on you and your relative



Which sleep problems are the most distressing for your relative?

Out of these, which one causes you the most stress?

How do your relative's sleep problems affect you and your own sleep?

Key Point:

If you are worried about your relative hurting themselves or falling at night, social services or your GP can advise you on 'telecare' and how to reduce any risks.

Managing the stress of sleep problems

- Caring for people with dementia can be physically and emotionally draining, especially if you are not sleeping well.

- Over time, stress can impact on your health and well-being and affect your sleep. While the challenges cannot be avoided, you can take steps to reduce the effect on you.

Common stress reactions include feeling:

Key Point:

We will provide you with some new skills and techniques which do not take up too much time and which are easy to do at home, even when your relative is around.

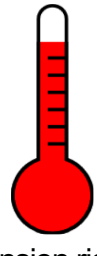
DREAMS: START

Managing Stress 1:

The Signal Breath

- The Signal Breath is a simple stress reduction technique that may help when you are coping with stressful situations.
- You can use it *anywhere*, at *any time*, and it is *quick*.
- Your relative may enjoy trying these exercises as well. Being more relaxed may help improve their sleep.

Stress Rating Before Exercise



5 = Terribly tense
4 = Really tense
3 = Moderately tense
2 = Slightly tense
1 = Not at all tense

- First, please rate your level of stress or tension right now, before we practice the signal breath.

Q! **On a scale of 1 to 5, how would you rate your tension? _____**

Summary

Today, we have talked about:

- Sleep and dementia
- What is sleep?
- What causes sleep problems in dementia?
- Making changes to improve sleep
- The impact of sleep problems on you and your relative
- Managing the stress that sleep problems can bring
- Managing stress: The signal breath

Key Point:
Although sleep difficulties in dementia are different for everyone and may be very complicated, there are small changes that you can try which may make a difference.

FOR NEXT WEEK: *Putting it into practice*

- **The signal breath:**

  Try to practice this every day and to use it in stressful situations. See if it helps.

- **Lifestyle and bedroom changes:**

  Please try out at least three of the changes you suggested on p.28 over the next week. There is a planning record on p.27 which you can note how it is going.

- **Sleep diary:**

  Please complete the sleep diary on p.26 about your relative's sleep each day over the coming week and bring it with you next time.

DREAMS: START *Putting it into Practice*

- Is there anything that might get in the way?
- Is there anything that might make it easier?
- **You can listen to these managing stress exercises any time on your CDs or by visiting: https://soundcloud.com/dreams-start**

Weekly Sleep Diary

Date	Noon	1pm	2pm	3pm	4pm	5pm	6pm	7pm	8pm	9pm	10pm	11pm	12am	1am	2am	3am	4am	5am	6am	7am	8am	9am	10am	11am
Tuesday May 14th	O		N							/			X X		X				/				N	O

Key:

/ = When your relative went to bed and when they got up in the morning

X = Every time your relative gets up in the night

N = When your relative takes a nap during the day

O = When your relative has been out of the house

E = When your relative has done any physical exercise

Planning record

- Here is a way of monitoring how the changes have gone for you and your relative.

Date(s)	What did you try?	How did it go for your relative?	How did it go for you?

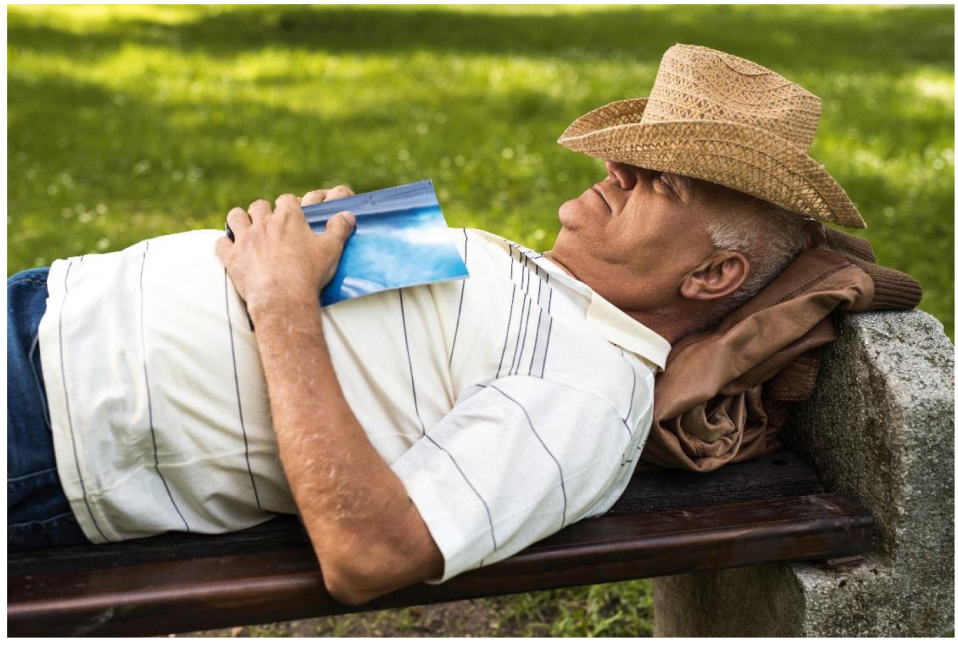
Changes to improve sleep

Lifestyle or bedroom changes to improve your relatives sleep	
1.	4.
2.	5.
3.	6.

DREAMS: START

Dementia Related Manual for Sleep: Strategies for Relatives

Facilitator Version



Facilitator Key
Numbers in blue boxes let you know how long each section should take.
Information in yellow boxes give instructions on how to facilitate tasks, as well as prompts for feedback and discussion.
Quotations in orange boxes are phrases you should say directly.

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General Tips for facilitating the intervention

Before you start:

- BE PREPARED: Be prepared for each session, bring all materials and equipment and when appropriate integrate individual data in advance of the session.

- STICK TO TIME, try and follow time guidelines for each section. Give yourself a few minutes to get organized and engage the carer before you start.

You will need:

- Manuals
- Pens
- Watch
- Relaxation CDs
- Light box
- Exercise leaflets and CD

General tips:

- If you feel that the examples are not relevant to the carer, try to think with the carer and between sessions of more relevant examples. **If a section really does not apply to them, for example their relative does not nap during the day or is already very active, then miss these bits out.**

- Carers will understand and use ideas from the manual at a difference pace and will vary in their literacy levels. It is important to adapt the pace to match the person you are delivering to. Repeat ideas if that is necessary.

- Encourage carers to write down key ideas and plans.

- Be observant; notice which sections work well and how the carer responds. Keep notes on what worked well and any challenges you faced.

- Undoubtedly problems will arise in sessions that haven't been anticipated. These should be recorded after the session to discuss during supervision.

- Balance making carers feel listened to and understood, with keeping focused on the manual. During talking points – facilitate discussion whilst being aware of sticking to time.

Key themes:

- Carers have a great deal of experience, it is important to value their experience and build upon their existing strategies and knowledge throughout the sessions.

- The importance of trying out tasks between sessions is highlighted in the first session. Try to reinforce the benefits of doing tasks throughout and offer encouragement when between session tasks have been completed.

5 mins

Introduction

Introduce yourself and ask: "What would you like me to call you" Remember what term they prefer and use it throughout the sessions.

"You can draw diagrams or write in it and you can look back over the manual in between sessions and after the sessions are finished".

- This is your manual to use.
- These sessions are about you, your rela
  both.
- They are based on **what has been shown to work**, and **what we know about people with dementia and with sleep problems**.
- Over the next few weeks we will work together to:
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  - Try out new strategies to help
  - Use information about sleep problems in dementia
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"Each of the 6 sessions are outlined below for you to refer back to."

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Session 1: Understanding sleep and dementia
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DREAMS: START

Session 1:

Understanding sleep and dementia

Plan for today

"This is the contents page for you to refer back to"

Refer to the contents but do not read the full list

Sleep and dementia	p. 7
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5 mins

Sleep and dementia

Talking point:

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- Sleep disturbance is very common in dementia. 50-90% of people with dementia have disturbed sleep at some point.
- Sleep difficulties can often start several years before being diagnosed with dementia and worsen as dementia becomes more severe.
- Some of the difficulties that you may see happening include:

"Tick the ones which you feel apply for your relative." Discuss any difficulties that have not been ticked/mentioned…

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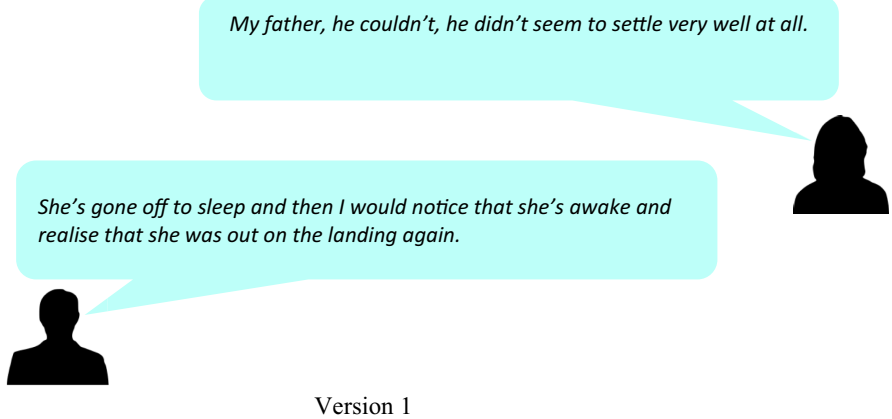

10mins

What is sleep?

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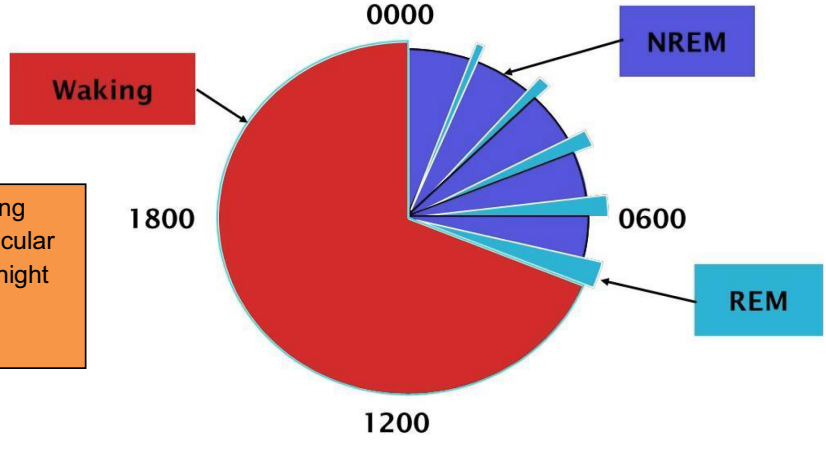
"Do you think being woken up at particular times during the night are worse than others?"



A typical sleep-wake cycle for someone going to bed at midnight and getting up at 7am

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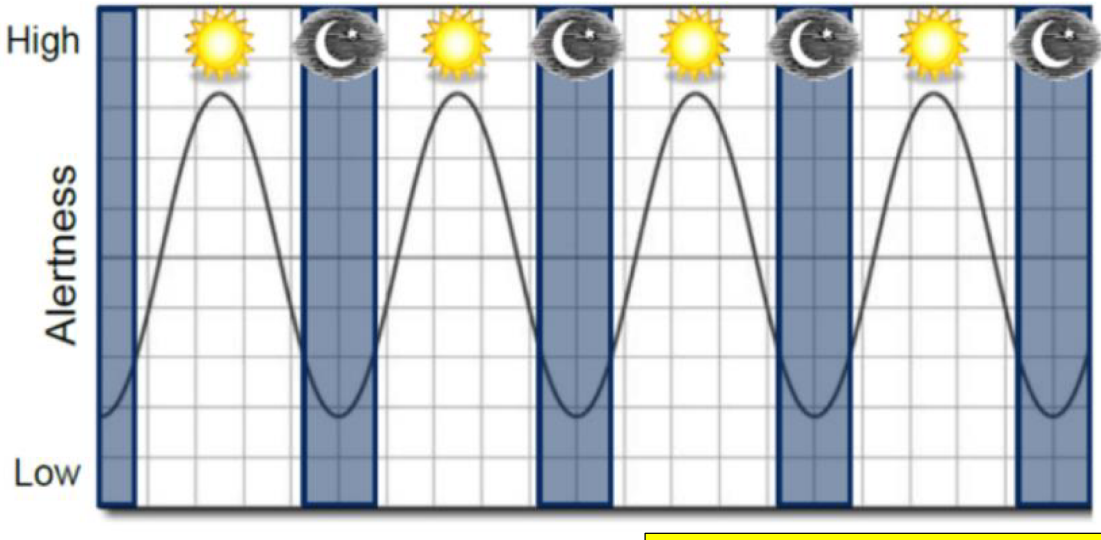

Check that they have understood circadian rhythms, if not, clarify.

- Dementia can affect the part of the brain that controls our ‘body clock’.
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- Reduced physical activity, irregular meal times, and reduced exposure to natural sunlight can disrupt the “body clock” so that they wake more at night.
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People with dementia often have a disrupted body clock which makes it harder to know when it is day or night

Sleep pressure

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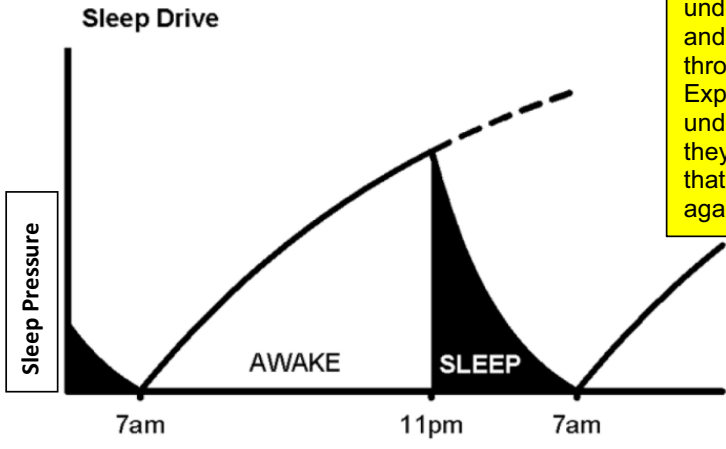
- When we wake up in the morning after a good night's sleep, we will have a very low sleep pressure. Sleep pressure will increase during the day until bedtime.
- By going to bed and having a good night's sleep, then sleep pressure will be reset for the start of the next day.
- So, at bed time, the 'sleep pressure' is at its highest, creating the perfect opportunity for sleep.

Check that they have understood 'sleep pressure' and if not, explain it / talk through the diagram again. Explain that if they do not understand any of the ideas they should let you know so that you can talk through it again.



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- When we do not get enough sleep, our concentration, mood and memory is affected.
- We also know that people who have poor sleep over long periods of time are more likely to get health problems like cardiovascular disease and diabetes.
- Going to bed and getting up at the same times each day, makes us more likely to experience good quality sleep and therefore be awake, active and healthy during the day.

Talking point:

Did your relative have problems sleeping before the diagnosis, if so, what helped then?

5 mins

What causes sleep problems in dementia?

Talking point:

People often have thoughts about what could be causing sleep problems in their relatives, is this something that you have thought about? What ideas have you had?

There are many reasons why sleep patterns are disturbed in dementia. Some changes occur as we become older and may affect you and your relative:

"Let's go through this list, tick the ones that you think may apply to your relative"

- ☐ Having more physical health problems, including pain
- ☐ Spending less time in deep restorative sleep and more time in lighter sleep
- ☐ Needing to go to the toilet more in the night
- ☐ Side effects of medication
- ☐ Not being active / napping during the day
- ☐ Not being in daylight
- ☐ Being confused about night and day
- ☐ Being frightened at night
- ☐ Going to bed very early and then waking up early

If it seems that there may be untreated medical problems or medication side effects recommend that they discuss with a pharmacist or a GP

10mins

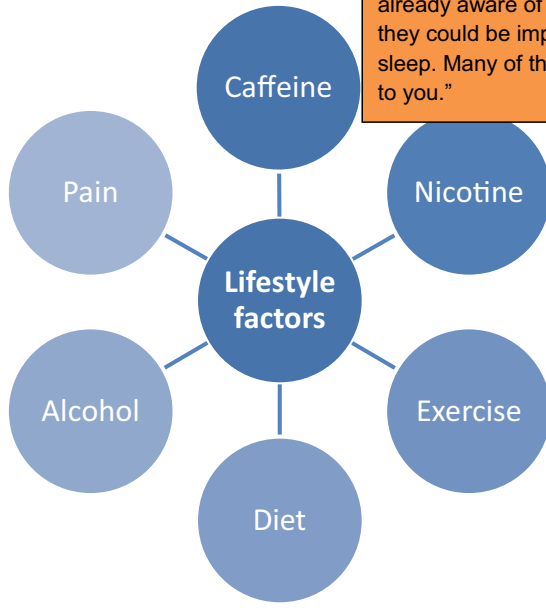
Making changes to improve sleep

- In our next session we will develop a plan to help you manage your relative's sleep difficulties based on the Actigraph information (wrist watch they wore), sleep diaries and our discussions today.

- In the meantime we will look at changes to your relative's lifestyle that can improve sleep.

"Some of these ideas will be familiar to you and may seem obvious, whilst others may be new. Even with the factors you were already aware of it is worth considering if they could be impacting upon your relative's sleep. Many of these factors will also apply to you."

Lifestyle factors that can impact on sleep:



As you go through the factors ask "What do you think could help?" to any factor that the carer feels is contributing to sleep difficulties.

"Tell me if each of these applies to your relative"

Caffeine

- Caffeine perks you up and it can be good to have in the morning to help wake up!
- Most people know caffeine is in coffee and tea, but it's also in chocolate, some soft drinks (i.e. coke), and also in some medicines. Check labels if you are not sure.
- If someone naps during the day or goes to bed early in the evening, having caffeine up until 6pm may help them to stay awake during early evening.
- However caffeine's effects can last for many hours so it is a good idea not to give your relative any caffeine for 4 to 6 hours before bedtime, or even the middle of night. Try decaffeinated drinks.

Ask if they or their relative drink alcohol

Alcohol

- Alcohol can disrupt sleep and may make your relative more confused or likely to fall.
- Alcohol may help people fall into a deep sleep at the beginning of the night, but it will then lead to disturbed sleep later in the night.
- Limit it to one small glass of wine or half a pint of beer. Do not drink a lot of alcohol in the evening.

Ask if they or their relative smoke

Nicotine

- Nicotine in cigarettes has effects like caffeine on sleep, making it harder to fall asleep and to stay asleep.
- If you or your relative smoke, try to cut down in the evening before you go to bed, and try not to smoke at all during the night.

Diet

- Hunger can wake people, so a light snack a little before bedtime can help sleep, but going to bed too full can disturb sleep.

- It may be true that milk and other dairy products help to promote sleep and, usually, makes people less hungry.

- Try to avoid giving your relative snacks during the middle of the night as the body may come to expect food at this time and it will get in the way of having a good day and night pattern.

Exercise

- People who are physically active have a better quality of sleep, so a good way to promote sleep is to get active, by exercising three times a week for 20-30 minutes!

- The type of exercise you and your relative do really depends on what you enjoy and your ability. We will be talking more about activities in future sessions.

We know that for some people moving at all can be difficult. In session three we will introduce a seated exercise plan for those with limited mobility. You can listen to this on: https://soundcloud.com/dreams-start and in session 3 we will talk more about putting it into practice.

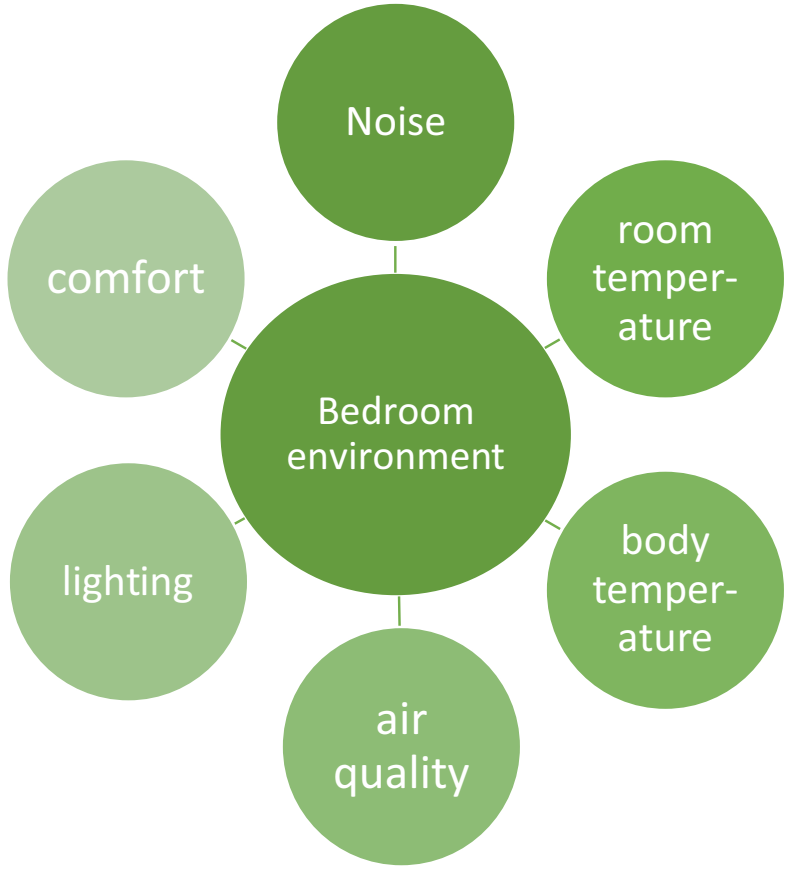
Pain

- Although pain is not a lifestyle factor it can interfere with sleep, and your relative may not be able to tell you if they are in pain.

- Do you feel your relative is in pain? If so, what do you do to manage the pain? And does it help?

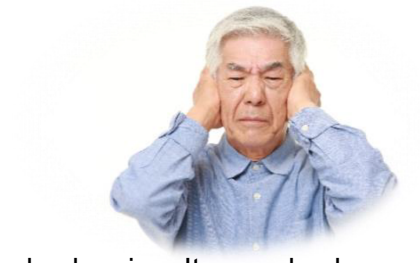
The bedroom environment

Being in relaxed surroundings is important for everyone, however people with dementia are particularly sensitive and discomfort makes it harder to sleep.



Ask “What do you think could help?” to any factor that the carer feels is contributing to sleep difficulties.

“Tell me if each of these applies to you”.



Noise

- Unexpected, sudden, loud noises will stop most people sleeping. It may also be difficult to fall back asleep having woken up. However, people can get used to noise after a while.

- Nonetheless sleep may be lighter if there is noise, so try and make sure the bedroom is as quiet as possible.

Room Temperature

- The recommended room temperature for most people is around **18° C**.

- Being too hot or too cold affects sleep. A hot room (more than 24° C) leads to restless and broken sleep. A cold room (less than 12° C) makes it difficult to get to sleep and can cause unpleasant and emotional dreams.

- It is a good idea to have a thermometer in the bedroom to help you get the blend of fresh air and temperature about right during different seasons.

“Does your relative shower or bath?”

