

# Rough Guide: SLEEP

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*A Dementia Guide*



With thanks to the members of  
**Butterflies Memory Loss Support Group**  
and all who participated in this project  
for sharing their stories and experiences to  
help others

**[www.butterflies.org.uk](http://www.butterflies.org.uk)**

# Rough Guides to dementia

Welcome to our Rough Guide to dementia series.

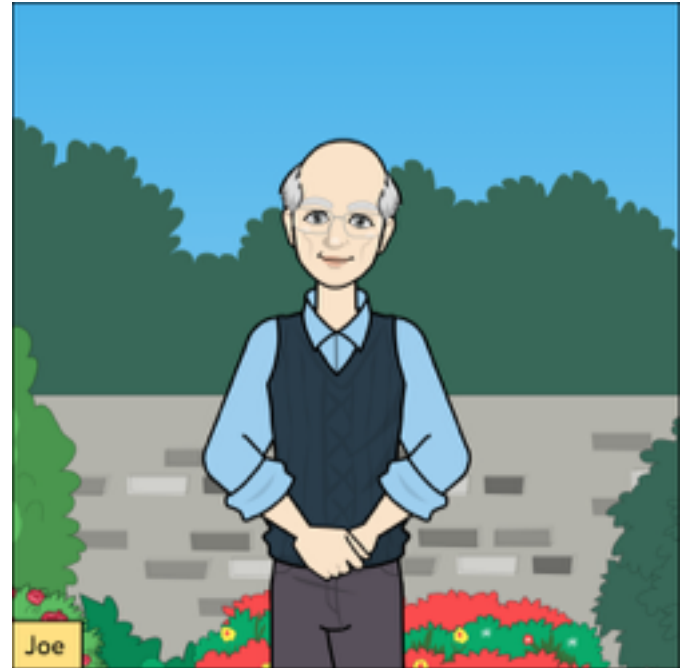
These guides were created by people living with dementia, family carers, staff at Butterflies Memory Loss Support Group, and other voluntary and statutory organisations.

They are based on our experiences of dementia - the rough and the smooth - we didn't want to leave anything out.

It's important to understand that not everyone has the same experience of dementia.

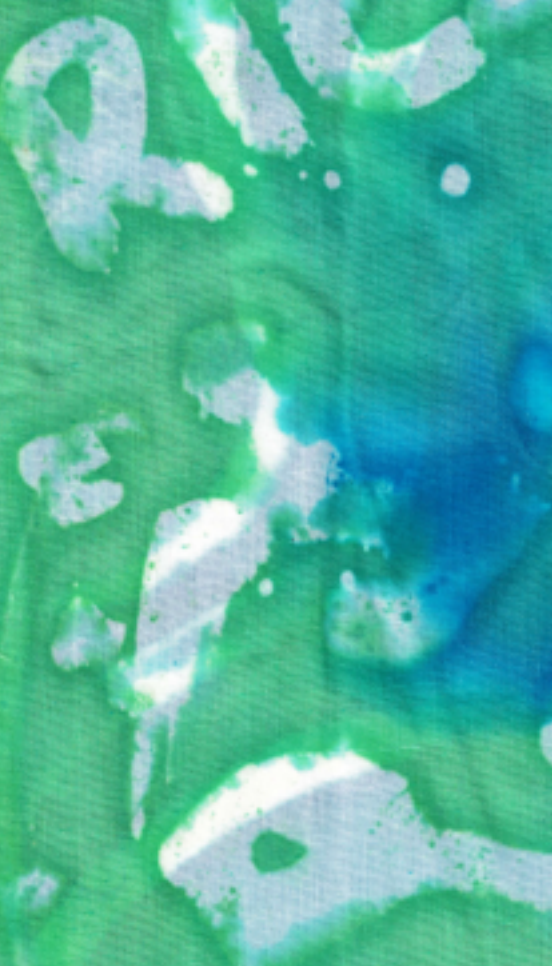
We hope these guides are useful to you.