Body Temperature

- Some people like a hot bath to relax before bed. However, poor sleepers often feel hot. We can best prepare for bed by having a bath about two hours before bedtime.

Air quality

- A stuffy room may cause an uncomfortable sleep. Fresh air promotes sleep. It may help to open a window for a bit before going to bed.

Lighting

- Too much light keeps people awake. Strong street lighting and thin curtains should be avoided! The simplest solution is to cover windows with thick curtains or blinds. Curtains in dark colours especially help to block out light.

- If you are worried about your relative getting confused or distressed when they wake up in the dark, you could try a plug-in night light that gives a little light, but is not too bright.

Comfort

- Feeling worried, frightened or upset can keep all of us awake, including when we wake in the middle of the night. This is no different for people with dementia, who may become especially agitated around bedtime.

- As well as having a relaxing bedroom, have a bedtime routine, including soothing activities, like a hand massage or listening to music, may help relax your relative before bed. If it's in the middle of the night, you can reassure them it is safe.

"Different people like different strategies. One carer said…"

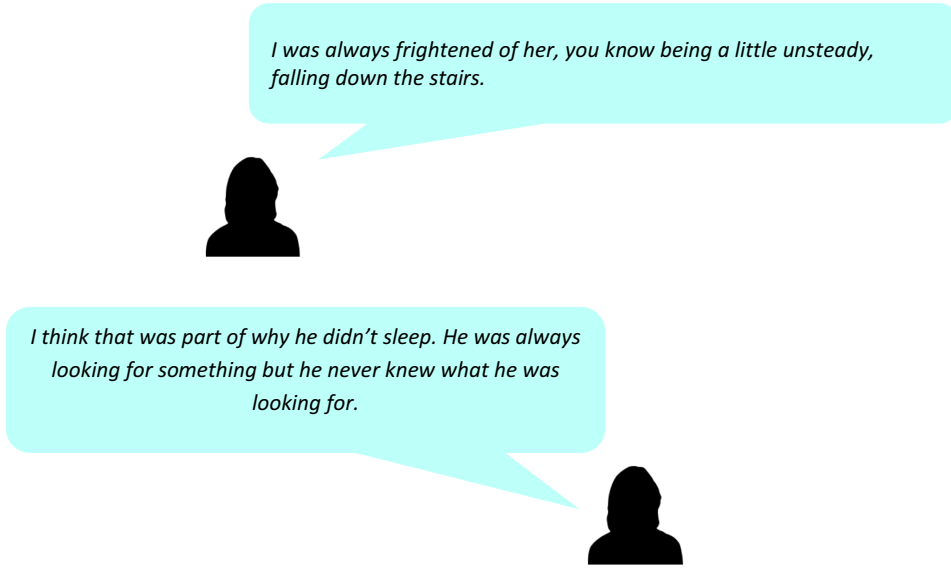
My mother likes to have a hot water bottle or something … I think she finds comfort in that to help her sleep

You know, we sleep in single beds but for her to fall asleep I go to hold her hand and wait until she is fast asleep.

Let's fill in the changes you mentioned (on the table on page 28)…

5 mins

The impact of sleep problems on you and your relative



Which sleep problems are the most distressing for your relative?

Out of these, which one causes you the most stress?

How do your relative's sleep problems affect you and your own sleep?

"Do you know about telecare?"

If no, then outline key point.

Key Point:

If you are worried about your relative hurting themselves or falling at night, social services or your GP can advise you on 'telecare' and how to reduce any risks.

10mins

Managing the stress of sleep problems

- Caring for people with dementia can be physically and emotionally draining, especially if you are not sleeping well.

- Over time, stress can impact on your health and well-being and affect your sleep. While the challenges cannot be avoided, you can take steps to reduce the effect on you.

Common stress reactions include feeling:

"You've talked about some of these emotions."

"Are there any other emotions that you experience?"

Key Point:

We will provide you with some new skills and techniques which do not take up too much time and which are easy to do at home, even when your relative is around.

"During the sessions we are going to help you to learn both how to recognise stress and gain control over it, we are not here to say, "When you are stressed, just relax", but to give you tools to reduce the effect on you. Some of the techniques will work for you and others won't, the key is to find the ones that fit for you. We are now going to try one of these techniques called the 'Signal breath…

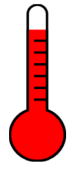
DREAMS: START

Managing Stress 1:

The Signal Breath

- The Signal Breath is a simple stress reduction technique that may help when you are coping with stressful situations.
- You can use it *anywhere*, at *any time*, and it is *quick*.
- Your relative may enjoy trying these exercises as well. Being more relaxed may help improve their sleep.

Stress Rating Before Exercise



5 = Terribly tense
4 = Really tense
3 = Moderately tense
2 = Slightly tense
1 = Not at all tense

- First, please rate your level of stress or tension right now, before we practice the signal breath.

Q! **On a scale of 1 to 5, how would you rate your tension? _____**

Summary

Today, we have talked about:

- Sleep and dementia
- What is sleep?
- What causes sleep problems in dementia?
- Making changes to improve sleep
- The impact of sleep problems on you and your relative
- Managing the stress that sleep problems can bring
- Managing stress: The signal breath

Key Point:
Although sleep difficulties in dementia are different for everyone and may be very complicated, there are small changes that you can try which may make a difference.

10mins

FOR NEXT WEEK: *Putting it into practice*

- **The signal breath:**

Try to practice this every day and to use it in stressful situations. See if it helps.

"If you would prefer to listen to the relaxation exercises on your smart phone or tablet you can access the MP3 files at: https://soundcloud.com/dreams-start
There is also a seated exercise plan that we will come to in session 3"

- **Lifestyle and bedroom changes:**

Please try out at least three of the changes you suggested on p.28 over the next week. There is a planning record on p.27 which you can note how it is going.

- **Sleep diary:**

Please complete the sleep diary on p.26 about your relative's sleep each day over the coming week and bring it with you next time.

DREAMS: START *Putting it into Practice*

- Is there anything that might get in the way?
- Is there anything that might make it easier?
- **You can listen to these managing stress exercises any time on your CDs or by visiting: https://soundcloud.com/dreams-start**

Weekly Sleep Diary

"Let's put tonight's date in the first box to get started…"

Date	Noon	1pm	2pm	3pm	4pm	5pm	6pm	7pm	8pm	9pm	10pm	11pm	12am	1am	2am	3am	4am	5am	6am	7am	8am	9am	10am	11am
Tuesday May 14th	O		N							/			X X		X				/				N	O

Key:

/ = When your relative went to bed and when they got up in the morning

X = Every time your relative gets up in the night

N = When your relative takes a nap during the day

O = When your relative has been out of the house

E = When your relative has done any physical exercise

Planning record

- Here is a way of monitoring how the changes have gone for you and your relative.

Date(s)	What did you try?	How did it go for your relative?	How did it go for you?

Changes to improve sleep

Lifestyle or bedroom changes to improve your relatives sleep	
1.	4.
2.	5.
3.	6.

DREAMS: START

Dementia Related Manual for Sleep: Strategies for Relatives

Session 2: Making a plan

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UCL Division of Psychiatry
6th Floor Maple House
149 Tottenham Court Road
London W1T 7NF
United Kingdom

Plan for today's session

Recap on understanding sleep and dementia	p. 3
Light and sleep	p. 4
Light, dementia and the body clock	p. 6
Your relative's sleep pattern	p. 13
Making a new sleep routine: Your relative's plan	p. 18
Managing stress 2: Focused Breathing	p. 19
Summary	p. 22
Putting it into practice	p. 23

Recap of session one: Understanding sleep and dementia

We talked about:

- Sleep and dementia
- What is sleep?
- What causes sleep problems in dementia?
- Making changes to improve sleep
- The impact of sleep problems on you and your relative
- Managing the stress that sleep problems can bring
- Managing stress 1: The signal breath

Q! **Did you make lifestyle or bedroom changes to improve your relative's sleep?**

Yes	No
• What changes did you try out? • How did it go? • What went well?	• What do you think got in the way? • What would make it easier in the future?

Yes	No
• How did it go? • What went well? • Did you notice any patterns?	• What do you think got in the way? • What would make it easier in the future?

Q! **Did you have a chance to complete the sleep diary?**

Light and sleep

- We talked about ‘sleep pressure’ and the ‘body clock’, the two ways our brain gives us a good sleep pattern.

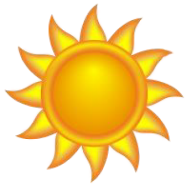
- We discussed how the body clock helps us sleep when it’s dark (at night) and be awake when it’s light (during the day).

- The body clock works out the time most importantly by sunlight because it is the brightest; but also by temperature and when mealtimes or activities happen.

- Sunlight during the day tells the brain and body that it should be awake; helping us to concentrate and be active.

- Regular light and being awake during the day helps us to sleep undisturbed through the night. This **creates a strong and stable sleep pattern.**

- Look at the picture on the opposite page.



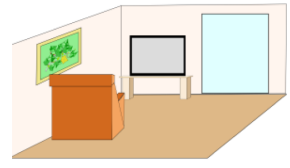
Sun overhead 100 000

10 000 Light box / light therapy lamp

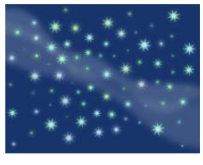
1000

Indoor light 30 – 500 lux

Circadian 'body clock' threshold 100



0.02 Full moon



Star light 0.0001

Light, dementia and the body clock

- You may have noticed that your relative mixes up night and day and is sleepy or wide awake at the wrong times.
- One reason for this is that dementia can damage the part of the brain controlling the 'body clock', giving people wrong signals about night and day.
- So people with dementia can be sleepier in the day or awake at night.
- As we get older our ability to see light through our eyes also gets worse, so less light gets to the body clock in the brain. This is worse in those with dementia.

Key Point:
Ensuring people with dementia receive enough light during the day is extremely important for their sleep at night

Losing track of time…day and night mix up

Yes, I suppose many people with dementia are inside quite a lot. People get very distressed around four or five o'clock pm, particularly in the winter

- Getting outdoors during the day (e.g. for a walk in a garden), even if the sun is not shining brightly, will help strengthen your relative's body clock.

- We know that getting outside with people with dementia is not always possible, perhaps your relative does not want to go out or they are not able to walk or manage stairs. However even very short periods of time outside can make a big difference.

- Before we make a plan for your relative, let's talk about how much light your relative is getting.

Q! **How much time do you think your relative is in natural light on a typical day?**

- Let's look at the information from the watch your relative wore for two weeks before we met. We will discuss how much your relative's is in light now, and their movement data a little later on in the session.

Your relative's light exposure

Insert the Actigraph data here in advance of session 2

Average lux:

Making a light therapy plan

- Let's make a plan to help your relative have more daytime light.

1. Increasing access to natural light:

- Let's write three activities to increase your relative's exposure to natural light. (Use the questions on the right to help you make a plan).

1. _____

2. _____

3. _____

- How often could you do this?
- What would make it easier?
- How long would it take?
- Could they do it alone or with you or someone else?
- Is there anything that could make it safer?

Try and get your relative out into natural light at least 3 times over the next week, if you do more, that's great.

2.

2. Using artificial light in the form of a light box or 'phototherapy':

- A light box may improve sleep in people with dementia.

- By providing strong light during the day, like natural light, our body-clock will get better at knowing when to be awake and when to be asleep.

- Use the light box for **30 minutes at the same time each morning**.

- Place the light box at arms-length with the screen towards your relative's face, so that the light reaches their eyes.

- Your relative does not need to stare at the box but can use it whilst doing other things like reading, having breakfast or watching TV.

- Dark glasses, tinted lenses and closing the eyes will reduce how well this works.

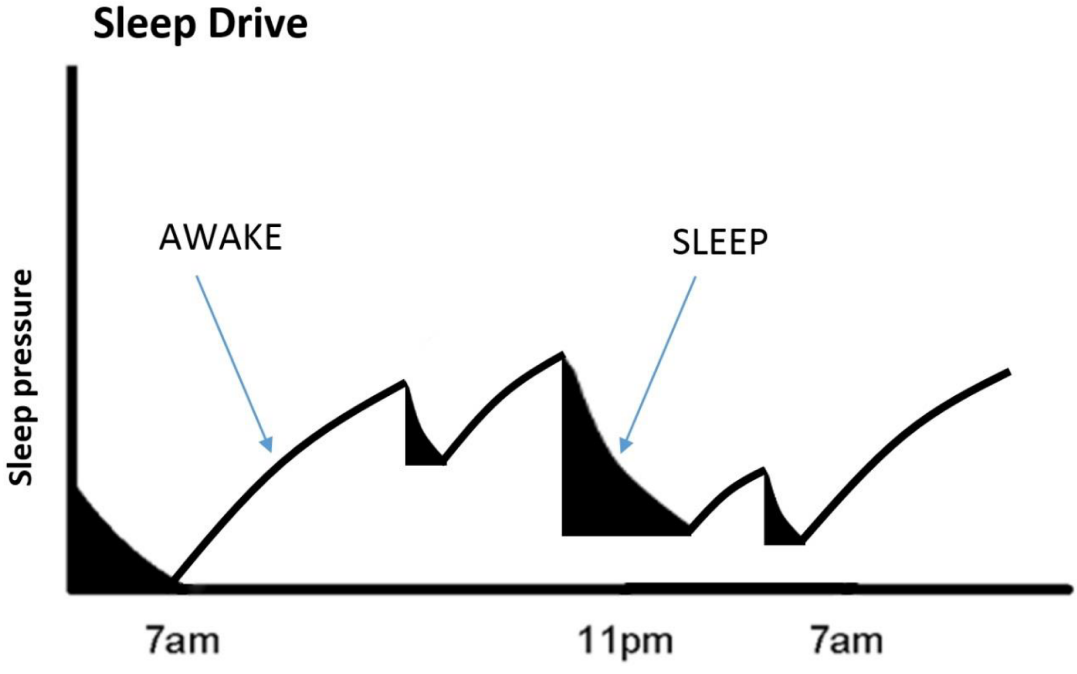
Q! **What difficulties do you see in using the light box?**

What would help to overcome these difficulties?

Your relative's sleep pattern

- We have talked about how the body-clock controls sleep and wake periods. We also need to think about 'sleep pressure' in relation to your relative's Actigraph.

- If a person naps during the day there is less "sleep pressure", so they will find it harder to fall asleep and are more likely to wake in the night



- If we go to bed too early, before sleep pressure is high and before the body-clock is ready to send sleep signals, then we may toss and turn, and become frustrated - it may lead to more broken sleep.

- Daytime napping, being inactive and going to bed early are all common in people with dementia and make it harder for them to sleep well.

- Let's now look at the information we obtained from the watch your relative wore that measured movement. This shows us how long your relative took to fall asleep and how many times they woke up in the night.

Actigraph data:

Insert data chart here and below in advance of session 2

Summary:

- Your relative spends around X hours in bed and sleeps for about X hours each night.
- This ratio of sleep time to time in bed is called **sleep efficiency**.
- **Your relative's sleep efficiency is X%.**
- Effective methods to improve sleep efficiency involve:
    1) Eliminating / reducing daytime naps
    2) Delaying the start of sleep by going to bed later.

Making a new routine - your relative's plan

Now let's use all that we have talked about today to make a plan on page 25.

Next week we will be talking more about increasing pleasant daytime events and activities for you and your relative.

DREAMS: START

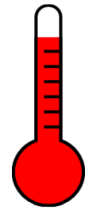
Managing Stress 2:

Focused breathing

Focused Breathing is a useful stress reduction technique:

- It can relax you, reducing the tension and stress that can come from caring.
- It can help you to briefly focus on yourself, and have a break from caring.
- It can also help you get to sleep after a stressful day.
- Focused breathing may also be a way for your relative to get nice and relaxed before bed time.

<u>Stress Rating Before Exercise</u>

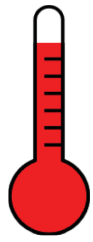


5 = Terribly tense
4 = Really tense
3 = Moderately tense
2 = Slightly tense
1 = Not at all tense

- First, please rate your level of stress or tension right now before we practice the Focused Breathing.

Q! **On a scale of 1 to 5, how would you rate your tension? _____**

Tension Rating After Exercise



5 = Terribly tense
4 = Really tense
3 = Moderately tense
2 = Slightly tense
1 = Not at all tense

- How would you rate your tension level now after practicing the Focused Breathing exercise?

Q! **Now, please rate your tension or stress level from 1 to 5 _____**

Summary

Today, we have talked about:

- Recap on understanding sleep and dementia
- Light and sleep
- Light, dementia and the body clock
- Your relative's sleep pattern
- Making a new sleep routine: Your relative's plan
- Managing stress 2: Focused Breathing

FOR NEXT WEEK: Putting it into practice

Key Point:

It is important for you try out the plan we have made building it into your routine. Using the plan regularly will help us see whether it works and help us to make further changes if it is not helping.

Focused breathing:

- Try to practice this every night before bed and with your relative if that is possible. See if it helps.

Putting the plan into action:

- Try and use the plan we made on page 25. Please continue to keep a sleep diary for your relative and try and fill in the record form on p.25.

DREAMS: START

Putting it into Practice

- When will you have an opportunity to do this?
- What might get in the way?
- What might make it easier?

Weekly Sleep Diary

Date	Noon	1pm	2pm	3pm	4pm	5pm	6pm	7pm	8pm	9pm	10pm	11pm	12am	1am	2am	3am	4am	5am	6am	7am	8am	9am	10am	11am
Tuesday May 14th	O		N							/			X X		X				/				N	O

Key:

/ = When your relative went to bed and when they got up in the morning

X = Every time your relative gets up in the night

N = When your relative takes a nap during the day

O = When your relative has been out of the house

E = When your relative has done any physical exercise

L = When you relative has used the light box

Planning record

- Here is a way of monitoring how the changes have gone for you and your relative.

	Action plan	How did it go for your relative?	How did it go for you?
Light box			
Increasing natural light			
Reducing daytime naps			
Time to bed and rise			
Lifestyle changes			

Facilitator Version

DREAMS: START

Dementia Related Manual for Sleep: Strategies for Relatives

Session 2: Making a plan

For each session:

- Encourage the carer to write down what works or key strategies or plans to refer back to.
- If content is clearly irrelevant or does not fit, for example someone is very active all day will not need a plan around daytime naps, miss these parts out.
- When setting exercises at the end, check that they remember what is in the plan if not explicitly covered in the content.

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UCL Division of Psychiatry
6th Floor Maple House
149 Tottenham Court Road
London W1T 7NF
United Kingdom

Plan for today's session

"This is the contents page for you to refer back to"

Refer to the contents but do not read the full list

Recap on understanding sleep and dementia	p. 3
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Summary	p. 22
Putting it into practice	p. 23

5mins

Recap of session one: Understanding sleep and dementia

We talked about:

- Sleep and dementia
- What is sleep?
- What causes sleep problems in dementia?
- Making changes to improve sleep
- The impact of sleep problems on you and your relative
- Managing the stress that sleep problems can bring
- Managing stress 1: The signal breath

"What stuck in your mind from last week? What were the changes that you wanted to make?"

"Let's talk about how this went – write down what you found so that you can look over it in the future"

Q! **Did you make lifestyle or bedroom changes to improve your relative's sleep?**

Yes	No
• What changes did you try out? • How did it go? • What went well?	• What do you think got in the way? • What would make it easier in the future?

Q! **Did you have a chance to complete the sleep diary?**

Yes	No
• How did it go? • What went well? • Did you notice any patterns?	• What do you think got in the way? • What would make it easier in the future?

"Keep using any strategies that you found helpful for you or your relative and continue to use the sleep diary over the coming week."

20mins Light and sleep

- We talked about ‘sleep pressure’ and the ‘body clock’, the two ways our brain gives us a good sleep pattern.

Check that they recall the discussion on sleep pressure and circadian rhythms – remind them of the key points

- We discussed how the body clock helps us sleep when it’s dark (at night) and be awake when it’s light (during the day).

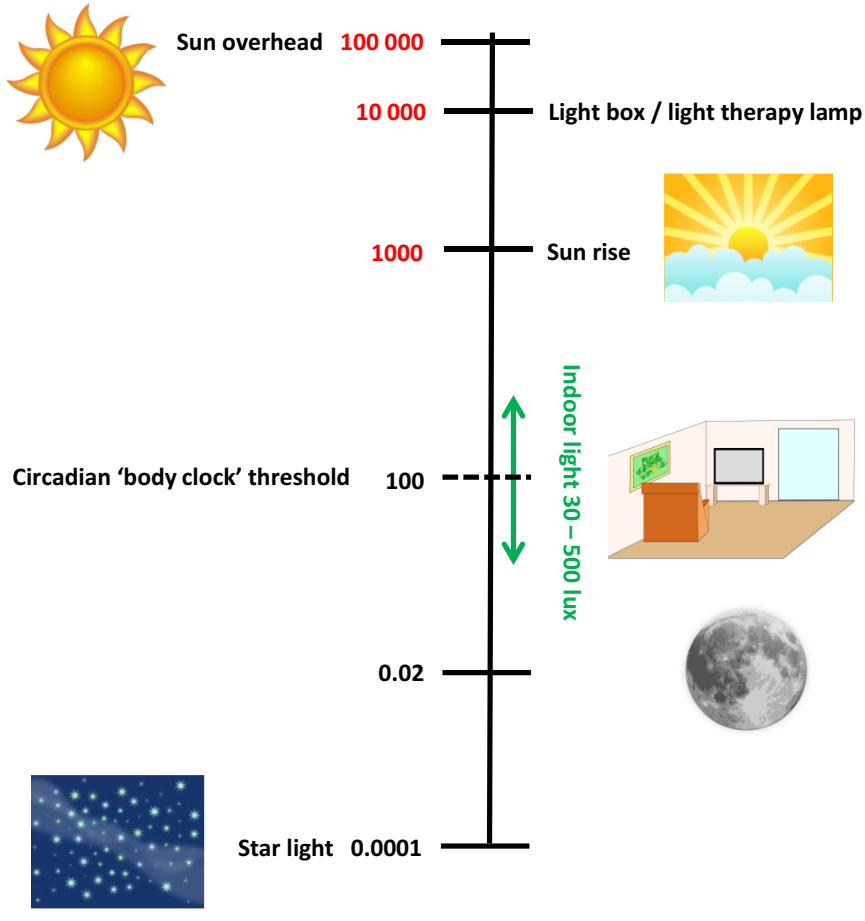
- The body clock works out the time most importantly by sunlight because it is the brightest; but also by temperature and when mealtimes or activities happen.

- Sunlight during the day tells the brain and body that it should be awake; helping us to concentrate and be active.

- Regular light and being awake during the day helps us to sleep undisturbed through the night. This **creates a strong and stable sleep pattern.**

- Look at the picture on the opposite page.

"This diagram shows how much light we get from different sources, showing how much more light we get from being out in natural light than artificial light. Talk through the diagram and check they have understood. Is this surprising for you?"



Light, dementia and the body clock

- You may have noticed that your relative mixes up night and day and is sleepy or wide awake at the wrong times.
- One reason for this is that dementia can damage the part of the brain controlling the 'body clock', giving people wrong signals about night and day.
- So people with dementia can be sleepier in the day or awake at night.
- As we get older our ability to see light through our eyes also gets worse, so less light gets to the body clock in the brain. This is worse in those with dementia.