Joan and Joe are going to share with you some of their experiences and comments from their friends about living with dementia.

Please be aware that everyone's journey is personal to them. Not everyone will experience the same symptoms and challenges.



## When?

*When am I going to get to sleep?*

*What can I do to make myself go to sleep?*

*I try to read.*

*I sing to myself.*

*I may get up and clean the kitchen.*

*I may make a cup of tea.*

*But it still doesn't come,*

*And by the time I'm ready to get up*

*I'm thinking*

*That's alright I'll sleep tomorrow.*

*I'll sleep this night hopefully.*

**ZZZ**

## What Our Carer Friends Are Telling Us

*“He gets up and walks around at all hours. He’s really anxious. I try to get him back to bed and he just gets agitated and angry with me.”*



## What Our Friends With Dementia Are Telling Us

*“I wake up sometimes and know I should be somewhere, but I’m not sure where. I get really upset that I will miss an appointment.”*

*“She will not go to sleep at night. It drives me crackers. I put her back to bed but she just refuses to sleep.”*



*“When it’s dark I don’t want to sleep. I am sure I’m not going to wake up in the morning.”*

*“It’s the broken sleep that crucifies me, I just can’t function the following day.”*



*“I have strange dreams that wake me up, I get up to make sure my family are safe, but sometimes I just want a cup of tea.”*

## Dementia and Sleep: What People With Dementia Are Saying



*I hear noises downstairs and have to go and look, it sounds like someone is in the house.*



*Are the kids home? They went nightclubbing tonight, they might ring for a lift home.*



*I really don't want to go to that thing they all want me to go to. I think it's tomorrow.*



*I know I'm a burden.*



*I talk in my sleep a lot and move around, apparently.*

## Dementia and Sleep: What People With Dementia Are Saying



*I haven't really noticed any difference to be honest, I go to bed, I fall asleep.*



*I have an Alexa. I couldn't manage without her. She tells me it's time for bed and reminds me to lock the doors. It's like having a wife, without the hassle!*