> *Key Point:*
> Ensuring people with dementia receive enough light during the day is extremely important for their sleep at night

Losing track of time…day and night mix up

Yes, I suppose many people with dementia are inside quite a lot. People get very distressed around four or five o'clock pm, particularly in the winter

- Getting outdoors during the day (e.g. for a walk in a garden), even if the sun is not shining brightly, will help strengthen your relative's body clock.

- We know that getting outside with people with dementia is not always possible, perhaps your relative does not want to go out or they are not able to walk or manage stairs. However even very short periods of time outside can make a big difference.

- Before we make a plan for your relative, let's talk about how much light your relative is getting.

Q! **How much time do you think your relative is in natural light on a typical day?**

Prompts if needed
Do they get out and about?
How often and where?

Do they sleep with a light on?
Do they ever get mixed up between day and night?

- Let's look at the information from the watch your relative wore for two weeks before we met. We will discuss how much your relative's is in light now, and their movement data a little later on in the session.

Your relative's light exposure

Insert the Actigraph data here in advance of session 2

Average lux:

Make sure that you have done this in advance of the session and that you are prepared to talk through the data and summarise the findings.

Talk through the data explaining what it means and what the data shows. Summarise the key patterns / findings

Check that they have understood what you are showing them.

Making a light therapy plan

- Let's make a plan to help your relative have more daytime light.

1. Increasing access to natural light:

- Let's write three activities to increase your relative's exposure to natural light. (Use the questions on the right to help you make a pla

Use the questions to guide your discussion and encourage them to write down specifics of what they are going to try out

1. _____

2. _____

3. _____

- How often could you do this?
- What would make it easier?
- How long would it take?
- Could they do it alone or with you or someone else?
- Is there anything that could make it safer?

Try and get your relative out into natural light at least 3 times over the next week, if you do more, that's great.

2.

If they are stuck you can prompts them.

e.g.
- Sitting out in the garden/ balcony
- Going on local errands either alone or together
- Visiting the park
- Sitting by open windows
- Walking instead of driving
- Any other activities

If they say they do not think they can do anything, do not push them, talk with them about what the barriers are and what might have to happen for things to be different.

"It might not always be possible for your relative to get out into natural light but there are other ways to increase their access to light whilst indoors. We are going to talk about one of these now…"

2. Using artificial light in the form of a light box or 'phototherapy':

- A light box may improve sleep in people with dementia.

- By providing strong light during the day, like natural light, our body-clock will get better at knowing when to be awake and when to be asleep.

Show the person how to use the light box and check that they understand the mechanism and can work it independently.

Try to keep the light box on in the session so people can get used to it.

Remind them that they do not have to be staring at it but having it nearby and getting on with other activities is fine as

Think in advance based upon Actigraph data what time it may be best in the morning for them to use the box but be tentative and flexible with any suggestions, based upon what they feel would work best.

- Use the light box for **30 minutes at the same time each morning**.

- Place the light box at arms-length with the screen towards your relative's face, so that the light reaches their eyes.

- Your relative does not need to stare at the box but can use it whilst doing other things like reading, having breakfast or watching TV.

- Dark glasses, tinted lenses and closing the eyes will reduce how well this works.

Q! **What difficulties do you see in using the light box?**

What would help to overcome these difficulties?

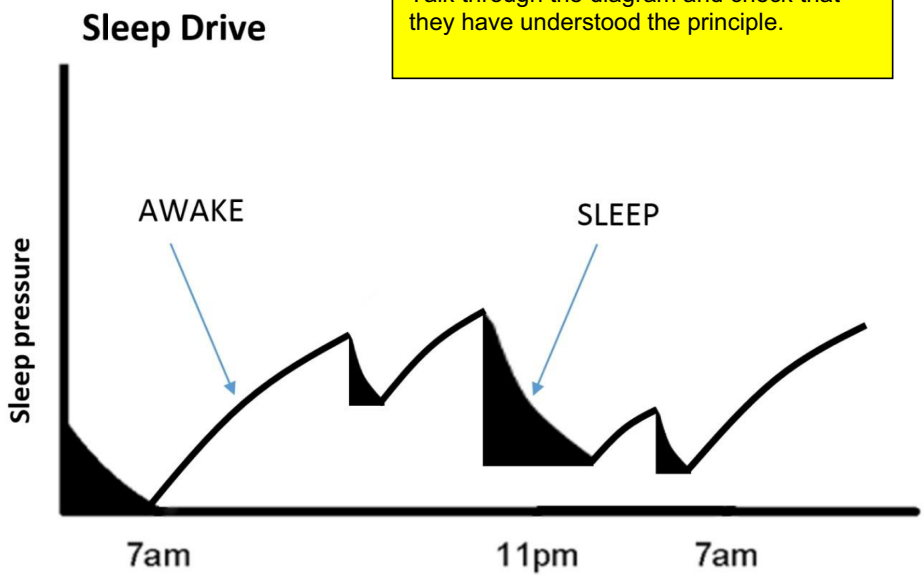
10 mins

Your relative's sleep pattern

- We have talked about how the body-clock controls sleep and wake periods. We also need to think about 'sleep pressure' in relation to your relative's Actigraph.

- If a person naps during the day there is less "sleep pressure", so they will find it harder to fall asleep and are more likely to wake in the night

Talk through the diagram and check that they have understood the principle.



- If we go to bed too early, before sleep pressure is high and before the body-clock is ready to send sleep signals, then we may toss and turn, and become frustrated - it may lead to more broken sleep.

- Daytime napping, being inactive and going to bed early are all common in people with dementia and make it harder for them to sleep well.

- Let's now look at the information we obtained from the watch your relative wore that measured movement. This shows us how long your relative took to fall asleep and how many times they woke up in the night.

Actigraph data:

Insert data chart here and below in advance of session 2

Make sure that you have done this in advance of the session and that you are prepared to talk through the data and summarise the findings.

Check that they have understood what you are showing them. Try to link it to what they have just told you about their relative's sleep pattern.

Ask them if what you can see in the data fits with their experiences' of their relatives sleep pattern

Summary:

Fill in in advance of the session

- Your relative spends around X hours in bed and sleeps for about X hours each night.
- This ratio of sleep time to time in bed is called **sleep efficiency**.
- **Your relative's sleep efficiency is X%.**
- Effective methods to improve sleep efficiency involve:
  1) Eliminating / reducing daytime naps
  2) Delaying the start of sleep by going to bed later.

Consider this in advance of the session, it may not be relevant for everyone.

Q! If your relative tends to nap often, what would help you to reduce this?

If your relative goes to bed very early, do you think you could keep them awake later?

What effect would these changes have on you?

Could you try to shift bedtime to _____ and encourage your relative to get up at _____

10mins

Making a new routine - your relative's plan

Now let's use all that we have talked about today to make a plan on page 25.

Next week we will be talking more about increasing pleasant daytime events and activities for you and your relative.

"Each week we are going to try a new stress reduction technique. Last week we learnt the 'signal breath'. This week we will practise a focused breathing exercise."

First, let's think about the signal breath. Did you get a chance to try it out this week?

If you did, how did you find it? When did you use it? What effect did it have on how you felt?

If you did not get a chance to try it, what got in the way?

Please try and carry on practising the signal breath.

Now we are going to learn a new stress reduction technique, 'focused breathing'."

10 mins

DREAMS: START

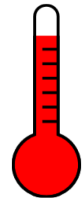
Managing Stress 2:

Focused breathing

Focused Breathing is a useful stress reduction technique:

- It can relax you, reducing the tension and stress that can come from caring.
- It can help you to briefly focus on yourself, and have a break from caring.
- It can also help you get to sleep after a stressful day.
- Focused breathing may also be a way for your relative to get nice and relaxed before bed time.

Stress Rating Before Exercise



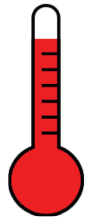
5 = Terribly tense
4 = Really tense
3 = Moderately tense
2 = Slightly tense
1 = Not at all tense

- First, please rate your level of stress or tension right now before we practice the Focused Breathing.

Q! **On a scale of 1 to 5, how would you rate your tension? _____**

"Now I am going to talk you through the focused breathing exercise…"

Tension Rating After Exercise



5 = Terribly tense
4 = Really tense
3 = Moderately tense
2 = Slightly tense
1 = Not at all tense

- How would you rate your tension level now after practicing the Focused Breathing exercise?

Q! **Now, please rate your tension or stress level from 1 to 5 _____**

Discuss:
- Did your level of tension change?
- What was this experience like for you?
- Can you think of specific times when this might have helped?

Summary

Today, we have talked about:

- Recap on understanding sleep and dementia
- Light and sleep
- Light, dementia and the body clock
- Your relative's sleep pattern
- Making a new sleep routine: Your relative's plan
- Managing stress 2: Focused Breathing

5mins

FOR NEXT WEEK: Putting it into practice

Key Point:

It is important for you try out the plan we have made building it into your routine. Using the plan regularly will help us see whether it works and help us to make further changes if it is not helping.

Focused breathing:

- Try to practice this every night before bed and with your relative if that is possible. See if it helps.

Putting the plan into action:

- Try and use the plan we made on page 25. Please continue to keep a sleep diary for your relative and try and fill in the record form on p.25.

Go through the forms and check that they have a clear plan written down and have understood the task

DREAMS: START

Putting it into Practice

- When will you have an opportunity to do this?
- What might get in the way?
- What might make it easier?

Weekly Sleep Diary

"We have added the letter L to the key for when your relative has used the light box. Otherwise, the sleep diary is the same as last week"

Date	Noon	1pm	2pm	3pm	4pm	5pm	6pm	7pm	8pm	9pm	10pm	11pm	12am	1am	2am	3am	4am	5am	6am	7am	8am	9am	10am	11am
Tuesday May 14th	O		N							/			X X		X				/				N	O

Key:

/ = When your relative went to bed and when they got up in the morning

X = Every time your relative gets up in the night

N = When your relative takes a nap during the day

O = When your relative has been out of the house

E = When your relative has done any physical exercise

L = When you relative has used the light box

Planning record

"We can write in the action plan together now…If you would like to make it simpler for how each action plan went then you can use a tick or a cross."

- Here is a way of monitoring how the changes have gone for you and your relative.

	Action plan	How did it go for your relative?	How did it go for you?
Light box			
Increasing natural light			
Reducing daytime naps			
Time to bed and rise			
Lifestyle changes			

Remember to encourage them to develop SMART goals based on discussion for each point and write down specifics. **Get them to write the specific plan down on the record form.**

DREAMS: START

Dementia **Re**l**a**ted **M**anual for **S**leep:

Str**a**tegies for **R**ela**t**ives

Session 3: Daytime activity and routine

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UCL Division of Psychiatry
6th Floor Maple House
149 Tottenham Court Road
London W1T 7NF
United Kingdom

Plan for today's session: Daytime activity and routine

Recap on making a plan	p. 3
The importance of daytime activity and routine	p. 5
Planning daytime activity	p. 6
Sleep, exercise and physical activity	p. 9
Establishing a good day and night routine	p. 11
Managing stress 3: Guided Imagery	p. 14
Summary	p. 17
Putting it into practice	p. 18
Seated exercises visual guide	p. 21

Recap of session 2: Making a plan

We talked about:

- Light and sleep
- Light, dementia and the body clock
- Your relative's sleep pattern
- Making a new sleep routine: Your relative's plan
- Focused Breathing
- Summary
- Putting it into practice

Q! **Did you have a chance to try out the plan we made together last week and record it on the record form? Let's have a look at the record form and sleep diary you completed last week.**

Area for change	How did it go?	
	What made it harder?	What made it easier?
Light box		
Increasing natural light		
Reducing daytime naps		
Time to bed and rise		
Lifestyle changes		

Please continue to use the plan and complete the sleep diary. Remember, completing the record form helps us to see what is working and what is not.

The importance of daytime activity and routine

- This session is about things people enjoy: pleasant daytime events and physical activity.
- Poor sleep at night is often related to having too few stimulating and pleasant activities in our lives. This is no different for people with dementia.
- People with dementia find it harder to organise their own activities. Even with lots of people around they can still feel lonely or bored.
- Caring for a relative with dementia can also mean that you find it hard to make time for your own enjoyment and activity, which may make you feel worse and sleep less well.
- You may think "It seems like there's nothing I can do to make things better." However, you can feel better by making sure your day has a few events that bring you pleasure.

List two activities that your relative enjoys	**List two activities that you enjoy**
1. 2.	1. 2.

Key Point:

Anything a person likes to do is a pleasant event. People's interests can change when they have dementia and they may enjoy activities that they did not before, or no longer enjoy what they used to.

Planning daytime activity

- Pleasant activities don't have to be long. They don't need a lot of planning or to be big activities. Small things can make a big difference and might make somebody's day.

- Here are some examples of pleasurable and stimulating activities, not all of these activities will suit your relative. Take a few moments to look over this list and tick the activities you think they would enjoy either together or separately.

Events	**Tick** ✓	**Events**	**Tick** ✓
Listen to music		Go to a place of worship	
Go to the shops		Watch sports	
Go for a walk		Talk about happy memories	
Read/listen to books, newspapers, magazines or prayer books		Holding things like a stress ball or bubble wrap	
Sit with them for a tea and chat		Have a leisurely bath	
Relaxation and sensory exercises		Chat to friends or family on the phone	
Write letters or cards etc		Spend time on an ipad using apps or skype	
Drawing, painting, crafts		Play cards, games or puzzles	
Exercise e.g. yoga, chair based exercise, stretching		Talk about family or current events	
Watch a film		Special occasion meals or parties	
Go into the garden or balcony		Dance	
Have a picnic or a BBQ		Live musicians / concerts / singing	
DIY / Sewing		Bingo	
Gardening		Cook or bake	
Listen to the radio		Helping with domestic tasks e.g. setting the table	
Watch a favourite TV programme		Have a glass of wine or beer (if appropriate)	
Watch wildlife or be around animals or pets		Hold soft toys or dolls	
Look at photos		Have hair done / manicure / pedicure	
Memory books / boxes		Hand or foot massage	
Other activities:			

Let's think of four pleasant activities for you and your relative. If possible choose at least two that would need your relative to be physically active:

1

2

3

4.

Key Point:

It is important to plan activities or events that are manageable and achievable.

When planning activities, ask yourself: Is it possible to still do those activities? If not, can they be changed in any way?

For example, if you used to take long walks together, can you now take short walks? As long as you find things your relative enjoys and is able to do, you will be helping them to be stimulated and feel better.

Some activities require more planning than others. Because we want you to be successful in planning pleasant events for your relative, we have put together a list of questions to help you plan:

Choose one of the pleasant activities that you would like to try with your relative:

- What materials or preparation are needed?
- When will it take place?
- How often can it be done?
- How much time will it take?

Before the next session with your relative we would like you to try out a new pleasant activity.

Remember:

- Don't force them to participate: Encourage or reward him/her often.
- Try to think of things that are similar to some hobbies, interests, or games they used to enjoy.
- Have a few activities available, so if they become bored you can switch easily.
- Plan to do activities in short bursts
- Try to involve other friends or family if at all possible.
- Activities that involve movement can be good, since people with dementia are often restless and have relatively short attention spans.
- There is no harm if your relative enjoys crafts, games, or music that are simpler than before.

Sleep, exercise and physical activity

- We know that as people get older there are many reasons why it may be harder to exercise, but even lighter forms of exercise like walking, can improve sleep in older people and those with dementia.

- Physical activity is good for our mental and physical health, it helps keep our bodies and mind in good shape.

- People who are physically active are more likely to have regular, good quality sleep at night and be more alert during the day.

- Physical activity may improve sleep by making people feel better and telling our body clock that it is time to be awake.

- For those with mobility problems it is recommended that they have at least three periods of physical activity a week to improve balance and prevent falls.

Q! **Let's look again at the sleep diary from last week:**

- **How much physical activity does your relative get?**
- **What type of physical activity do they enjoy?**
- **What type of physical activity are they able to do?**

Key Point:
If possible, we would like your relative to walk for up to 30 minutes at least three times a week, you may wish to build up to this gradually.

- Let's talk together about whether this would be possible for your relative and what you may be able to try instead.
- What concerns do you have, if any, about your relative being more physically active?
- If your relative finds it difficult to walk, what else could they try instead? (Let's look at this leaflet from the Alzheimer's Society which has some good ideas.)

Walking / exercise goal:

Write down a realistic and achievable walking goal for your relative over the next week

Walking for _____ minutes at least _____ times / week

Or _____ for _____ minutes at least _____ times/week

Establishing a good day and night routine

- So far we have talked about a number of small changes that could help improve your relative's sleep. These include:

    - Lifestyle changes
    - The bedroom environment
    - Natural and artificial light
    - Reducing daytime naps
    - Going to bed at a regular time
    - Being physically and mentally active during the day

- All of these things remind the body clock that it should be awake during the day and asleep at night and help the brain feel pressure to fall asleep.

- As we discussed, it can help to **build a strong link between bed and sleep**.

- Things you can do to help your relative to make a strong connection between sleep and bed include:

Bedtime wind-down

Your relative's pre-bed routine should start about 60 - 90 minutes before bed when you can start helping them to relaxing and prepare for sleep. This could include things like stopping activity, brushing teeth or putting pyjamas on.

The routine may be more involved: for example encouraging your relative to sit down an hour or so before bedtime with a decaffeinated drink, read or watch TV or listen to relaxing music.

Bedtime activities

It is important not to use your bed for anything except sleep. This means that watching TV, reading, eating, and using a phone or iPad are out!

Avoiding napping

As we discussed last week, napping during the day can weaken the pressure to sleep at night. Being more active during the day, especially out in natural light, will reduce the amount of time your relative is unstimulated and perhaps dozing, during the day.

Feeling sleepy

It is important to only go to bed when feeling sleepy. Try to encourage your relative not to go to bed too early, we know that evenings may be an important time for you to get things done around the house, but going to bed too early can weaken the link between bed and sleep.

Regular mealtimes & a day time routine

As you will know, for people with dementia, who may have a disrupted body clock making it harder to know when it is day or night, any clues to remind people that it is day time or night time will be helpful. This may be having meals or doing certain activities at a set time or it may be making sure they get out into daylight every day.

You can get large clocks with sun and moon symbols and the words 'Day and Night' on them. I found holding ours up to my mother got the message across that it wasn't the right time to be doing something.

Key Point:

Many of these points will apply for you too! Don't forget to think about what might help you to improve your own sleep.

Q! How can you strengthen your relative's bed-sleep connection?

Strengthening the link between bed and sleep	Suggestions	What could you try for your relative?	What could you try for yourself?
Bedtime wind down	• Having warm (caffeine free) drink) • Getting into bed clothes • Listening to relaxing music		
Bedtime activities	• Turning off the TV or radio in the bedroom. • Leaving phones or ipad away from the bed		
Daytime napping	• Involving your relative in chores at home • Doing gentle physical activity • Making sure the room is well lit • Keeping active after lunch		
Feeling sleepy	• Having a chat or playing a game in the early evening • Delaying bedtime until your relative is tired		
Daytime routine	• Having meals at a regular time • Having activities planned during the day		

DREAMS: START

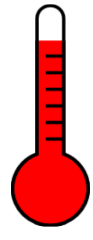
Managing Stress 3:

Guided Imagery - Meadow and Stream

Guided Imagery is a stress reduction technique that allows you to have "time out" from daily worries.

- It should be done in a quiet setting where you will not be disturbed.
- Some people find use this type of exercise before they go to bed in the evening. It is best to get used to it at other times of day first.
- The more you practice, the more useful it will be.

Stress Rating Before Exercise

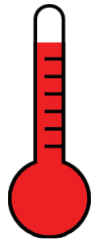


5 = Terribly tense
4 = Really tense
3 = Moderately tense
2 = Slightly tense
1 = Not at all tense

- First, please rate your level of stress or tension right now, before we practice the Guided Imagery exercise.

Q! **On a scale of 1 to 5, how would you rate your tension? _____**

Tension Rating After Exercise



5 = Terribly tense
4 = Really tense
3 = Moderately tense
2 = Slightly tense
1 = Not at all tense

- How would you rate your tension level now, after practicing the Guided Imagery exercise?

Q! **Now, please rate your tension or stress level from 1 to 5 _____**

Summary

Today, we have talked about:

- Recap on making a plan
- The importance of daytime activity and routine
- Sleep, exercise and physical activity
- Planning daytime activity
- Establishing a good day and night routine
- Managing stress 3: Guided imagery

FOR NEXT WEEK: Putting it into practice

Key Point:

Doing more during the day, being stimulated, active and exposed to natural light will help your relative sleep better at night-time.

Guided imagery:

- Try to practice this every day and to use it in stressful situations. See if it helps. If possible, try it with your relative as part of a bed time wind-down.

Daytime activity:

- Try out a daytime activity with your relative every day over the next week, even if it is the same one every day or if it is just for fifteen minutes. Record how it went on the record form on the next page.

- If appropriate, try out the walking / exercise plan we made on page 10.

Continue to follow the plan we made last week using light and establishing a regular routine.

DREAMS: START *Putting it into Practice*

- When will you have an opportunity to do this?
- What might get in the way?
- What might make it easier?

Pleasant events record:

Day	What did you try?	How did it go?

Weekly Sleep Diary

Date	Noon	1pm	2pm	3pm	4pm	5pm	6pm	7pm	8pm	9pm	10pm	11pm	12am	1am	2am	3am	4am	5am	6am	7am	8am	9am	10am	11am
Tuesday May 14th	O		N							/			X X		X				/				N	O

Key:

/ = When your relative went to bed and when they got up in the morning

X = Every time your relative gets up in the night

N = When your relative takes a nap during the day

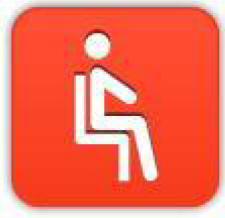
O = When your relative has been out of the house

E = When your relative has done any physical exercise

L = When you relative has used the light box

NHS choices

Exercises for older people



Sitting

Getting started

If you've not done much physical activity for a while, you may want to get the all-clear from a GP before starting.

For the exercises that require a chair, chose one that is stable, solid and without wheels. You should be able to sit with feet flat on the floor and knees bent at right angles. Avoid chairs with arms as this will restrict your movement.

Wear loose, comfortable clothing and keep some water handy.

Try to attempt these exercises at least twice a week, this will help to improve muscle strength, balance and co-ordination.

Build up slowly and aim to increase the repetitions of each exercise over time.

As your fitness improves, why not look for a group session near you? Age UK have lots of ideas. **www.ageuk.org.uk**

There are three other sets of exercises in this series: Flexibility, Strength and Balance. Go to **www.nhs.uk/exercises-for-older-people** to download.

Sitting

CHEST STRETCH

This stretch is good for posture.

A. Sit upright and away from the back of the chair. Pull your shoulders back and down. Extend arms out to the side.

B. Gently push your chest forwards and up until you feel a stretch across your chest.

Hold for five to 10 seconds and repeat five times.

UPPER BODY TWIST

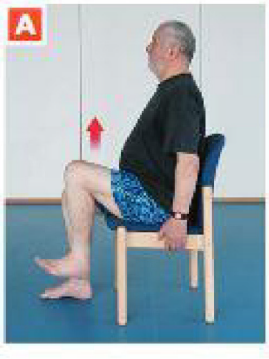
This will develop and maintain flexibility in the upper back.

A. Sit upright with feet flat on the floor, cross your arms and reach for your shoulders.

B. Without moving your hips, turn your upper body to the left as far as is comfortable.

Hold for five seconds. Repeat going right. Do five of each.

HIP MARCHING



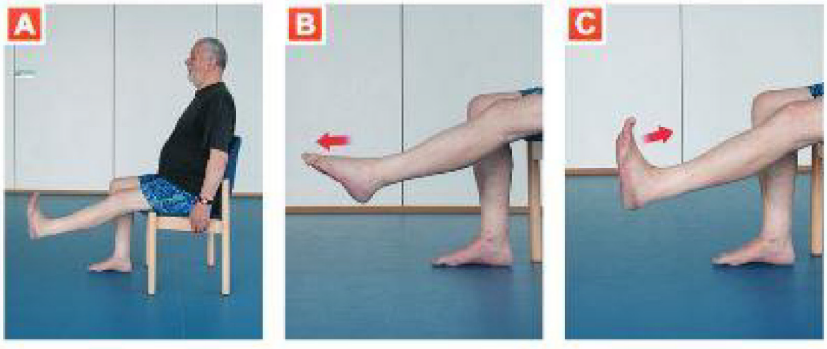
This will strengthen hips and thighs and improve flexibility.

A. Sit upright and away from the back of the chair. Hold on to the sides of the chair.

B. Lift your left leg, with your knee bent, as far as is comfortable. Place foot down with control.

Repeat with the opposite leg. Do five lifts with each leg.

ANKLE STRETCH



This will improve ankle flexibility and reduce blood clot risk.

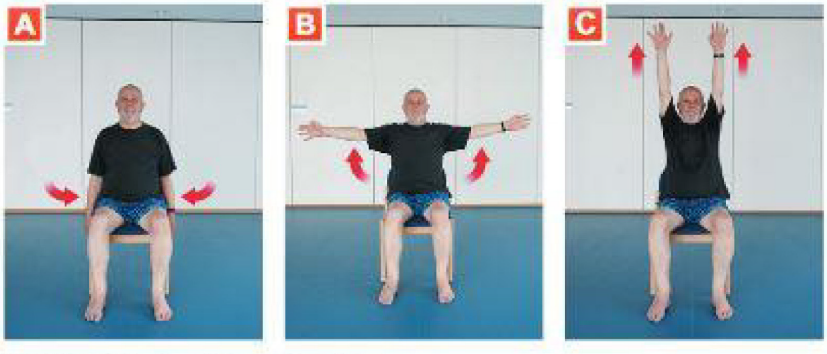
A. Sit upright, hold on to the side of the chair and straighten your left leg with your foot off the floor.

B. With leg straight and raised, point your toes away from you.

C. Point toes back towards you.

Try two sets of five stretches with each foot.

ARM RAISES



This builds shoulder strength.

A. Sit upright, arms by your sides.

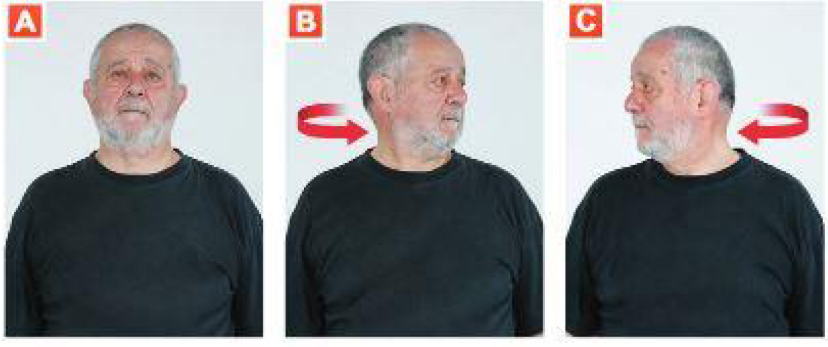
B. With palms forwards, raise both arms out and to the side and up as far as is comfortable. Then return.

C. Keep your shoulders down and arms straight throughout.

Breathe out as you raise your arms and breathe in as you lower them. Repeat five times.

Sitting

NECK ROTATION



This stretch is good for improving neck mobility and flexibility.

A. Sit upright with shoulders down. Look straight ahead.

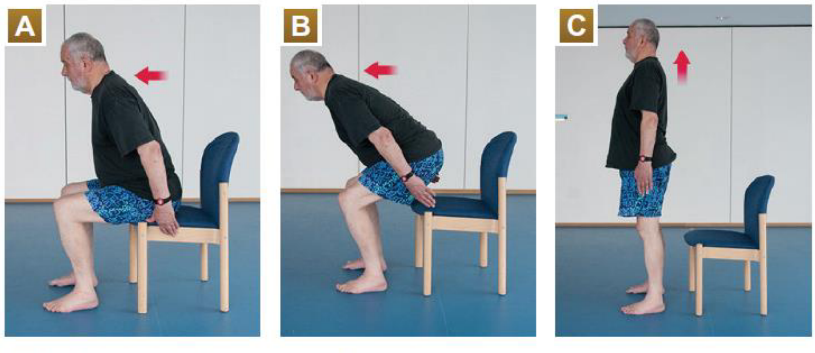
B. Slowly turn your head towards your left shoulder as far as is comfortable. Hold for five seconds and return to starting position.

C. Repeat going right.

Do three rotations on each side.

Strength

SIT TO STAND



This is good for leg strength.

A. Sit on the edge of the chair, feet hip-width apart. Lean slightly forwards.

B. Stand up slowly, using your legs, not arms. Keep looking forwards, not down.

C. Stand upright before slowly sitting down, bottom-first.

Aim for five repetitions - the slower the better.

Facilitator Version

DREAMS: START

Dementia Related Manual for Sleep: Strategies for Relatives

Session 3: Daytime activity and routine

For each session:

- Encourage the carer to write down what works or key strategies or plans to refer back to.
- If content is clearly irrelevant or does not fit, for example someone is very active all day will not need a plan around daytime naps, miss these parts out.
- When setting exercises at the end, check that they remember what is in the plan if not explicitly covered in the content.

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UCL Division of Psychiatry
6th Floor Maple House
149 Tottenham Court Road
London W1T 7NF
United Kingdom

Session 3 Version 1

Plan for today's session: Daytime activity and routine

"This is the contents page for you to refer back to"

Refer to the contents but do not read the full list

Recap on making a plan	p. 3
The importance of daytime activity and routine	p. 5
Planning daytime activity	p. 6
Sleep, exercise and physical activity	p. 9
Establishing a good day and night routine	p. 11
Managing stress 3: Guided Imagery	p. 14
Summary	p. 17
Putting it into practice	p. 18
Seated exercises visual guide	p. 21

10mins

Recap of session 2: Making a plan

We talked about:

- Light and sleep
- Light, dementia and the body clock
- Your relative's sleep pattern
- Making a new sleep routine: Your relative's plan
- Focused Breathing
- Summary
- Putting it into practice

Q! **Did you have a chance to try out the plan we made together last week and record it on the record form? Let's have a look at the record form and sleep diary you completed last week.** "Write down what you found, especially what worked well so that you can use this in future"

Area for change	How did it go?	
	What made it harder?	What made it easier?
Light box		
Increasing natural light		
Reducing daytime naps		
Time to bed and rise		
Lifestyle changes		

Please continue to use the plan and complete the sleep diary. Remember, completing the record form helps us to see what is working and what is not.

10mins

The importance of daytime activity and routine

- This session is about things people enjoy: pleasant daytime events and physical activity.
- Poor sleep at night is often related to having too few stimulating and pleasant activities in our lives. This is no different for people with dementia.
- People with dementia find it harder to organise their own activities. Even with lots of people around they can still feel lonely or bored.
- Caring for a relative with dementia can also mean that you find it hard to make time for your own enjoyment and activity, which may make you feel worse and sleep less well.
- You may think "It seems like there's nothing I can do to make things better." However, you can feel better by making sure your day has a few events that bring you pleasure.

Key point: You don't need to plan big activities to make a difference to people's lives – it is about building on what is already happening

List two activities that your relative enjoys	**List two activities that you enjoy**
1. 2.	1. 2.

Key Point:

Anything a person likes to do is a pleasant event. People's interests can change when they have dementia and they may enjoy activities that they did not before, or no longer enjoy what they used to.

10mins

Planning daytime activity

- Pleasant activities don't have to be long. They don't need a lot of planning or to be big activities. Small things can make a big difference and might make somebody's day.

- Here are some examples of pleasurable and stimulating activities, not all of these activities will suit your relative. Take a few moments to look over this list and tick the activities you think they would enjoy either together or separately.

Events	Tick	Events	Tick
Listen to music		Go to a place of worship	
Go to the shops		Watch sports	
Go for a walk		Talk about happy memories	
Read/listen to books, newspapers, magazines or prayer books		Holding things like a stress ball or bubble wrap	
Sit with them for a tea and chat		Have a leisurely bath	
Relaxation and sensory exercises		Chat to friends or family on the phone	
Write letters or cards etc		Spend time on an ipad using apps or skype	
Drawing, painting, crafts		Play cards, games or puzzles	
Exercise e.g. yoga, chair based exercise, stretching		Talk about family or current events	
Watch a film		Special occasion meals or parties	
Go into the garden or balcony		Dance	
Have a picnic or a BBQ		Live musicians / concerts / singing	
DIY / Sewing		Bingo	
Gardening		Cook or bake	
Listen to the radio		Helping with domestic tasks e.g. setting the table	
Watch a favourite TV programme		Have a glass of wine or beer (if appropriate)	
Watch wildlife or be around animals or pets		Hold soft toys or dolls	
Look at photos		Have hair done / manicure / pedicure	
Memory books / boxes		Hand or foot massage	
Other activities:			

"Include things that you are already doing, some are activities can easily be done and others require a bit more planning?" (Give a couple of minutes)

"Are there any other activities or events that you would add to the list?"

Let's think of four pleasant activities for you and your relative. If possible choose at least two that would need your relative to be physically active:

1

2

3

4.

Encourage people to choose activities that are realistic and can easily be built into existing routines without too much adjustment.

Explain that you will be talking about the importance of physical activity for sleep next, unless it is not appropriate e.g. the person is unable to be physically active.

Key Point:

It is important to plan activities or events that are manageable and achievable.

When planning activities, ask yourself: Is it possible to still do those activities? If not, can they be changed in any way?

For example, if you used to take long walks together, can you now take short walks? As long as you find things your relative enjoys and is able to do, you will be helping them to be stimulated and feel better.

Some activities require more planning than others. Because we want you to be successful in planning pleasant events for your relative, we have put together a list of questions to help you plan:

Choose one of the pleasant activities that you would like to try with your relative:

- What materials or preparation are needed?
- When will it take place?
- How often can it be done?
- How much time will it take?

Give them the leaflet that could help with any travel or financial barriers to planning activities.

Before the next session with your relative we would like you to try out a new pleasant activity.

Remember:

- Don't force them to participate: Encourage or reward him/her often.
- Try to think of things that are similar to some hobbies, interests, or games they used to enjoy.
- Have a few activities available, so if they become bored you can switch easily.
- Plan to do activities in short bursts
- Try to involve other friends or family if at all possible.
- Activities that involve movement can be good, since people with dementia are often restless and have relatively short attention spans.
- There is no harm if your relative enjoys crafts, games, or music that are simpler than before.

Sleep, exercise and physical activity

- We know that as people get older there are many reasons why it may be harder to exercise, but even lighter forms of exercise like walking, can improve sleep in older people and those with dementia.

- Physical activity is good for our mental and physical health, it helps keep our bodies and mind in good shape.

- People who are physically active are more likely to have regular, good quality sleep at night and be more alert during the day.

- Physical activity may improve sleep by making people feel better and telling our body clock that it is time to be awake.

- For those with mobility problems it is recommended that they have at least three periods of physical activity a week to improve balance and prevent falls.

"Now we are going to talk about how much physical activity your relative is currently doing, we know that everyone has different levels of mobility and that for some people moving even small amounts can be very hard. We also know that it is not always easy to get a person with dementia to do something that they do not want to. We will talk about what is realistic and achievable for you and your relative."

Q! **Let's look again at the sleep diary from last week:**

- **How much physical activity does your relative get?**
- **What type of physical activity do they enjoy?**
- **What type of physical activity are they able to do?**

Key Point:

If possible, we would like your relative to walk for up to 30 minutes at least three times a week, you may wish to build up to this gradually.

This is for people without any mobility problems – make clear we do not expect those with more limited mobility or those at risk of falls to do this.

- Let's talk together about whether this would be possible for your relative and what you may be able to try instead.
- What concerns do you have, if any, about your relative being more physically active?
- If your relative finds it difficult to walk, what else could they try instead? (Let's look at this leaflet from the Alzheimer's Society which has some good ideas.)

Talk through seated exercise plan where appropriate and give them the recording and leaflet, answer any questions. Explain that it will be easier for their relative to follow if they do it at the same time with the audio playing so that their relative has visual cues.

Walking / exercise goal:

Write down a realistic and achievable walking goal for your relative over the next week

Walking for _____ minutes at least _____ times / week

Or _____ for _____ minutes at least _____ times/week

10mins

Establishing a good day and night routine

- So far we have talked about a number of small changes that could help improve your relative's sleep. These include:

    - Lifestyle changes
    - The bedroom environment
    - Natural and artificial light
    - Reducing daytime naps
    - Going to bed at a regular time
    - Being physically and mentally active during the day

- All of these things remind the body clock that it should be awake during the day and asleep at night and help the brain feel pressure to fall asleep.

- As we discussed, it can help to **build a strong link between bed and sleep**.

- Things you can do to help your relative to make a strong connection between sleep and bed include:

"You may already be doing some of these things but there may also be some new ideas that you could try"

Bedtime wind-down

Your relative's pre-bed routine should start about 60 - 90 minutes before bed when you can start helping them to relaxing and prepare for sleep. This could include things like stopping activity, brushing teeth or putting pyjamas on.

The routine may be more involved: for example encouraging your relative to sit down an hour or so before bedtime with a decaffeinated drink, read or watch TV or listen to relaxing music.

Bedtime activities

It is important not to use your bed for anything except sleep. This means that watching TV, reading, eating, and using a phone or iPad are out!

Avoiding napping

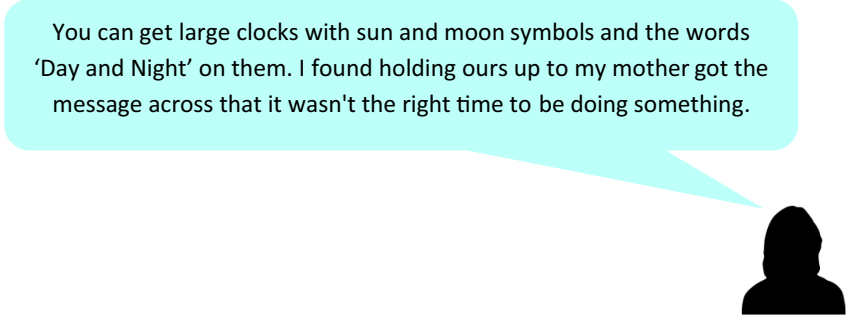
As we discussed last week, napping during the day can weaken the pressure to sleep at night. Being more active during the day, especially out in natural light, will reduce the amount of time your relative is unstimulated and perhaps dozing, during the day.

Feeling sleepy

It is important to only go to bed when feeling sleepy. Try to encourage your relative not to go to bed too early, we know that evenings may be an important time for you to get things done around the house, but going to bed too early can weaken the link between bed and sleep.

Regular mealtimes & a day time routine

As you will know, for people with dementia, who may have a disrupted body clock making it harder to know when it is day or night, any clues to remind people that it is day time or night time will be helpful. This may be having meals or doing certain activities at a set time or it may be making sure they get out into daylight every day.



Key Point:

Many of these points will apply for you too! Don't forget to think about what might help you to improve your own sleep.

Q! How can you strengthen your relative's bed-sleep connection?

Strengthening the link between bed and sleep	Suggestions	What could you try for your relative?	What could you try for yourself?
Bedtime wind down	• Having warm (caffeine free) drink) • Getting into bed clothes • Listening to relaxing music		
Bedtime activities	• Turning off the TV or radio in the bedroom. • Leaving phones or ipad away from the bed		
Daytime napping	• Involving your relative in chores at home • Doing gentle physical activity • Making sure the room is well lit • Keeping active after lunch		
Feeling sleepy	• Having a chat or playing a game in the early evening • Delaying bedtime until your relative is tired		
Daytime routine	• Having meals at a regular time • Having activities planned during the day		

Not all of these will be relevant – skip the ones that do not apply.

10mins

DREAMS: START

Managing Stress 3:

Guided Imagery - Meadow and Stream

"Now we are going to try a new stress reduction technique, last week we learnt the 'focused breathing'. This week we will practise a guided imagery exercise.

First, let's think about the focused breathing. Did you get a chance to try it out this week?

If you gave it a go, how did you find it? When did you use it? What effect did it have on how you felt?

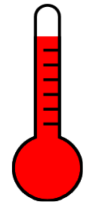
If you did not get a chance to try it, what got in the way?

Please try and carry on practicing the focused breathing exercise."

Guided Imagery is a stress reduction technique that allows you to have "time out" from daily worries.

- It should be done in a quiet setting where you will not be disturbed.
- Some people find use this type of exercise before they go to bed in the evening. It is best to get used to it at other times of day first.
- The more you practice, the more useful it will be.

Stress Rating Before Exercise



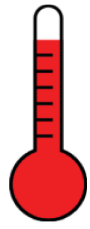
5 = Terribly tense
4 = Really tense
3 = Moderately tense
2 = Slightly tense
1 = Not at all tense

- First, please rate your level of stress or tension right now, before we practice the Guided Imagery exercise.

Q! **On a scale of 1 to 5, how would you rate your tension? _____**

"Now I am going to talk you through the guided imagery exercise…"

Tension Rating After Exercise



5 = Terribly tense
4 = Really tense
3 = Moderately tense
2 = Slightly tense
1 = Not at all tense

- How would you rate your tension level now, after practicing the Guided Imagery exercise?

Q! Now, please rate your tension or stress level from 1 to 5 _____

Discuss:
- Did your level of tension change?
- What was this experience like for you?
- Can you think of specific times when this might have helped?

Summary

Today, we have talked about:

- Recap on making a plan
- The importance of daytime activity and routine
- Sleep, exercise and physical activity
- Planning daytime activity
- Establishing a good day and night routine
- Managing stress 3: Guided imagery

10mins

FOR NEXT WEEK: Putting it into practice

Key Point:

Doing more during the day, being stimulated, active and exposed to natural light will help your relative sleep better at night-time.

Guided imagery:

- Try to practice this every day and to use it in stressful situations. See if it helps. If possible, try it with your relative as part of a bed time wind-down.

Daytime activity:

- Try out a daytime activity with your relative every day over the next week, even if it is the same one every day or if it is just for fifteen minutes. Record how it went on the record form on the next page.

- If appropriate, try out the walking / exercise plan we made on page 10.

Continue to follow the plan we made last week using light and establishing a regular routine.

DREAMS: START *Putting it into Practice*

- When will you have an opportunity to do this?
- What might get in the way?
- What might make it easier?

Pleasant events record:

Day	What did you try?	How did it go?

Weekly Sleep Diary

Date	Noon	1pm	2pm	3pm	4pm	5pm	6pm	7pm	8pm	9pm	10pm	11pm	12am	1am	2am	3am	4am	5am	6am	7am	8am	9am	10am	11am
Tuesday May 14th	O		N							/			X X		X				/				N	O

Key:

/ = When your relative went to bed and when they got up in the morning

X = Every time your relative gets up in the night

N = When your relative takes a nap during the day

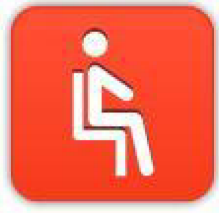
O = When your relative has been out of the house

E = When your relative has done any physical exercise

L = When you relative has used the light box

NHS choices

Exercises for older people



Sitting

Getting started

If you've not done much physical activity for a while, you may want to get the all-clear from a GP before starting.

For the exercises that require a chair, chose one that is stable, solid and without wheels. You should be able to sit with feet flat on the floor and knees bent at right angles. Avoid chairs with arms as this will restrict your movement.

Wear loose, comfortable clothing and keep some water handy.

Try to attempt these exercises at least twice a week, this will help to improve muscle strength, balance and co-ordination.

Build up slowly and aim to increase the repetitions of each exercise over time.

As your fitness improves, why not look for a group session near you? Age UK have lots of ideas. **www.ageuk.org.uk**

There are three other sets of exercises in this series: Flexibility, Strength and Balance. Go to **www.nhs.uk/exercises-for-older-people** to download.

www.nhs.uk

CHEST STRETCH

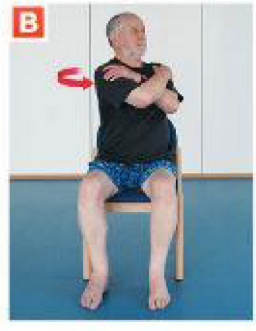
This stretch is good for posture.

A. Sit upright and away from the back of the chair. Pull your shoulders back and down. Extend arms out to the side.

B. Gently push your chest forwards and up until you feel a stretch across your chest.

Hold for five to 10 seconds and repeat five times.

UPPER BODY TWIST



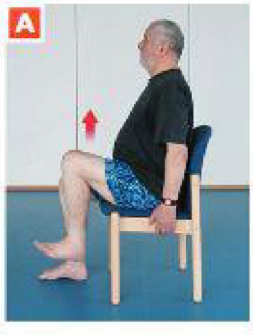
This will develop and maintain flexibility in the upper back.

A. Sit upright with feet flat on the floor, cross your arms and reach for your shoulders.

B. Without moving your hips, turn your upper body to the left as far as is comfortable.

Hold for five seconds. Repeat going right. Do five of each.

HIP MARCHING



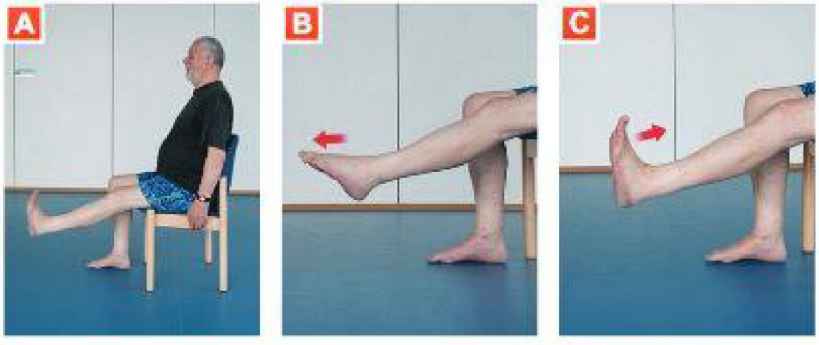
This will strengthen hips and thighs and improve flexibility.

A. Sit upright and away from the back of the chair. Hold on to the sides of the chair.

B. Lift your left leg, with your knee bent, as far as is comfortable. Place foot down with control.

Repeat with the opposite leg. Do five lifts with each leg.

ANKLE STRETCH



This will improve ankle flexibility and reduce blood clot risk.

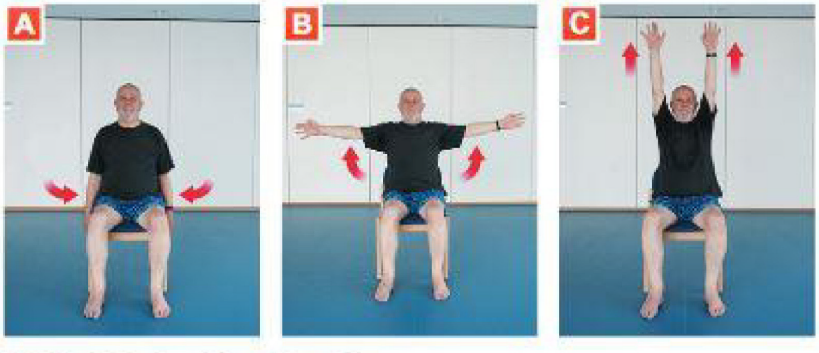
A. Sit upright, hold on to the side of the chair and straighten your left leg with your foot off the floor.

B. With leg straight and raised, point your toes away from you.

C. Point toes back towards you.

Try two sets of five stretches with each foot.

ARM RAISES



This builds shoulder strength.

A. Sit upright, arms by your sides.

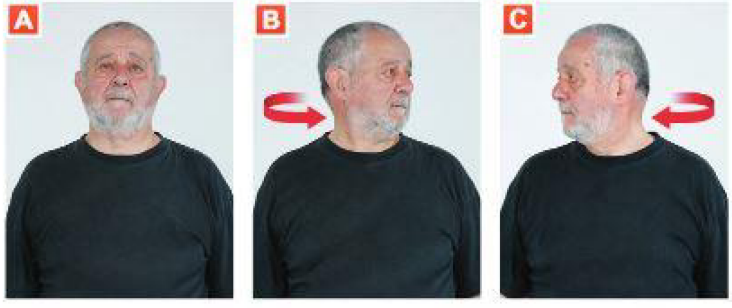
B. With palms forwards, raise both arms out and to the side and up as far as is comfortable. Then return.

C. Keep your shoulders down and arms straight throughout.

Breathe out as you raise your arms and breathe in as you lower them. Repeat five times.

Sitting

NECK ROTATION



This stretch is good for improving neck mobility and flexibility.

A. Sit upright with shoulders down. Look straight ahead.

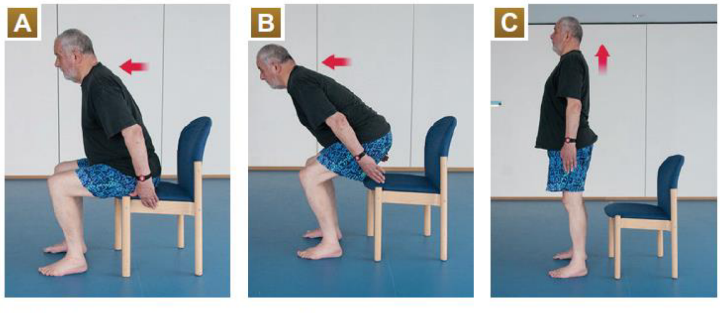
B. Slowly turn your head towards your left shoulder as far as is comfortable. Hold for five seconds and return to starting position.

C. Repeat going right.

Do three rotations on each side.

Strength

SIT TO STAND



This is good for leg strength.

A. Sit on the edge of the chair, feet hip-width apart. Lean slightly forwards.

B. Stand up slowly, using your legs, not arms. Keep looking forwards, not down.

C. Stand upright before slowly sitting down, bottom-first.

Aim for five repetitions - the slower the better.

DREAMS: START

Dementia **Re**l**a**ted **M**anual for **S**leep:

Str**a**tegies for **R**ela**t**ives

Session 4:

Difficult night-time behaviours

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UCL Division of Psychiatry
6th Floor Maple House
149 Tottenham Court Road
London W1T 7NF
United Kingdom

Plan for today's session

Recap on daytime activity and routine	p. 3
Troubleshooting: putting plans into action	p. 4
Managing night-time behaviour problems	p. 8
Describing and investigating behaviours	p. 9
Managing stress 4: Stretching	p.16
Summary	p. 18
Putting it into practice	p. 19

Recap of session 3: Daytime activities and routine

We talked about:

- The importance of daytime activity and routine
- Sleep, exercise and physical activity
- Planning daytime activity
- Establishing a good day and night routine
- Managing stress 3: Guided imagery
- Summary
- Putting it into practice

Q! **Did you have a chance to try out new daytime activities and exercise with your relative and record this on the form?**

If Yes…	
How did this go?	
What did you notice happening?	
What made it easier?	
If No…	
What got in the way?	
What would make it easier in the future?	

Key Point:

Please continue to put the agreed plan into action and complete the sleep diary / record forms. Remember, completing the record forms helps to see what is working and what is not.

Troubleshooting: putting plans into action

So far, during the sessions we have made a plan to help improve your relative's sleep. Depending on their situation this may have involved:

- Increasing daytime stimulation, pleasant activity and exercise
- Being in daylight at set times and using the light box
- Establishing daytime and bedtime routines
- Making lifestyle and bedroom changes
- Using relaxation exercises (you and your relative)

It can take a while for these changes to take effect so please keep going with them. Now let's look at the plans we made in session 2 & 3 and discuss how this has been working so far for you and your relative.

Your relative's plan

Area for change	Action
Light box	
Increasing natural light	
Reducing daytime naps	
Time to bed and rise	
Lifestyle changes	
Increasing daytime activity / physical exercise	

Talking point:

- Which parts have you managed to do?

- What effects have you noticed on your relative?

- What effects have you noticed on yourself?

- Is there anything else you have noticed happening?

- Which are the parts that you are finding harder to put into practice?

- Can you think of some reasons why you and/or your relative are finding these parts more difficult to do?

Let's think together about possible solutions to these difficulties and how we could adapt the plan to make it easier for you to use:

1.

2.

3.

Managing night-time behaviour problems

During our first session, we identified these difficult behaviours:

- X
- Y
- Z
-

Would you keep the same list or add any other behaviours? Let's rank these in order of how difficult they are to manage:

1.

2.

3.

Key Point:
There is always a cause for night-time behaviours, but the person with dementia is not doing it on purpose and can't control these.

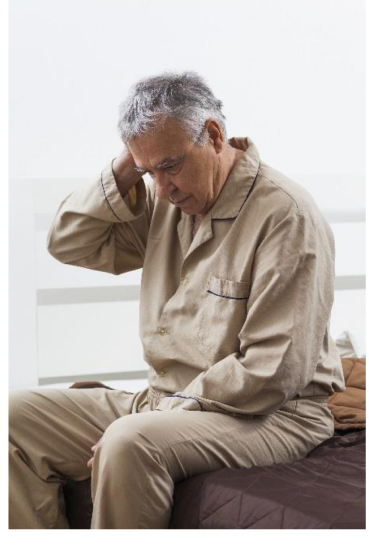
- Often there will be several factors causing night-time behaviours. Our challenge is to work out **what is causing each behaviour** and **what we can do about it.**

Describing and investigating behaviours

Describing in detail difficult night-time behaviours can help to make sense of what is happening and work out how to make it happen less.

Choose one of the sleep problems you identified on the previous page. Start by describing what happens. Imagine it as a film and try to be as detailed as possible. Use the questions below to help:

- **What exactly happens?**
- **How often and at what time does it happen?**
- **Where exactly does it happen?**
- **Does your relative talk to you at the time, what do they say?**
- **How do you think they are feeling at the time?**
- **What might they be thinking?**
- **How do you react when it happens?**



Now let's think about what may be causing this behaviour.

- Here are some of the main causes of sleep difficulties, which we will next discuss in turn:

1. Environment / routine
2. Fears or emotions
3. How we respond
4. Pain and discomfort
5. The effects of dementia

1. Is there something about the environment/routine?

- **There may be things about a person's surroundings or routine that may increase sleep difficulties. These may include:**

  - Too much noise or light in the bedroom
  - Uncomfortable surroundings e.g. too warm or cold
  - Sleeping during the day or lack of activity
  - Change in routine e.g. irregular meal or bed times
  - Fear the dark / disorientation
  - Being inside all the time and not getting enough fresh air and light

Talking point:

Think of the difficulty you described a few minutes ago. Do you think it could be caused or made worse by surroundings or routine?

Have any of the changes you have already been trying made a difference to this problem?

2. Are they feeling distressed or frightened?

Key Point:

Having dementia can be frightening and distressing for people, who cannot always explain or understand their own feelings. Like for all of us, this can feel worse at night.

Some of what you may see happening includes:

- Nightmares
- Waking up distressed or confused
- Being frightened to go to bed or be alone
- Fear of the dark
- Screaming or crying out in the night

Even though you could see her worrying, she was silent, but when we weren't there then she was continually on the phone no matter what time of day or night it was

It can be hard to work out what a person with dementia is feeling and they may not always be able to tell you, especially at night.

Talking point:

What would be signs to you that your relative was feeling upset or frightened in the night? What do you notice happening?

What do you find helps to comfort or calm down your relative?

3. Are night-time difficulties affected by how we respond?

- We know that being woken up or disturbed in the night can be extremely stressful and it is not always easy to think clearly in the middle of the night, especially when you are exhausted.

- There may be practical ways of responding during the night or things you can do in advance to make it easier for you and your relative to get back to sleep.

Key Point:
Changing how we react to difficult night-time behaviours can help to manage the problem.

Talking point Let's look at the example below:

Ted is caring for his wife Lena who has dementia. Lena wakes up three or four times in the night and wanders around the house. She goes downstairs and tries to make toast. Ted has been woken by the smoke alarm a few times.

Ted has started to lock their bedroom door so that Lena cannot go downstairs. When Lena tries to open the door she gets upset, crying and wakes up Ted, saying she needs to get the breakfast ready for the children in time for school.

What could Ted try in this situation?

4. Are difficulties caused by pain or discomfort?

There may be physical problems that are waking or keeping your relative up at night, but they may not always know or be able to tell you what is wrong. These could include:

- Pain
- Incontinence
- Needing to go the toilet often

Talking point:

Let's think of three things that you can do to find out if a person is unwell or in pain?

1.

2.

3.

Some common medical problems that can cause sleep difficulties include:

Problem	What you may notice
Pain	• Holding or rubbing part of body • Fast breathing • Groaning or moaning • Tension • Making a face or grimacing • Pushing away when touched
Constipation	• Pain and difficulty opening bowels • Hard faeces • Pain on touching stomach
UTI (Urinary tract infections)	• Urinating more frequently • Cloudy or different smelling urine • Pain in back when touched • Being more confused • Burning pain on passing urine

5. Are difficulties caused by the dementia?

Dementia may directly cause sleep difficulties through its effects on the brain and therefore our body-clock. Below is a reminder of some of the sleep difficulties that may occur in dementia.

- Not feeling tired at night
- Waking during the night
- Being more mixed up and restless at night
- Excessive sleepiness during the day
- Restlessness during sleep (e.g. acting out dreams)
- Breathing pauses during sleep (sleep apnoea)
- Restless/fidgety legs before or during sleep

Talking point:

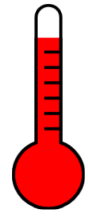
Think back to the examples you described earlier in the session.
How might your relative's sleep difficulties been caused by their dementia?

DREAMS: START

Managing Stress 4: *Stretching*

- Simply stretching tired muscles can go a long way toward reducing tension and stress.
- Stretching exercises can be used almost anywhere, at any time, for as long as you want, so they can be an especially convenient relaxation technique.
- It is important to do stretching exercises that feel good to you. As we practice this today, please tell us if you experience any discomfort.

Tension rating before exercise

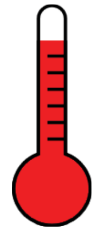


5 = Terribly tense
4 = Really tense
3 = Moderately tense
2 = Slightly tense
1 = Not at all tense

- First, please rate your level of stress or tension right now, before we practise the stretching exercise.

Q! **On a scale of 1 to 5, how would you rate your tension? ____**

Tension rating after exercise



5 = Terribly tense
4 = Really tense
3 = Moderately tense
2 = Slightly tense
1 = Not at all tense

- How would you rate your tension level now after practising the stretching exercise?

Q! **Now, please rate your tension or stress level from 1 to 5 _____**

Summary

Today, we have talked about:

- Recap on daytime activity and routine
- Troubleshooting: putting plans into action
- Managing night-time behaviour problems
- Describing and investigating behaviours
- Managing stress 4: Stretching

FOR NEXT WEEK: Putting it into practice

Stretching:

- Try to practice this every day and to use it in stressful situations. See if it helps.

Managing night-time behaviour problems:

- Try to complete the behaviour record on p.20 for three separate episodes of difficult night-time behaviours this week. Try to focus on **describing** and **investigating** what happened.

Putting the plan into action:

- Continue to use the sleep plan we made for your relative, thinking about any changes we talked about earlier to make the plan more manageable.

- Keep a sleep diary for you and your relative this week so we can compare them next time.

DREAMS: START

Putting it into practice

- When will you have an opportunity to do this?
- What might make it easier?
- What might get in the way?

Behaviour Record

Describe	Investigate…	What did you find out?
	☐ Environment/routine?	
	☐ Fears or emotions?	
	☐ How we respond?	
	☐ Uncomfortable /Unwell?	
	☐ Dementia?	
	☐ Environment/routine?	
	☐ Fears or emotions?	
	☐ How we respond?	
	☐ Uncomfortable /Unwell?	
	☐ Dementia?	
	☐ Environment/routine?	
	☐ Fears or emotions?	
	☐ How we respond?	
	☐ Uncomfortable /Unwell?	
	☐ Dementia?	

Weekly Sleep Diary (Carer)

Date	Noon	1pm	2pm	3pm	4pm	5pm	6pm	7pm	8pm	9pm	10pm	11pm	12am	1am	2am	3am	4am	5am	6am	7am	8am	9am	10am	11am
Tuesday May 14th	O		N							/			X X		X				/				N	O

Key:

/ = When you went to bed and got up in the morning

X = Every time you get up in the night

N = When you take a nap during the day

O = When you have been out of the house

E = When you have done any physical exercise

Weekly Sleep Diary (Relative)

Date	Noon	1pm	2pm	3pm	4pm	5pm	6pm	7pm	8pm	9pm	10pm	11pm	12am	1am	2am	3am	4am	5am	6am	7am	8am	9am	10am	11am
Tuesday May 14th	O		N							/			X X		X				/				N	O

Key:

/ = When your relative went to bed and when they got up in the morning

X = Every time your relative gets up in the night

N = When your relative takes a nap during the day

O = When your relative has been out of the house

E = When your relative has done any physical exercise

L = When you relative has used the light box

Facilitator Version

DREAMS: START

Dementia Related Manual for Sleep:

Strategies for Relatives

Session 4:

Difficult night-time behaviours

For each session:

- Encourage the carer to write down what works or key strategies or plans to refer back to.
- If content is clearly irrelevant or does not fit, for example someone is very active all day will not need a plan around daytime naps, miss these parts out.
- When setting exercises at the end, check that they remember what is in the plan if not explicitly covered in the content.

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UCL Division of Psychiatry
6th Floor Maple House
149 Tottenham Court Road
London W1T 7NF
United Kingdom

Plan for today's session

"This is the contents page for you to refer back to"

Refer to the contents but do not read the full list

Recap on daytime activity and routine	p. 3
Troubleshooting: putting plans into action	p. 4
Managing night-time behaviour problems	p. 8
Describing and investigating behaviours	p. 9
Managing stress 4: Stretching	p.16
Summary	p. 18
Putting it into practice	p. 19

15mins

Recap of session 3: Daytime activities and routine

We talked about:

- The importance of daytime activity and routine
- Sleep, exercise and physical activity
- Planning daytime activity
- Establishing a good day and night routine
- Managing stress 3: Guided imagery
- Summary
- Putting it into practice

Q! **Did you have a chance to try out new daytime activities and exercise with your relative and record this on the form?**

"Write down what you found, especially what worked well so that you can use this in future"
Remember to ask about pleasant activities and exercise ask what they did

If Yes…	
How did this go?	
What did you notice happening?	
What made it easier?	
If No…	
What got in the way?	
What would make it easier in the future?	

Key Point:

Please continue to put the agreed plan into action and complete the sleep diary / record forms. Remember, completing the record forms helps to see what is working and what is not.

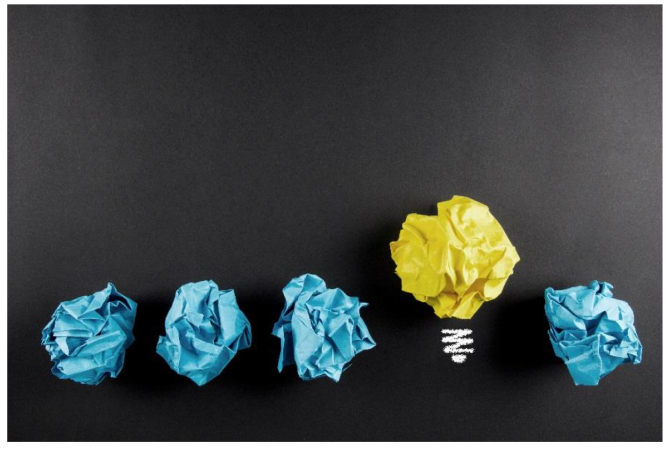
Now let's talk more generally about how the changes are going…

Troubleshooting: putting plans into action

So far, during the sessions we have made a plan to help improve your relative's sleep. Depending on their situation this may have involved:

- Increasing daytime stimulation, pleasant activity and exercise
- Being in daylight at set times and using the light box
- Establishing daytime and bedtime routines
- Making lifestyle and bedroom changes
- Using relaxation exercises (you and your relative)

It can take a while for these changes to take effect so please keep going with them. Now let's look at the plans we made in session 2 & 3 and discuss how this has been working so far for you and your relative.



Your relative's plan

Type up the plan made in session 2 and add in the exercise activity plan from session 3 and insert here. You should also bring **an extra typed up copy** to give to carers so they can keep referring to the table as they work through the talking points over the page (allowing them to take notes if they wish to.)

Area for change	Action
Light box	
Increasing natural light	
Reducing daytime naps	
Time to bed and rise	
Lifestyle changes	
Increasing daytime activity / physical exercise	

Talking point:

Remember to try and make this an open discussion, not jumping in with solutions too quickly encouraging people to come up with their own strategies. Refer to sleep diary if completed.

- Which parts have you managed to do?

- What effects have you noticed on your relative?

- What effects have you noticed on yourself?

- Is there anything else you have noticed happening?

- Which are the parts that you are finding harder to put into practice?

- Can you think of some reasons why you and/or your relative are finding these parts more difficult to do?

Encourage them to make a specific change to the plan and write down clearly here.

Let's think together about possible solutions to these difficulties and how we could adapt the plan to make it easier for you to use:

1.

2.

3.

5mins

Managing night-time behaviour problems

During our first session, we identified these difficult behaviours:

- X
- Y
- Z
-

Insert the behaviours identified in session 1 here in advance of the session

Would you keep the same list or add any other behaviours? Let's rank these in order of how difficult they are to manage:

1.

2.

3.

Key Point:
There is always a cause for night-time behaviours, but the person with dementia is not doing it on purpose and can't control these.

- Often there will be several factors causing night-time behaviours. Our challenge is to work out **what is causing each behaviour** and **what we can do about it.**

20mins

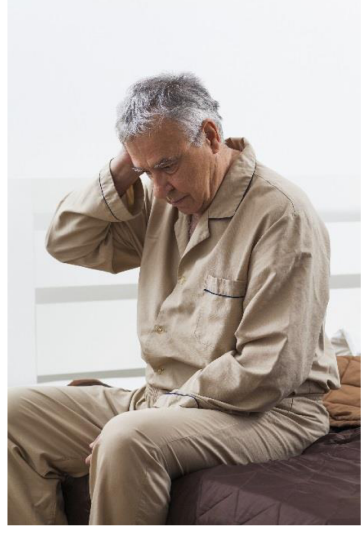
Describing and investigating behaviours

Describing in detail difficult night-time behaviours can help to make sense of what is happening and work out how to make it happen less.

Choose one of the sleep problems you identified on the previous page. Start by describing what happens. Imagine it as a film and try to be as detailed as possible. Use the questions below to help:

"These questions are a guide, there are no right or wrong answers, it is more to help us work out together what might be happening"

- **What exactly happens?**
- **How often and at what time does it happen?**
- **Where exactly does it happen?**
- **Does your relative talk to you at the time, what do they say?**
- **How do you think they are feeling at the time?**
- **What might they be thinking?**
- **How do you react when it happens?**



Now let's think about what may be causing this behaviour.

- Here are some of the main causes of sleep difficulties, which we will next discuss in turn:

"We will go through these one by one but often they occur together. Understanding and investigating what may be causing sleep difficulties can help us to work out the best ways to manage it"

1. Environment / routine
2. Fears or emotions
3. How we respond
4. Pain and discomfort
5. The effects of dementia

1. Is there something about the environment/routine?

- **There may be things about a person's surroundings or routine that may increase sleep difficulties. These may include:**

  - Too much noise or light in the bedroom
  - Uncomfortable surroundings e.g. too warm or cold
  - Sleeping during the day or lack of activity
  - Change in routine e.g. irregular meal or bed times
  - Fear the dark / disorientation
  - Being inside all the time and not getting enough fresh air and light

Talking point:

Think of the difficulty you described a few minutes ago. Do you think it could be caused or made worse by surroundings or routine?

Have any of the changes you have already been trying made a difference to this problem?

Encourage people to write down ideas they had not thought of before

2. Are they feeling distressed or frightened?

Key Point:

Having dementia can be frightening and distressing for people, who cannot always explain or understand their own feelings. Like for all of us, this can feel worse at night.

Some of what you may see happening includes:

- Nightmares
- Waking up distressed or confused
- Being frightened to go to bed or be alone
- Fear of the dark
- Screaming or crying out in the night

Even though you could see her worrying, she was silent, but when we weren't there then she was continually on the phone no matter what time of day or night it was

It can be hard to work out what a person with dementia is feeling and they may not always be able to tell you, especially at night.

Talking point:

What would be signs to you that your relative was feeling upset or frightened in the night? What do you notice happening?

Prompts:
Crying, calling out, wandering around, looking for people that are not there, wanting people with them

What do you find helps to comfort or calm down your relative?

Prompts:
Staying with them, having a warm, drink, reassurance, touch, night light.

3. Are night-time difficulties affected by how we respond?

- We know that being woken up or disturbed in the night can be extremely stressful and it is not always easy to think clearly in the middle of the night, especially when you are exhausted.

- There may be practical ways of responding during the night or things you can do in advance to make it easier for you and your relative to get back to sleep.

Key Point:
Changing how we react to difficult night-time behaviours can help to manage the problem.

Talking point Let's look at the example below:

Ted is caring for his wife Lena who has dementia. Lena wakes up three or four times in the night and wanders around the house. She goes downstairs and tries to make toast. Ted has been woken by the smoke alarm a few times.

Ted has started to lock their bedroom door so that Lena cannot go downstairs. When Lena tries to open the door she gets upset, crying and wakes up Ted, saying she needs to get the breakfast ready for the children in time for school.

What could Ted try in this situation?

Prompts:
- Making sure she is safe, e.g. telecare sensors / moving the toaster at night
- Settling her to get to sleep using touch / relaxation / talking / singing
- Reassurance and talking with her about the children
- Using cues to remind her it is night time.

4. Are difficulties caused by pain or discomfort?

There may be physical problems that are waking or keeping your relative up at night, but they may not always know or be able to tell you what is wrong. These could include:

- Pain
- Incontinence
- Needing to go the toilet often

Talking point:

Let's think of three things that you can do to find out if a person is unwell or in pain?

1.
2.
3.

Prompts:
- Ask them if they are in pain (even if they cannot say , they may show you)
- Touch them gently in places that they may be in pain – see their response
- Be observant – watch, notice if they are groaning, crying, tensing, especially when touched
- Give them pain medication e.g. paracetamol and see if this reduces agitation

Some common medical problems that can cause sleep difficulties include:

Problem	**What you may notice**
Pain	• Holding or rubbing part of body • Fast breathing • Groaning or moaning • Tension • Making a face or grimacing • Pushing away when touched
Constipation	• Pain and difficulty opening bowels • Hard faeces • Pain on touching stomach
UTI (Urinary tract infections)	• Urinating more frequently • Cloudy or different smelling urine • Pain in back when touched • Being more confused • Burning pain on passing urine

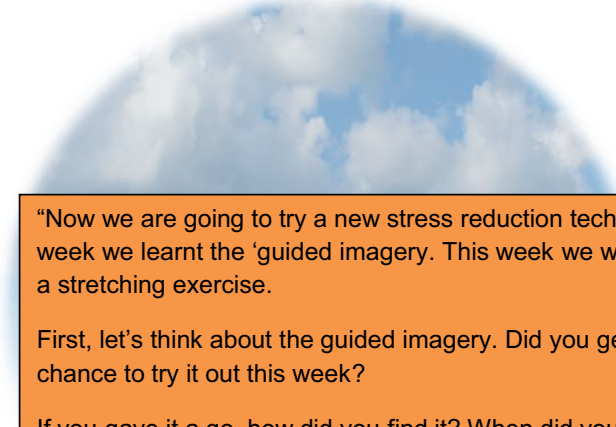
5. Are difficulties caused by the dementia?

Dementia may directly cause sleep difficulties through its effects on the brain and therefore our body-clock. Below is a reminder of some of the sleep difficulties that may occur in dementia.

- Not feeling tired at night
- Waking during the night
- Being more mixed up and restless at night
- Excessive sleepiness during the day
- Restlessness during sleep (e.g. acting out dreams)
- Breathing pauses during sleep (sleep apnoea)
- Restless/fidgety legs before or during sleep

Talking point:

Think back to the examples you described earlier in the session.
How might your relative's sleep difficulties been caused by their dementia?



"Now we are going to try a new stress reduction technique, last week we learnt the 'guided imagery. This week we will practise a stretching exercise.

First, let's think about the guided imagery. Did you get a chance to try it out this week?

If you gave it a go, how did you find it? When did you use it? What effect did it have on how you felt?

If you did not get a chance to try it, what got in the way?

Please try and carry on practicing the guided imagery exercise."

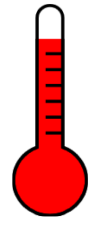
10mins

DREAMS: START

Managing Stress 4: *Stretching*

- Simply stretching tired muscles can go a long way toward reducing tension and stress.
- Stretching exercises can be used almost anywhere, at any time, for as long as you want, so they can be an especially convenient relaxation technique.
- It is important to do stretching exercises that feel good to you. As we practice this today, please tell us if you experience any discomfort.

Tension rating before exercise



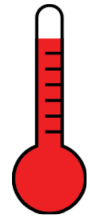
5 = Terribly tense
4 = Really tense
3 = Moderately tense
2 = Slightly tense
1 = Not at all tense

- First, please rate your level of stress or tension right now, before we practise the stretching exercise.

Q! **On a scale of 1 to 5, how would you rate your tension? ____**

"Now I am going to talk you through the stretching exercise…"

Tension rating after exercise



5 = Terribly tense
4 = Really tense
3 = Moderately tense
2 = Slightly tense
1 = Not at all tense

- How would you rate your tension level now after practising the stretching exercise?

Q! **Now, please rate your tension or stress level from 1 to 5 _____**

Discuss:
- Did your level of tension change?
- What was this experience like for you?
- Can you think of specific times when this might have helped?

Summary

Today, we have talked about:

- Recap on daytime activity and routine
- Troubleshooting: putting plans into action
- Managing night-time behaviour problems
- Describing and investigating behaviours
- Managing stress 4: Stretching

10mins

FOR NEXT WEEK: Putting it into practice

Stretching:

- Try to practice this every day and to use it in stressful situations. See if it helps.

If your relative is physically very frail or has found it difficult to do the seated exercise introduced last week, you could try this simpler stretching exercise with them.

Managing night-time behaviour problems:

- Try to complete the behaviour record on p.20 for three separate episodes of difficult night-time behaviours this week. Try to focus on **describing** and **investigating** what happened.

"Look back over the session to help you with this…"
Talk through the behaviour record form and check that they have understood the task.

Putting the plan into action:

- Continue to use the sleep plan we made for your relative, thinking about any changes we talked about earlier to make the plan more manageable.

- Keep a sleep diary for you and your relative this week so we can compare them next time.

Make sure they understand that they should keep a diary for themselves as well.

DREAMS: START

Putting it into practice

- When will you have an opportunity to do this?
- What might make it easier?
- What might get in the way?

Behaviour Record

Describe	Investigate…	What did you find out?
	☐ Environment/routine?	
	☐ Fears or emotions?	
	☐ How we respond?	
	☐ Uncomfortable /Unwell?	
	☐ Dementia?	
	☐ Environment/routine?	
	☐ Fears or emotions?	
	☐ How we respond?	
	☐ Uncomfortable /Unwell?	
	☐ Dementia?	
	☐ Environment/routine?	
	☐ Fears or emotions?	
	☐ How we respond?	
	☐ Uncomfortable /Unwell?	
	☐ Dementia?	

Weekly Sleep Diary (Carer)

Date	Noon	1pm	2pm	3pm	4pm	5pm	6pm	7pm	8pm	9pm	10pm	11pm	12am	1am	2am	3am	4am	5am	6am	7am	8am	9am	10am	11am
Tuesday May 14th	O		N							/			X X		X				/				N	O

Key:

/ = When you went to bed and got up in the morning

X = Every time you get up in the night

N = When you take a nap during the day

O = When you have been out of the house

E = When you have done any physical exercise

Weekly Sleep Diary (Relative)

Date	Noon	1pm	2pm	3pm	4pm	5pm	6pm	7pm	8pm	9pm	10pm	11pm	12am	1am	2am	3am	4am	5am	6am	7am	8am	9am	10am	11am
Tuesday May 14th	O		N							/			X X		X				/				N	O

Key:

/ = When your relative went to bed and when they got up in the morning

X = Every time your relative gets up in the night

N = When your relative takes a nap during the day

O = When your relative has been out of the house

E = When your relative has done any physical exercise

L = When you relative has used the light box

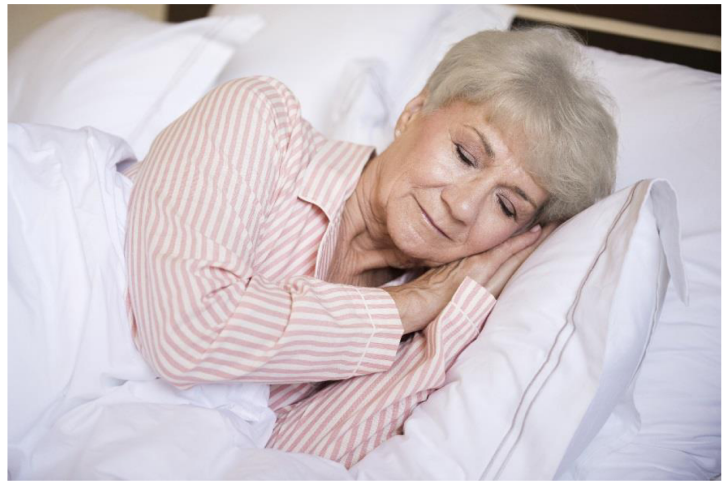
DREAMS: START

Dementia **Re**l**a**ted **M**anual for **S**leep:

Str**a**tegies for **R**ela**t**ives

Session 5:

Taking care of your own sleep



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UCL Division of Psychiatry
6th Floor Maple House
149 Tottenham Court Road
London W1T 7NF
United Kingdom

Plan for today's session

Recap on night-time behaviour problems	p. 3
Creating strategies for managing behaviours	p. 4
Managing your own sleep	p. 5
Challenging unhelpful thoughts and feelings	p. 9
Managing stress 5: Guided imagery – ocean escape	p. 16
Summary	p. 19
Putting it into practice	p. 20

Recap of session 4: Difficult night-time behaviours

We talked about:

- Troubleshooting putting plans into action
- Managing night-time behaviour problems
- Describing and investigating behaviours
- Managing stress: Stretching
- Summary
- Putting it into practice

- *Q!* Did you get a chance to use the behaviour record to describe and investigate three separate episodes of difficult night-time behaviours this week?

If Yes…	
How did this go?	
What did you notice happening?	
What made it easier?	

If No…	
What got in the way?	
What would make it easier in the future?	

Please continue to use the plan we have made for improving sleep

Creating strategies for managing behaviours

Choose one of the behaviours you recorded during the week or we discussed last week. Let's remind ourselves what you identified as the possible causes of the behaviour:

1. Environment / routine
2. Fears or emotions
3. How we respond
4. Pain and discomfort
5. The effects of dementia

We will now think of *strategies* that you can use to *prevent* the behaviour from occurring or to help you respond differently. Be creative, and write down at least **two** in the behaviour record on page 21.

- Regardless of which behaviour and strategies you choose, try to be consistent and use the strategy **every time** even if it doesn't work every time.

- **Problem-solving is a process of trial and error. There is no right or wrong answers.** It's possible that the strategy that you came up with may work at some times and not others. Be flexible, patient and creative!

Managing your own sleep

- We know from existing research and talking to people caring for a relative with dementia, that sleep difficulties are also common among people caring for a relative. Your relative's sleep difficulties are likely to affect your own sleep.

- This may be because you are being woken up at night or early in the morning, or it may be that you are feeling stressed and worried and that this is affecting your sleep.

Q! How do you feel that your sleep is affected by your relative's sleep difficulties and dementia?

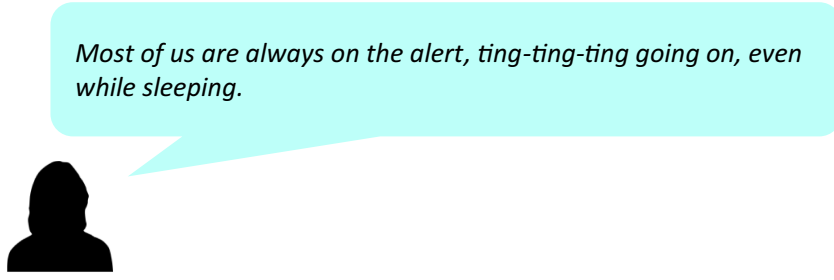
- Many carers report that they go to bed late or get up early so that they can have a little more time to themselves or get things done. This may then lead to a change in your own sleep pattern and routine.

- Although caring for a relative is time consuming, it is important that you make time for things you enjoy. This is because if you spend all your time caring, you may begin to feel burned out and frustrated, and also find it harder to sleep.

- In addition to the relaxation exercises we have each week, there are other simple things you could try to improve your sleep. Even if your sleep is not a problem you may find some of the following advice useful.

When the carer hasn't had any sleep they are short tempered in the morning and it is very difficult to cope, you know how you should be coping but it's not so easy to do it when you've not had any sleep

Managing thoughts and feelings



There are a number of other techniques that you can use to manage the thoughts and feelings that keep you awake at night:

1. **Putting the day to rest**

You may find this technique useful for thoughts that have to do with your caring role. The aim is to put the day to bed so that you can get to sleep.

To put the day to rest you need to follow these simple steps:

- Set aside 20 minutes in the early evening (say around 7 pm)
- Sit down with a pen and paper
- Think of what has happened during the day, how it has gone and how you feel about it - put it to rest!
- Write down anything you still need to do on a 'to do' list with steps that you can take to complete any 'loose ends'
- Try to use your 20 minutes to leave you feeling more in control
- When it comes to bedtime remind yourself that you have already dealt with things
- If new thoughts come up in bed note them down on a piece of paper at your bedside to be dealt with the next day.

2. **Thought-blocking**

Another way to manage repetitive thoughts in your mind is called thought blocking. This works best with trivial, unimportant thoughts rather than with more worrying problems.

Sometimes these thoughts come to people when they wake up in the middle of the night. It is best to start the thought blocking immediately upon wakening before you get too wide awake!

To use thought blocking follow three simple steps:

- Repeat the word "the" every 2 seconds in your head with your eyes closed
- Don't say it out loud, but it sometimes helps to 'mouth' it
- Keep up the repetitions for about 5 minutes (if you can!)

3. **The 15 minute rule**

Of course, there will be nights when you put your head down and sleep will not come quickly. When this happens, try not to just lie in bed worrying about your sleep.

Here are the steps you can take to follow the 15 minute rule:

- If sleep does not come within 15 minutes, you should get out of bed and go into another room.
- If it feels hard to get out of bed to make it easier you could:
    - leave the heating on
    - leave a lamp on in the living room
    - prepare a flask of a warm drink before bed
    - listen to music, read or do relaxation when you are up

Go back to bed when you feel sleepy again.
If you still cannot sleep get up again.

4. **Giving up trying**

Sometimes people are unable to sleep because they are simply trying too hard! Trying to fall asleep actually keeps you wakeful and may lead to irritability when you don't succeed.

Unlike many other things in life, sleep is not something that you can make happen by sheer force of will. In fact, the harder you try, the less likely it is to happen.

[redacted]

Talking point: Which of these techniques do you think may help you?

Challenging unhelpful thoughts and feelings

- Looking after someone with dementia, especially if you are being kept awake at night, can leave you overwhelmed and stressed. When we feel like this, it can be helpful to pay attention to our thoughts.

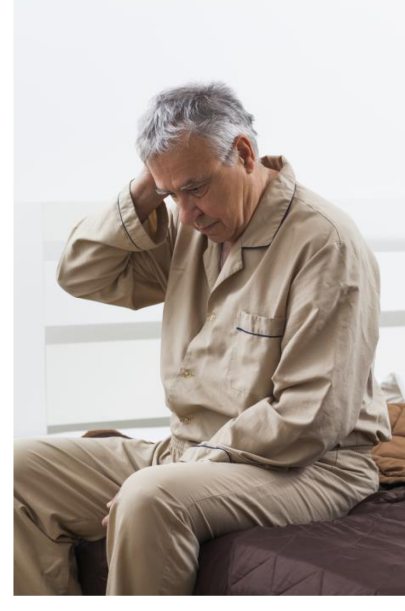
- In general, our feelings are linked to our thoughts. **The way you think about something directly affects the way you feel about it.** So thoughts can make you feel worse.

- You may use your time in bed as a time to think things through, but if you have trouble sleeping or are woken in the night, thoughts and worries could keep you awake. Thinking at night because of your busy life may not be a good solution.

- Some say that they feel exhausted, but still they can't stop that racing mind!

- First of all, let's consider the kinds of things that we think about when we are in bed and unable to get to sleep. There are several 'types' of thoughts that are common:

  - Rehearsing and planning
  - Problem-solving
  - Thinking about your relative's and your own health
  - Thinking about your relative's and your own sleep
  - Thinking about thinking
  - Worrying about the future



- There are three steps to changing your unhelpful thoughts:

  1. S*top and identify* your current thoughts.
  2. C*hallenge and replace* your unhelpful thoughts with more helpful ones.
  3. *Pay attention to how you feel* in that moment

1. We will start by focusing on step one, which is to ***stop and identify*** the thoughts that are contributing to your unpleasant feelings.

What are the thoughts that go around your head or keep you awake at night?

_____

_____

_____

_____

2. The next step is to ***challenge and replace your unhelpful thoughts*** with more helpful ones. This can be difficult at times, but with practice you should find it helps. There are common patterns of thinking called “automatic thought patterns”. Here are some techniques for changing unhelpful thoughts.

    1. Look at it from someone else’s point of view.
    2. Ask other people what they think or get more information (during the day!).
    3. Change how you talk to yourself.
    4. Try not to jump to conclusions.
    5. Decide to think about something pleasant at night

Let’s consider the following example whilst going through these thought challenging techniques:

> Alice is 64 years old and cares for her 90 year old mother. She believes that she is not a good daughter. She feels guilty as she wants to visit her friends. Alice thinks, "I should always stay with my mother because something bad will happen to her when I leave. Other people can't take care of her the way I do. If something happens I will never forgive myself for not being a good daughter."

1. **Look at it from a different point of view:** Talk to yourself as if someone who cares about you is talking to you.

In our example, as Alice blames herself for wanting to spend time away from home, she could ask herself: "How would my close friend Marie view this - and what would she have to say about my situation?" Alice could also imagine what her friend (who cares about her) would think about her leaving her mother for short periods.

Talking point:

- What do you think Alice's friend Marie would say?

- If your friend was here what would they say to you?

- What if your friend was in your situation, what would you say to them?

2. **Take action/ Ask others:**

Some carers find it helpful to get additional information to challenge their unhelpful thoughts.

Alice could challenge her thoughts about "not being a good daughter" by talking to other carers about how they handle similar situations. Alice could also plan to leave her mother with someone she trusts for a short period, to test out her concerns that her mother will have a crisis when she is gone.

Talking point:

- Is there anyone you can talk to about your caring role?

- What do you believe you need to do, to be a dependable carer?

- Do you have any concerns? What could you do to test out your concerns?

3. Change how you talk to yourself:

We often create negative labels for others or ourselves without realising what we are doing, for example thinking “If I can’t be there all the time, I am not good enough, I am not giving what my relative deserves”.

We also may believe that we must behave, think, or feel a certain way. This might often include us saying things to ourselves like “I must/ I should do ... ”. Allowing yourself to think “It’s OK not to be perfect” and “It’s also important I look after myself” can help you see the situation from a different point of view.

If Alice tried to think about what her label of "Not being a good daughter” really meant, she would see that she was expecting the impossible and this expectation would set herself up to fail.

She could also change, "I should always stay with mother" to, "My mother likes me being there, but she could enjoy being with others too, and it would be good for both of us if I get a break and feel a bit better".

Talking point:

- Do you ever have these kinds of thoughts?

- How else could you think about your situation? Is there any other way you could think about your situation?

4. Try not to think of things as all or nothing:

Remind yourself to think of different options. Don't assume that if you can't do something perfectly; it is not worth doing at all.

Could Alice consider other alternatives to never going out? Must she think of herself as either a good daughter **OR** *not* a good daughter?

It is important Alice recognises all the good things she is doing and how much she is coping with.

Talking point:

- Do you ever have these kinds of thoughts?

- Tell me some of the positives about caring for your relative

Key Point:

Remember that the thoughts that interfere at bedtime will be easier to dismiss if they have already been dealt with… at a time when you were more awake!

Making time for yourself

- As we discussed for your relative, daytime napping and lack of daytime activity can make it harder to sleep at night, the same will be true for you.

- Building pleasurable activity and time for yourself into the day will also have a positive effect upon your mood.

Yes I think it's essential for every carer to have something that they can do that's totally different from the caring role, you know, to survive

Key Point:

<u>Anything you like to do</u> is a pleasant event, e.g. having lunch with a friend or calling a relative for a chat

- Adding pleasant events to your daily life can be difficult. You may think "I don't have the time to do pleasant activities!" or feel guilty about making time for yourself or having time apart from the person you care for.

- These can be barriers but it is important to overcome them. **Being a good carer means taking care of yourself too!**

Rule A: ***Start small and be simple.*** The most important thing to remember is to choose events that you can do everyday or a few times a week. You may enjoy travelling, but realistically you cannot take a trip every day.

A smaller and more realistic activity would be going to the shops, cycling or walking.

Rule B: ***Focus on events you want to do more often.***

Let's think of four pleasant activities for you

1

2

3

4

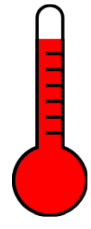
DREAMS: START

Managing Stress 5:

Guided Imagery – Ocean Escape

Today we are going to do another Guided Imagery exercise. This exercise will involve imagining your experience at the ocean, far away from the cares of everyday life.

Stress rating before exercise



5 = Terribly tense
4 = Really tense
3 = Moderately tense
2 = Slightly tense
1 = Not at all tense

- First, please rate your level of stress or tension right now, before we practise the guided imagery.

Q! **On a scale of 1 to 5, how would you rate your tension? _____**

Stress Reduction Technique
Guided Imagery – Ocean Escape

We are about to begin the guided relaxation imagery exercise. Soon, I will be describing a relaxing scene for you. But first of all, make sure you get yourself into a comfortable position in your chair, with your arms by your side.

Close your eyes, and take in a deep signal breath, holding it for a few moments... and then let go, relaxing as you do so.

Now as I continue talking to you, you can allow a calm relaxed feeling to settle over your body and mind…Let go of any unnecessary tension in your shoulders, arms, and hands.... As your shoulders and arms hang loosely by your side, let all of the tension drain out through the tips of your fingers.

Let the relaxation flow from your shoulders into the back of your neck ... as the tension dissolves and melts away... relaxing your neck and scalp... and also your face, including your mouth, tongue, and jaw.

Let the relaxation flow down the rest of your body... your chest... abdomen... and back.

Feel all the muscles of your body becoming loose and relaxed. Letting the relaxing feelings flow into your legs, ankles, and feet. Just allow your entire body to become loose, heavy, and relaxed. And now... picture yourself somewhere by the ocean.

Just project yourself to any relaxing place along the ocean... perhaps a place you have been to or a place you would like to go... It may be a sandy beach or a rocky beach... you may be on a pier or even on a cliff, overlooking the ocean... any place you choose is fine..

Look around... what do you see? Can you see it clearly in your mind? ... Do you notice the vastness of the ocean... stretching out as far as you can see? Perhaps you see a dolphin or whale swimming by...Now inhale deeply, smelling the fresh sea air.... Feel the warmth of the sun,... the cool breeze. How peaceful and relaxing it is...

And now listen more closely to the sounds... especially the sound of the waves. Pay close attention to the sound of the waves and notice how soothing and relaxing the sound is...as you hear the waves roll in... and out again... In... and out...the constant rhythm of the waves... the ebb... and flow... And each time the waves flow in... and out, you find yourself becoming more deeply relaxed... deeper... and deeper... as your muscles go loose... and limp... and the tranquility of this place surrounds you. *[Long pause]*

And now spend a few minutes doing whatever you would like. You may just want to lie on the sand and soak up the sun...

you may want to walk along the beach... or swim in the cool water... perhaps you

would like to do some fishing... go sailing...Whatever you would like to do at the ocean is okay... but no matter what you do, just continue being aware of this relaxation...

[*Allow participants a few moments to enjoy this imagery*]. And now, I will bring you back slowly from this relaxation by counting backwards from 3 to 1. When I get to 1, you'll be alert, refreshed, and comfortable.

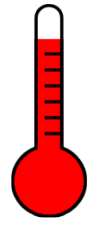
Okay,

"3" much more alert;

"2" feeling refreshed and comfortable, and

"1" as you open your eyes and return your awareness to the room you are in.

Stress rating after exercise



5 = Terribly tense
4 = Really tense
3 = Moderately tense
2 = Slightly tense
1 = Not at all tense

- How would you rate your tension level now, after practicing the guided imagery exercise?

Q! **Now, please rate your tension or stress level from 1 to 5 _____**

Summary

Today, we have talked about:

- Recap on night-time behaviour problems
- Creating strategies for managing behaviours
- Managing your own sleep
- Challenging unhelpful thoughts and feelings
- Managing stress 5: Guided imagery – Ocean escape

FOR NEXT WEEK: Putting it into practice

Guided imagery: Ocean escape:

- Try to practice this every day and to use it in stressful situations. See if it helps.

Trying out strategies for managing difficult behaviours / challenging unhelpful thoughts about sleep:

- Try out the strategies developed on the behaviour record with your relative each night, and record what happened.
- Make time to do something pleasant for yourself at least three times this week.
- Try to complete the thought record on p.24 at least three times this week.

Putting the plan into action:

- Continue to use the sleep plan we made for your relative and record how it goes.

DREAMS: START

Putting it into Practice

- When will you have an opportunity to do this?
- What might make it easier?
- What might get in the way?

Behaviour record

Try out these strategies over the next week and note on the behaviour record what happens.

Describe	Investigate	Create Strategies	Evaluate Did it work?
	☐ Environment/routine?		
	☐ Fears or emotions?		
	☐ How we respond?		
	☐ Uncomfortable /Unwell?		
	☐ Dementia?		
	☐ Environment/routine?		
	☐ Fears or emotions?		
	☐ How we respond?		
	☐ Uncomfortable /Unwell?		
	☐ Dementia?		

Thought record

Thoughts I have in bed	How they make me feel	An alternative response would be

Weekly Sleep Diary

Date	Noon	1pm	2pm	3pm	4pm	5pm	6pm	7pm	8pm	9pm	10pm	11pm	12am	1am	2am	3am	4am	5am	6am	7am	8am	9am	10am	11am
Tuesday May 14th	O		N							/			X X		X				/				N	O

Key:

/ = When your relative went to bed and when they got up in the morning

X = Every time your relative gets up in the night

N = When your relative takes a nap during the day

O = When your relative has been out of the house

E = When your relative has done any physical exercise

L = When you relative has used the light box

DREAMS: START

Dementia Related Manual for Sleep:

Strategies for Relatives

Facilitator Version

Session 5:

Taking care of your own sleep

For each session:

- Encourage the carer to write down what works or key strategies or plans to refer back to.
- If content is clearly irrelevant or does not fit, for example someone is very active all day will not need a plan around daytime naps, miss these parts out.
- When setting exercises at the end, check that they remember what is in the plan if not explicitly covered in the content.

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UCL Division of Psychiatry
6th Floor Maple House
149 Tottenham Court Road
London W1T 7NF
United Kingdom

Plan for today's session

"This is the contents page for you to refer back to"

Refer to the contents but do not read the full list

Recap on night-time behaviour problems	p. 3
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10mins

Recap of session 4: Difficult night-time behaviours

We talked about:

- Troubleshooting putting plans into action
- Managing night-time behaviour problems
- Describing and investigating behaviours
- Managing stress: Stretching
- Summary
- Putting it into practice

- *Q!* Did you get a chance to use the behaviour record to describe and investigate three separate episodes of difficult night-time behaviours this week?

If Yes…	
How did this go?	
What did you notice happening?	
What made it easier?	

If No…	
What got in the way?	
What would make it easier in the future?	

Please continue to use the plan we have made for improving sleep

"How has this been going, did you make changes based on the troubleshooting last week, is there anything you would like to discuss now?"

10mins

Creating strategies for managing behaviours

Choose one of the behaviours you recorded during the week or we discussed last week. Let's remind ourselves what you identified as the possible causes of the behaviour:

Choose together one of the episodes they described and talk about what they feel is causing the difficulties, explain that you are now going to go on and look at potential solutions

1. Environment / routine
2. Fears or emotions
3. How we respond
4. Pain and discomfort
5. The effects of dementia

Ask them to write in their strategies in the behaviour record on page 21.

We will now think of *strategies* that you can use to *prevent* the behaviour from occurring or to help you respond differently. Be creative, and write down at least **two** in the behaviour record on page 21.

- Regardless of which behaviour and strategies you choose, try to be <u>consistent</u> and use the strategy **every time** even if it doesn't work every time.

- **Problem-solving is a process of trial and error. There is no right or wrong answers.** It's possible that the strategy that you came up with may work at some times and not others. Be flexible, patient and creative!

5mins

Managing your own sleep

"Now let's spend some time thinking about your own sleep…

- We know from existing research and talking to people caring for a relative with dementia, that sleep difficulties are also common among people caring for a relative. Your relative's sleep difficulties are likely to affect your own sleep.

- This may be because you are being woken up at night or early in the morning, or it may be that you are feeling stressed and worried and that this is affecting your sleep.

Q! How do you feel that your sleep is affected by your relative's sleep difficulties and dementia?

Ask about what they noticed completing a sleep diary for themselves and their relatives this week.

- Many carers report that they go to bed late or get up early so that they can have a little more time to themselves or get things done. This may then lead to a change in your own sleep pattern and routine.

- Although caring for a relative is time consuming, it is important that you make time for things you enjoy. This is because if you spend all your time caring, you may begin to feel burned out and frustrated, and also find it harder to sleep.

- In addition to the relaxation exercises we have each week, there are other simple things you could try to improve your sleep. Even if your sleep is not a problem you may find some of the following advice useful.

When the carer hasn't had any sleep they are short tempered in the morning and it is very difficult to cope, you know how you should be coping but it's not so easy to do it when you've not had any sleep

Managing thoughts and feelings

Most of us are always on the alert, ting-ting-ting going on, even while sleeping.

There are a number of other techniques that you can use to manage the thoughts and feelings that keep you awake at night:

"Not all of these ideas will fit for you, but there may be some techniques here that you might want to give a go"

1. **Putting the day to rest**

You may find this technique useful for thoughts that have to do with your caring role. The aim is to put the day to bed so that you can get to sleep.

To put the day to rest you need to follow these simple steps:

- Set aside 20 minutes in the early evening (say around 7 pm)
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- Try to use your 20 minutes to leave you feeling more in control
- When it comes to bedtime remind yourself that you have already dealt with things
- If new thoughts come up in bed note them down on a piece of paper at your bedside to be dealt with the next day.

2. Thought-blocking

Another way to manage repetitive thoughts in your mind is called thought blocking. This works best with trivial, unimportant thoughts rather than with more worrying problems.

"We are going to talk next about how to manage the more complex and worrying thoughts that you may be having."

Sometimes these thoughts come to people when they wake up in the middle of the night. It is best to start the thought blocking immediately upon wakening before you get too wide awake!

To use thought blocking follow three simple steps:

- Repeat the word "the" every 2 seconds in your head with your eyes closed
- Don't say it out loud, but it sometimes helps to 'mouth' it
- Keep up the repetitions for about 5 minutes (if you can!)

3. The 15 minute rule

Of course, there will be nights when you put your head down and sleep will not come quickly. When this happens, try not to just lie in bed worrying about your sleep.

Here are the steps you can take to follow the 15 minute rule:

- If sleep does not come within 15 minutes, you should get out of bed and go into another room.
- If it feels hard to get out of bed to make it easier you could:
    - leave the heating on
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    - prepare a flask of a warm drink before bed
    - listen to music, read or do relaxation when you are up

Go back to bed when you feel sleepy again.
If you still cannot sleep get up again.

4. **Giving up trying**

Sometimes people are unable to sleep because they are simply trying too hard! Trying to fall asleep actually keeps you wakeful and may lead to irritability when you don't succeed.

Unlike many other things in life, sleep is not something that you can make happen by sheer force of will. In fact, the harder you try, the less likely it is to happen.

[redacted]

Talking point: Which of these techniques do you think may help you?

10mins

Challenging unhelpful thoughts and feelings

- Looking after someone with dementia, especially if you are being kept awake at night, can leave you overwhelmed and stressed. When we feel like this, it can be helpful to pay attention to our thoughts.

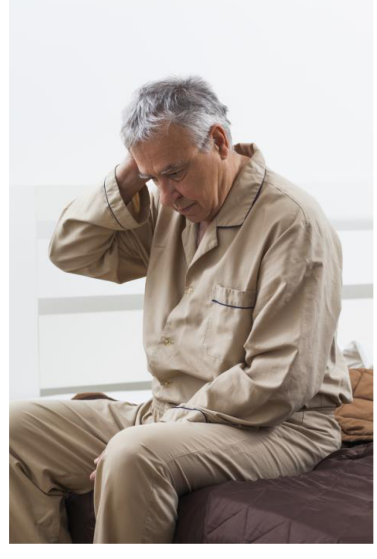
- In general, our feelings are linked to our thoughts. **The way you think about something directly affects the way you feel about it.** So thoughts can make you feel worse.

- You may use your time in bed as a time to think things through, but if you have trouble sleeping or are woken in the night, thoughts and worries could keep you awake. Thinking at night because of your busy life may not be a good solution.

- Some say that they feel exhausted, but still they can't stop that racing mind!

- First of all, let's consider the kinds of things that we think about when we are in bed and unable to get to sleep. There are several 'types' of thoughts that are common:

  - Rehearsing and planning
  - Problem-solving
  - Thinking about your relative's and your own health
  - Thinking about your relative's and your own sleep
  - Thinking about thinking
  - Worrying about the future



- There are three steps to changing your unhelpful thoughts:

  1. S*top and identify* your current thoughts.
  2. C*hallenge and replace* your unhelpful thoughts with more helpful ones.
  3. *Pay attention to how you feel* in that moment

1. We will start by focusing on step one, which is to ***stop and identify*** the thoughts that are contributing to your unpleasant feelings.

What are the thoughts that go around your head or keep you awake at night?

_____

_____

_____

_____

2. The next step is to ***challenge and replace your unhelpful thoughts*** with more helpful ones. This can be difficult at times, but with practice you should find it helps. There are common patterns of thinking called “automatic thought patterns”. Here are some techniques for changing unhelpful thoughts.

    1. Look at it from someone else’s point of view.
    2. Ask other people what they think or get more information (during the day!).
    3. Change how you talk to yourself.
    4. Try not to jump to conclusions.
    5. Decide to think about something pleasant at night

Let’s consider the following example whilst going through these thought challenging techniques:

> Alice is 64 years old and cares for her 90 year old mother. She believes that she is not a good daughter. She feels guilty as she wants to visit her friends. Alice thinks, "I should always stay with my mother because something bad will happen to her when I leave. Other people can't take care of her the way I do. If something happens I will never forgive myself for not being a good daughter."

1. **Look at it from a different point of view:** Talk to yourself as if someone who cares about you is talking to you.

In our example, as Alice blames herself for wanting to spend time away from home, she could ask herself: "How would my close friend Marie view this - and what would she have to say about my situation?" Alice could also imagine what her friend (who cares about her) would think about her leaving her mother for short periods.

Talking point:

- What do you think Alice's friend Marie would say?

- If your friend was here what would they say to you?

- What if your friend was in your situation, what would you say to them?

2. **Take action/ Ask others:**

Some carers find it helpful to get additional information to challenge their unhelpful thoughts.

Alice could challenge her thoughts about "not being a good daughter" by talking to other carers about how they handle similar situations. Alice could also plan to leave her mother with someone she trusts for a short period, to test out her concerns that her mother will have a crisis when she is gone.

Talking point:

- Is there anyone you can talk to about your caring role?

- What do you believe you need to do, to be a dependable carer?

- Do you have any concerns? What could you do to test out your concerns?

3. Change how you talk to yourself:

We often create negative labels for others or ourselves without realising what we are doing, for example thinking “If I can’t be there all the time, I am not good enough, I am not giving what my relative deserves”.

We also may believe that we must behave, think, or feel a certain way. This might often include us saying things to ourselves like “I must/ I should do ... ”. Allowing yourself to think “It’s OK not to be perfect” and “It’s also important I look after myself” can help you see the situation from a different point of view.

If Alice tried to think about what her label of "Not being a good daughter” really meant, she would see that she was expecting the impossible and this expectation would set herself up to fail.

She could also change, "I should always stay with mother" to, "My mother likes me being there, but she could enjoy being with others too, and it would be good for both of us if I get a break and feel a bit better".

Talking point:

- Do you ever have these kinds of thoughts?
- How else could you think about your situation? Is there any other way you could think about your situation?

4. Try not to think of things as all or nothing:

Remind yourself to think of different options. Don't assume that if you can't do something perfectly; it is not worth doing at all.

Could Alice consider other alternatives to never going out? Must she think of herself as either a good daughter **OR** *not* a good daughter?

It is important Alice recognises all the good things she is doing and how much she is coping with.

Talking point:

- Do you ever have these kinds of thoughts?

- Tell me some of the positives about caring for your relative

Key Point:

Remember that the thoughts that interfere at bedtime will be easier to dismiss if they have already been dealt with… at a time when you were more awake!

5mins

Making time for yourself

- As we discussed for your relative, daytime napping and lack of daytime activity can make it harder to sleep at night, the same will be true for you.

- Building pleasurable activity and time for yourself into the day will also have a positive effect upon your mood.

Yes I think it's essential for every carer to have something that they can do that's totally different from the caring role, you know, to survive

Key Point:

<u>Anything you like to do</u> is a pleasant event, e.g. having lunch with a friend or calling a relative for a chat

- Adding pleasant events to your daily life can be difficult. You may think "I don't have the time to do pleasant activities!" or feel guilty about making time for yourself or having time apart from the person you care for.

- These can be barriers but it is important to overcome them. **Being a good carer means taking care of yourself too!**

Rule A: ***Start small and be simple.*** The most important thing to remember is to choose events that you can do everyday or a few times a week. You may enjoy travelling, but realistically you cannot take a trip every day.

A smaller and more realistic activity would be going to the shops, cycling or walking.

Rule B: ***Focus on events you want to do more often.***

Let's think of four pleasant activities for you

1

2

3

4

"Now we are going to try a new stress reduction technique, last week we learnt the stretching. This week we will practise another guided imagery exercise.

First, let's think about the stretching. Did you get a chance to try it out this week?

If you gave it a go, how did you find it? When did you use it? What effect did it have on how you felt?

If you did not get a chance to try it, what got in the way?

Please try and carry on practicing the stretching exercise."

10mins

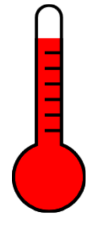
DREAMS: START

Managing Stress 5:

Guided Imagery – Ocean Escape

Today we are going to do another Guided Imagery exercise. This exercise will involve imagining your experience at the ocean, far away from the cares of everyday life.

Stress rating before exercise



5 = Terribly tense
4 = Really tense
3 = Moderately tense
2 = Slightly tense
1 = Not at all tense

- First, please rate your level of stress or tension right now, before we practise the guided imagery.

Q! **On a scale of 1 to 5, how would you rate your tension? _____**

"Now I am going to talk you through the guided imagery exercise…"

Stress Reduction Technique
Guided Imagery – Ocean Escape

We are about to begin the guided relaxation imagery exercise. Soon, I will be describing a relaxing scene for you. But first of all, make sure you get yourself into a comfortable position in your chair, with your arms by your side.

Close your eyes, and take in a deep signal breath, holding it for a few moments... and then let go, relaxing as you do so.

Now as I continue talking to you, you can allow a calm relaxed feeling to settle over your body and mind…Let go of any unnecessary tension in your shoulders, arms, and hands.... As your shoulders and arms hang loosely by your side, let all of the tension drain out through the tips of your fingers.

Let the relaxation flow from your shoulders into the back of your neck ... as the tension dissolves and melts away... relaxing your neck and scalp... and also your face, including your mouth, tongue, and jaw.

Let the relaxation flow down the rest of your body... your chest... abdomen... and back.

Feel all the muscles of your body becoming loose and relaxed. Letting the relaxing feelings flow into your legs, ankles, and feet. Just allow your entire body to become loose, heavy, and relaxed. And now... picture yourself somewhere by the ocean.

Just project yourself to any relaxing place along the ocean... perhaps a place you have been to or a place you would like to go... It may be a sandy beach or a rocky beach... you may be on a pier or even on a cliff, overlooking the ocean... any place you choose is fine..

Look around... what do you see? Can you see it clearly in your mind? ... Do you notice the vastness of the ocean... stretching out as far as you can see? Perhaps you see a dolphin or whale swimming by...Now inhale deeply, smelling the fresh sea air.... Feel the warmth of the sun,... the cool breeze. How peaceful and relaxing it is...

And now listen more closely to the sounds... especially the sound of the waves. Pay close attention to the sound of the waves and notice how soothing and relaxing the sound is...as you hear the waves roll in... and out again... In... and out...the constant rhythm of the waves... the ebb... and flow... And each time the waves flow in... and out, you find yourself becoming more deeply relaxed... deeper... and deeper... as your muscles go loose... and limp... and the tranquility of this place surrounds you. *[Long pause]*

And now spend a few minutes doing whatever you would like. You may just want to lie on the sand and soak up the sun...

you may want to walk along the beach... or swim in the cool water... perhaps you

would like to do some fishing... go sailing...Whatever you would like to do at the ocean is okay... but no matter what you do, just continue being aware of this relaxation...

[*Allow participants a few moments to enjoy this imagery*]. And now, I will bring you back slowly from this relaxation by counting backwards from 3 to 1. When I get to 1, you'll be alert, refreshed, and comfortable.

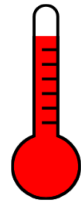
Okay,

"3" much more alert;

"2" feeling refreshed and comfortable, and

"1" as you open your eyes and return your awareness to the room you are in.

Stress rating after exercise



5 = Terribly tense
4 = Really tense
3 = Moderately tense
2 = Slightly tense
1 = Not at all tense

- How would you rate your tension level now, after practicing the guided imagery exercise?

Q! **Now, please rate your tension or stress level from 1 to 5 _____**

Discuss:
- Did your level of tension change?
- What was this experience like for you?
- Can you think of specific times when this might have helped?

Summary

Today, we have talked about:

- Recap on night-time behaviour problems
- Creating strategies for managing behaviours
- Managing your own sleep
- Challenging unhelpful thoughts and feelings
- Managing stress 5: Guided imagery – Ocean escape

10mins

FOR NEXT WEEK: Putting it into practice

Guided imagery: Ocean escape:

- Try to practice this every day and to use it in stressful situations. See if it helps.

Trying out strategies for managing difficult behaviours / challenging unhelpful thoughts about sleep:

- Try out the strategies developed on the behaviour record with your relative each night, and record what happened.
- Make time to do something pleasant for yourself at least three times this week.
- Try to complete the thought record on p.24 at least three times this week.

Putting the plan into action:

- Continue to use the sleep plan we made for your relative and record how it goes.

DREAMS: START

Putting it into Practice

- When will you have an opportunity to do this?
- What might make it easier?
- What might get in the way?

Give people time to consider what might work. Ask open questions and think about the possible causes. If people are struggling make tentative suggestions but check that these fit for them. The strategies may be things that they are already doing that they can do more of.

Behaviour record

Try out these strategies over the next week and note on the behaviour record what happens.

Describe	Investigate	Create Strategies	Evaluate Did it work?
	☐ Environment/routine?		
	☐ Fears or emotions?		
	☐ How we respond?		
	☐ Uncomfortable /Unwell?		
	☐ Dementia?		
	☐ Environment/routine?		
	☐ Fears or emotions?		
	☐ How we respond?		
	☐ Uncomfortable /Unwell?		
	☐ Dementia?		

Thought record

Thoughts I have in bed	How they make me feel	An alternative response would be

Weekly Sleep Diary

Date	Noon	1pm	2pm	3pm	4pm	5pm	6pm	7pm	8pm	9pm	10pm	11pm	12am	1am	2am	3am	4am	5am	6am	7am	8am	9am	10am	11am
Tuesday May 14th	O		N							/			X X		X				/				N	O

Key:

/ = When your relative went to bed and when they got up in the morning

X = Every time your relative gets up in the night

N = When your relative takes a nap during the day

O = When your relative has been out of the house

E = When your relative has done any physical exercise

L = When you relative has used the light box

Ses

DREAMS: START

Dementia **Re**l**a**ted **M**anual for **S**leep:

Str**a**tegies for **R**el**a**t**t**ives

Session 6:

What works? Using strategies in the future

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UCL Division of Psychiatry
6th Floor Maple House
149 Tottenham Court Road
London W1T 7NF
United Kingdom

Session 6 Version 1

Plan for today's session

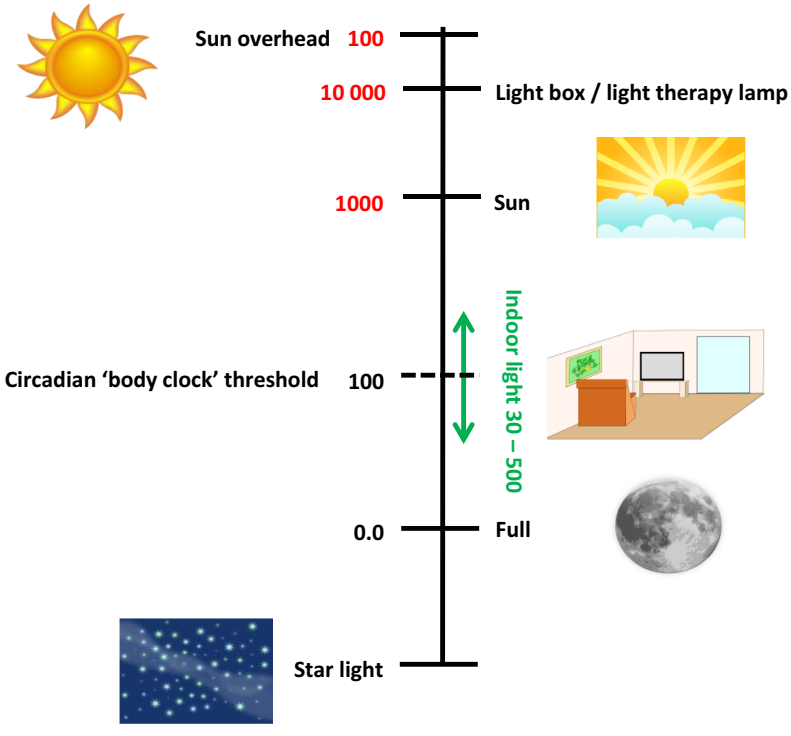
Putting it all together	p. 4
What works? Light, sleep and dementia	p. 5
What works? The importance of daytime activity	p. 6
What works? Making a new sleep routine	p. 7
What works? Making changes to improve sleep	p. 8
What works? Managing night-time behaviours	p. 9
What works? Challenging unhelpful thoughts and feelings	p. 10
What works? Relaxation	p. 11
Keeping it going – developing an action plan	p. 12
Action plan for you and your relative	p. 13
Summary	p. 14

Putting it all together

- Today is about bringing together **what works for you,** both **old and new strategies**. We will use this to put together a **personal** sleep action plan so that you can keep using DREAMS: START in the future.

What works? Light, sleep and dementia

In session two we talked about how important light is for good sleep, especially for people with dementia. We made a plan for increasing your relative's time in natural light and for using the light box.



Talking point:

- Shall we talk through how you have increased your relative's access to light?

Summary – light and sleep: What worked best?

What works? The importance of daytime activity

In session three we talked about how pleasant activities and physical exercise can help people to stay alert during the day and get better sleep at night.

We made a plan for increasing exercise and pleasant events for your relative.

Talking point:

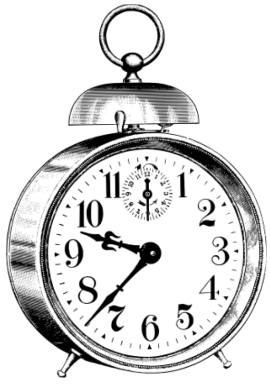
- Let's talk through how you have increased your relative's pleasant activities and physical exercise? What has gone well?

Summary – daytime activity: What worked best?

What works? Making a new sleep routine

In sessions two and three we discussed how daytime napping, spending too much or too little time in bed (e.g through going to bed too early or late), and having a variable sleep pattern from night-to-night, can make it harder for people with dementia to sleep well.

We looked at ways to strengthen the link between bed and sleep.Some of the ways we discussed included:



- Winding down at bedtime
- Using the bedroom only for sleeping
- Reducing daytime napping
- Increasing daytime activity
- Only going to bed when tired
- Using the 15 minute rule
- Having a daytime routine
- Going to bed and getting up at a set time

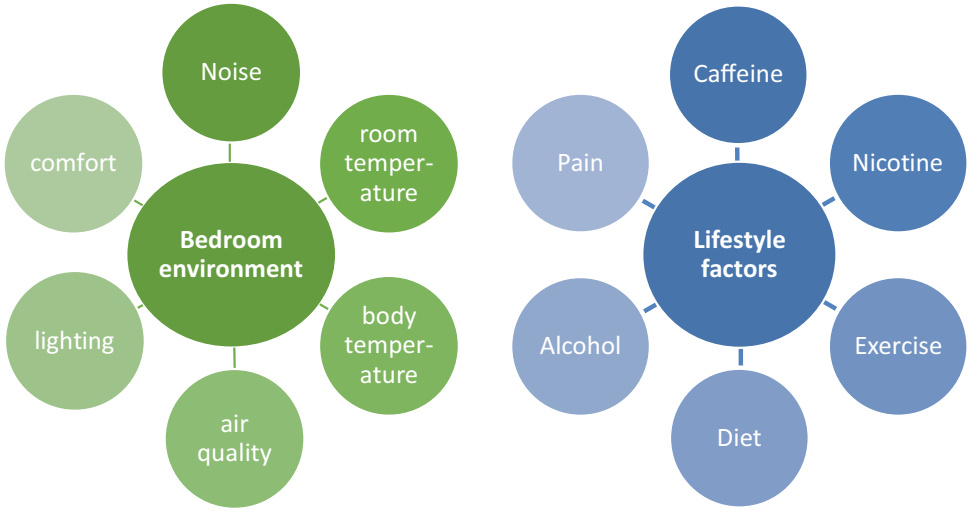
Talking point:

- Let's discuss any changes to your relatives sleep routine. What worked well?

Summary – sleep routine: What worked best?

What works? Making changes to improve sleep

In our first session we identified small changes that can be made to improve sleep.



Talking point:

- Let's discuss any changes you have made for you or your relative? Which did you find helpful?

Summary – bedroom and lifestyle: What worked best?

What works? Managing night-time behaviour

In sessions four and five we discussed how describing and investigating behaviours can help us to develop specific strategies to try and overcome problems.

Remember, there is always a cause for night-time behaviours, but the person with dementia is not doing it on purpose and can't control these.

1. Environment / routine
2. Fears or emotions
3. How we respond
4. Pain and discomfort
5. The effects of dementia

Talking point:

- Have you been able to use this approach to managing night-time behaviour problems? If so, did you find helpful?

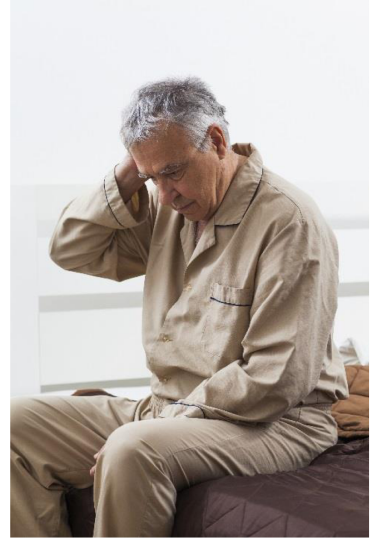
Summary – night-time behaviours: What worked best?

What works? Challenging unhelpful thoughts and looking after yourself

In session five we talked about how to manage your own sleep and make time to look after yourself.

We discussed how to challenge the thoughts that can keep you awake at night by:

1. S*topping to identify* your current thoughts.
2. C*hallenging and replacing* unhelpful thoughts with more helpful ones.
3. *Paying attention to how you feel* in that moment.



We also discussed how making time to look after yourself.

Talking point:

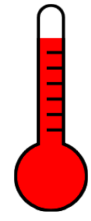
- Shall we talk about how you found challenging unhelpful thoughts and making time to look after yourself?

Summary – thoughts and feelings: What worked best?

What works? Relaxation

Each week we have practiced a different relaxation technique for you and/or your relative to use. These included:

1. Signal breath
2. Focused breathing
3. Guided imagery: Meadow and stream
4. Stretching
5. Guided imagery: Ocean escape



Talking point:

- Let's talk about how you found the relaxation exercises. Which did you find most helpful?

Summary – relaxation techniques: What worked best?

Keeping it going: Developing an action plan

- We know from experience that making changes and keeping them going is difficult and that some changes will work and others will not. Try not to be too discouraged.

- Some of the reasons it can be difficult include:
  - The advice and strategies are not relevant to you
  - It is tricky to get the hang of some of the strategies
  - It is hard to break established patterns

- Here are some suggestions to help you keep going!
  - Make use of the manual to remind yourself what you learnt in sessions
  - Keep using the sleep diary and record forms to notice patterns, especially to see what is working
  - Remember small changes can make a big difference over time, so keep trying things out and practicing

Key Point:

Please continue to put into practice what you have learnt during DREAMS: START. Focus on doing what works and be flexible. If it stops working, try something else.

Action plan for you and your relative

Let's go through your old plan and update it based on what worked best and what you want to keep doing more of. Remember to think about yourself and your relative.

Area for change	Action
Increasing natural light / Light box	
Increasing daytime activity / physical exercise	
Making a new routine / strengthening the link between bed and sleep	
Bedroom and lifestyle changes to improve sleep	
Managing night-time behaviours	
Looking after yourself / challenging unhelpful thoughts	
Relaxation	

Summary

We hope you have found these sessions helpful and will continue to use what you have learnt for you and your relative.

You have told us what you have found helpful and what strategies you will keep using.

You can keep and refer back to the manual to remind yourself of the techniques discussed throughout the sessions.

We have included copies of all the record forms and sleep diary at the end of this session.

Different researchers will be coming back to see how doing this has affected you and your relative. Do not tell them whether you received these sessions or not so we can fairly judge how much it helps! (This will mean putting the light box, thermometer, CD and the manual out of sight when they visit.)

Thank you for taking part.

Copies of record forms / sleep diary

Planning record

Date(s)	What did you try?	How did it go for your relative?	How did it go for you?

Planning record

	Action plan	How did it go for your relative?	How did it go for you?
Light box			
Increasing natural light			
Reducing daytime naps			
Time to bed and rise			
Lifestyle changes			

Pleasant events record:

Day	What did you try?	How did it go?

Behaviour Record

Describe	Investigate…	What did you find out?
	☐ Environment/routine?	
	☐ Fears or emotions?	
	☐ How we respond?	
	☐ Uncomfortable /Unwell?	
	☐ Dementia?	
	☐ Environment/routine?	
	☐ Fears or emotions?	
	☐ How we respond?	
	☐ Uncomfortable /Unwell?	
	☐ Dementia?	
	☐ Environment/routine?	
	☐ Fears or emotions?	
	☐ How we respond?	
	☐ Uncomfortable /Unwell?	
	☐ Dementia?	

Behaviour record

Describe	Investigate	Create Strategies	Evaluate Did it work?
	☐ Environment/routine? ☐ Fears or emotions? ☐ How we respond? ☐ Uncomfortable /Unwell? ☐ Dementia?		
	☐ Environment/routine? ☐ Fears or emotions? ☐ How we respond? ☐ Uncomfortable /Unwell? ☐ Dementia?		

Thought record

Thoughts I have in bed	How they make me feel	An alternative response would be

Weekly Sleep Diary

Date	Noon	1pm	2pm	3pm	4pm	5pm	6pm	7pm	8pm	9pm	10pm	11pm	12am	1am	2am	3am	4am	5am	6am	7am	8am	9am	10am	11am
Tuesday May 14th	O		N							/			X X		X				/				N	O

Key:

/ = When your relative went to bed and when they got up in the morning

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E = When your relative has done any physical exercise

L = When you relative has used the light box

DREAMS: START

Dementia **Re**l**a**ted **M**anual for **S**leep:

Str**a**tegies for **R**ela**t**ives

Facilitator Version

Session 6:

What works? Using strategies in the future

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UCL Division of Psychiatry
6th Floor Maple House
149 Tottenham Court Road
London W1T 7NF
United Kingdom

Session 6 Version 1

- ***Look at your notes from all prior sessions before the final session so that you are able to suggest and review ideas around each of the sessions e.g. “Do you think that using this strategy helped with xxx” or being able to remind people of the list of lifestyle changes or daytime activities”***.
- The purpose of the session is to get people to continue to use helpful strategies in the future.
- Try to encourage people to **focus on what worked** and if something was not useful, move on to the next section. Ask lots of questions to generate ideas**.**
- **Be flexible in this session, if people have not found a particular area useful do not push them, move on to the next thing.**
- Encourage people to write down what works and remind people to continue to use the record forms

Put/ print the action plan on page 13 separate. For each topic, discuss and then (if relevant) get the carer to decide on a goal and write it into the action plan as you go along.

Plan for today's session

"This is the contents page for you to refer back to"

Refer to the contents but do not read the full list

Putting it all together	p. 4
What works? Light, sleep and dementia	p. 5
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What works? Challenging unhelpful thoughts and feelings	p. 10
What works? Relaxation	p. 11
Keeping it going – developing an action plan	p. 12
Action plan for you and your relative	p. 13
Summary	p. 14

10mins

Putting it all together

- Today is about bringing together **what works for you,** both **old and new strategies**. We will use this to put together a **personal** sleep action plan so that you can keep using DREAMS: START in the future.

"We are now going to talk through the different parts of the DREAMS: START sessions to see what worked well and what you would like to do more of in the future."

What works? Light, sleep and dementia

In session two we talked about how important light is for good sleep, especially for people with dementia. We made a plan for increasing your relative's time in natural light and for using the light box.

Sun overhead 100

10 000 Light box / light therapy lamp

1000 Sun

Indoor light 30 – 500

Circadian 'body clock' threshold 100

0.0 Full

Star light

Talking point:

- Shall we talk through how you have increased your relative's access to light?

"Let's make a note of what worked best while we talk."

Summary – light and sleep: What worked best?

Prompts:

Remind people of key ideas including:

- Getting enough light during the day is extremely important for sleep at night
- Natural light is best – even if only for a small amount of time.

Ask them what worked best and what effects they have noticed on their relative during the day and at night.

Ask what made it easier for them to increase natural light.

What works? The importance of daytime activity

In session three we talked about how pleasant activities and physical exercise can help people to stay alert during the day and get better sleep at night.

We made a plan for increasing exercise and pleasant events for your relative.

Talking point:

- Let's talk through how you have increased your relative's pleasant activities and physical exercise? What has gone well?

Summary – daytime activity: What worked best?

Prompts:

Remind people of key ideas including:

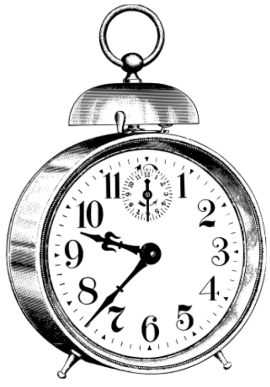
- Stimulation during the day helps the body-clock know when it is time to be awake or asleep and can help improve mood.
- Even small activities can make a big difference

Ask what worked best? What have they noticed happening? What did their relatives enjoy most? Have there been things that they have done together? How do they encourage their relatives? What made it easier?

What works? Making a new sleep routine

In sessions two and three we discussed how daytime napping, spending too much or too little time in bed (e.g through going to bed too early or late), and having a variable sleep pattern from night-to-night, can make it harder for people with dementia to sleep well.

We looked at ways to strengthen the link between bed and sleep.Some of the ways we discussed included:



- Winding down at bedtime
- Using the bedroom only for sleeping
- Reducing daytime napping
- Increasing daytime activity
- Only going to bed when tired
- Using the 15 minute rule
- Having a daytime routine
- Going to bed and getting up at a set time

Talking point:

- Let's discuss any changes to your relatives sleep routine. What worked well?

Summary – sleep routine: What worked best?

Prompts:

Remind people of key ideas including:

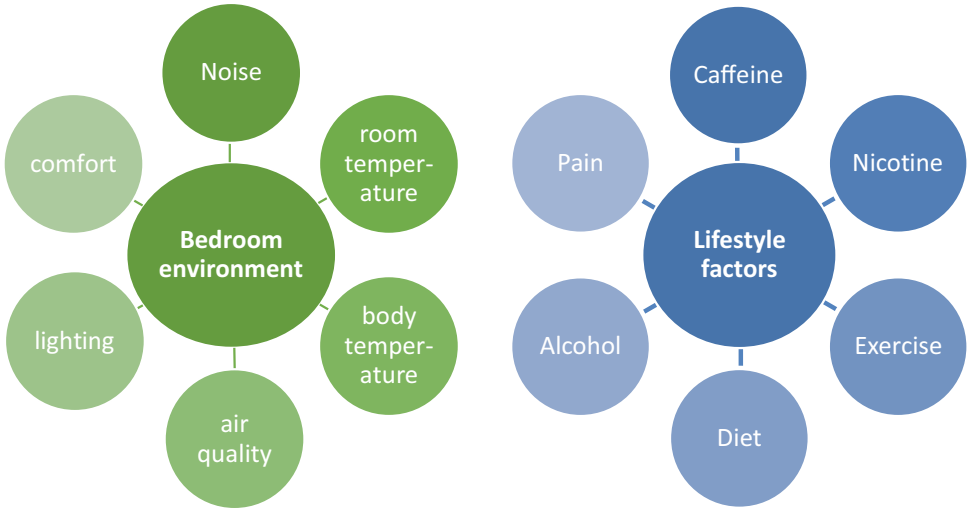
Reducing daytime naps / doing more during the day / having meals at set times can help, it will vary from person to person.

Ask them what worked best and what effects they have noticed on their relative during the day and at night and what made it easier?

Ask them if they have made any changes to their own sleep routine / habits

What works? Making changes to improve sleep

In our first session we identified small changes that can be made to improve sleep.



Talking point:

- Let's discuss any changes you have made for you or your relative? Which did you find helpful?

Summary – bedroom and lifestyle: What worked best?

Prompts:

Remind people of key ideas including:

- What works will vary from person to person and small changes can make a big difference.

  Ask them what worked best and what effects they have noticed on their relative? Have they noticed any effects on themselves? What made it easier for them to make the changes?

What works? Managing night-time behaviour

In sessions four and five we discussed how describing and investigating behaviours can help us to develop specific strategies to try and overcome problems.

Remember, there is always a cause for night-time behaviours, but the person with dementia is not doing it on purpose and can't control these.

1. Environment / routine
2. Fears or emotions
3. How we respond
4. Pain and discomfort
5. The effects of dementia

Talking point:

- Have you been able to use this approach to managing night-time behaviour problems? If so, did you find helpful?

Summary – night-time behaviours: What worked best?

Prompts:

Recap on the approach:

- Describe – in as much detail as possible, be specific
- Investigate
- Create strategies
- Evaluate – It is really important to try see what does and does not work to keep things going.

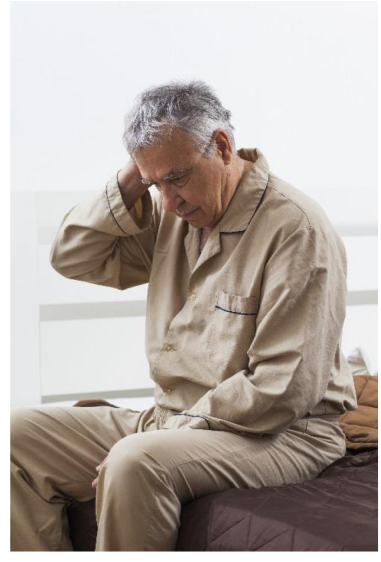
- Ask about specific times / situations – how this approach has helped
- Have people been, using record forms?
- Stress that if strategies do not help, it is good to try something else.

What works? Challenging unhelpful thoughts and looking after yourself

In session five we talked about how to manage your own sleep and make time to look after yourself.

We discussed how to challenge the thoughts that can keep you awake at night by:

1. S*topping to identify* your current thoughts.
2. C*hallenging and replacing* unhelpful thoughts with more helpful ones.
3. *Paying attention to how you feel* in that moment.



We also discussed how making time to look after yourself.

Talking point:

- Shall we talk about how you found challenging unhelpful thoughts and making time to look after yourself?

Summary – thoughts and feelings: What worked best?

Prompts: Recap on the approach

Strategies for managing thoughts that keep you awake also include:

- Putting the day to rest
- Thought blocking
- 15 minute rule
- Giving up trying

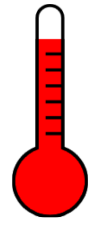
Ask if they have been able to make time for themselves, do more pleasant events?

What has worked best and what has made it easier challenge thoughts and do more for self?

What works? Relaxation

Each week we have practiced a different relaxation technique for you and/or your relative to use. These included:

1. Signal breath
2. Focused breathing
3. Guided imagery: Meadow and stream
4. Stretching
5. Guided imagery: Ocean escape



Talking point:

- Let's talk about how you found the relaxation exercises. Which did you find most helpful?

Summary – relaxation techniques: What worked best?

Prompts:

- What made it easier to find time to practice e.g.
  - Having set times and places to practice
  - Trying it out at home or on journeys
- Have people used relaxation with their relatives?
- Have they noticed an effect on their sleep?

Keeping it going: Developing an action plan

- We know from experience that making changes and keeping them going is difficult and that some changes will work and others will not. Try not to be too discouraged.

- Some of the reasons it can be difficult include:
  - The advice and strategies are not relevant to you
  - It is tricky to get the hang of some of the strategies
  - It is hard to break established patterns

- Here are some suggestions to help you keep going!
  - Make use of the manual to remind yourself what you learnt in sessions
  - Keep using the sleep diary and record forms to notice patterns, especially to see what is working
  - Remember small changes can make a big difference over time, so keep trying things out and practicing

Key Point:

Please continue to put into practice what you have learnt during DREAMS: START. Focus on doing what works and be flexible. If it stops working, try something else.

Action plan for you and your relative

Let's go through your old plan and update it based on what worked best and what you want to keep doing more of. Remember to think about yourself and your relative.

Area for change	Action
Increasing natural light / Light box	
Increasing daytime activity / physical exercise	
Making a new routine / strengthening the link between bed and sleep	
Bedroom and lifestyle changes to improve sleep	
Managing night-time behaviours	
Looking after yourself / challenging unhelpful thoughts	
Relaxation	

****Have a copy of the plan they made in session 4.** ** Go through each section and update or amend based on what they said worked best.

Remember that some areas won't apply or have worked for them so leave these out.

Make sure that they write a clear plan for the areas they want to keep going, Make sure that they are clear and specific.

Remember to try and make each goal –

S - Specific

M - Measurable

A – Attainable

R – Relevant

T – Time-bound

Summary

We hope you have found these sessions helpful and will continue to use what you have learnt for you and your relative.

You have told us what you have found helpful and what strategies you will keep using.

You can keep and refer back to the manual to remind yourself of the techniques discussed throughout the sessions.

We have included copies of all the record forms and sleep diary at the end of this session.

Different researchers will be coming back to see how doing this has affected you and your relative. Do not tell them whether you received these sessions or not so we can fairly judge how much it helps! (This will mean putting the light box, thermometer, CD and the manual out of sight when they visit.)

"Not telling the researchers that come back whether you have had the sessions helps us to know whether the training has worked as we do not want them to be affected by what you tell them…"

Remember, the best way to make a difference to your relative's sleep is to keep practicing the strategies you have developed during the sessions."

Copies of record forms / sleep diary

Planning record

Date(s)	What did you try?	How did it go for your relative?	How did it go for you?

Planning record

	Action plan	How did it go for your relative?	How did it go for you?
Light box			
Increasing natural light			
Reducing daytime naps			
Time to bed and rise			
Lifestyle changes			

Pleasant events record:

Day	What did you try?	How did it go?

Behaviour Record

Describe	Investigate…	What did you find out?
	☐ Environment/routine?	
	☐ Fears or emotions?	
	☐ How we respond?	
	☐ Uncomfortable /Unwell?	
	☐ Dementia?	
	☐ Environment/routine?	
	☐ Fears or emotions?	
	☐ How we respond?	
	☐ Uncomfortable /Unwell?	
	☐ Dementia?	
	☐ Environment/routine?	
	☐ Fears or emotions?	
	☐ How we respond?	
	☐ Uncomfortable /Unwell?	
	☐ Dementia?	

Behaviour record

Describe	Investigate	Create Strategies	Evaluate Did it work?
	☐ Environment/routine? ☐ Fears or emotions? ☐ How we respond? ☐ Uncomfortable /Unwell? ☐ Dementia?		
	☐ Environment/routine? ☐ Fears or emotions? ☐ How we respond? ☐ Uncomfortable /Unwell? ☐ Dementia?		

Thought record

Thoughts I have in bed	How they make me feel	An alternative response would be

Weekly Sleep Diary

Date	Noon	1pm	2pm	3pm	4pm	5pm	6pm	7pm	8pm	9pm	10pm	11pm	12am	1am	2am	3am	4am	5am	6am	7am	8am	9am	10am	11am
Tuesday May 14th	O		N							/			X X		X				/				N	O

Key:

/ = When your relative went to bed and when they got up in the morning

X = Every time your relative gets up in the night

N = When your relative takes a nap during the day

O = When your relative has been out of the house

E = When your relative has done any physical exercise

L = When you relative has used the light box