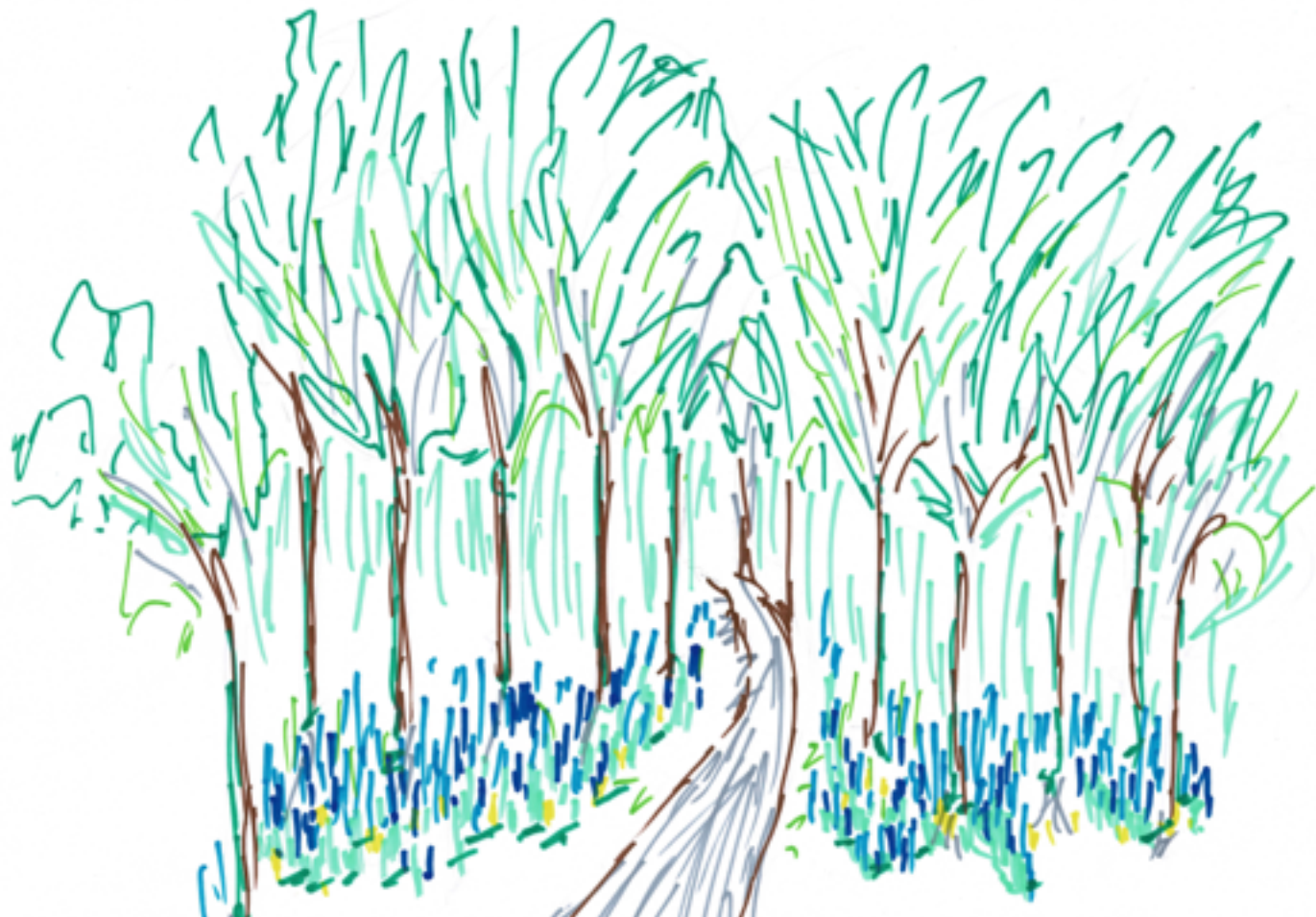


*I wake up sometimes and think 'there's somewhere I have to be', but I don't always know where, I just feel I am going to miss doctors or something, be late for work. I get up, I know it annoys her, so I just make a cup of tea. She gets so angry with me, I mean I am capable of making a cup of tea!*



*I dream a lot more now, and sometimes they are not nice dreams.*





## Dementia and Sleep: What Carers Are Saying



*When he wakes up and gets up and gets dressed, I think “Oh, where’s he gone?” Our bathroom is right next door to the stairs, which bothers me because you’re a bit dodderly aren’t you, when you wake up?! Consequently, I have to wake up, sit up, see that he’s gone into the bathroom, that he’s put the light on, that he’s come out and he’s okay. Then he comes back into the bedroom and we’re okay.*



*I am absolutely exhausted! Looking after my husband is like looking after a little one now, with his wants and needs. He just exhausts me, and by 9 o’clock, I’m in bed with him and I go straight to sleep. My head is a shed! That’s the only way I can describe it!*



*If he goes in the front bedroom I have to talk to him and say ‘You’re not going out. You’re coming back to bed with me’, and he’ll come back to bed fully dressed, expecting to get up and go to work.*

## Dementia and Sleep: What Carers Are Saying



*When he had an accident, when he was in hospital, I noticed how much better my sleep was. It was because I knew he wasn't there. You just wake up much more naturally. And there's probably a level of this too: "Oh, I've got up this morning and I don't have to do 30 of the jobs because he's not here."*



*He wakes up, I wake up. He gets up, I get up.*



*He gets up in the night wanting to go out, I try to get him back to bed but he's fully dressed for work. I give up in the end and get up with him. Another broken night. Arrgghh.*



*My dad has prostate cancer, so he's up a lot in the night anyway. I listen to the door and then he's gone past. Then I can hear when he's back in bed.*



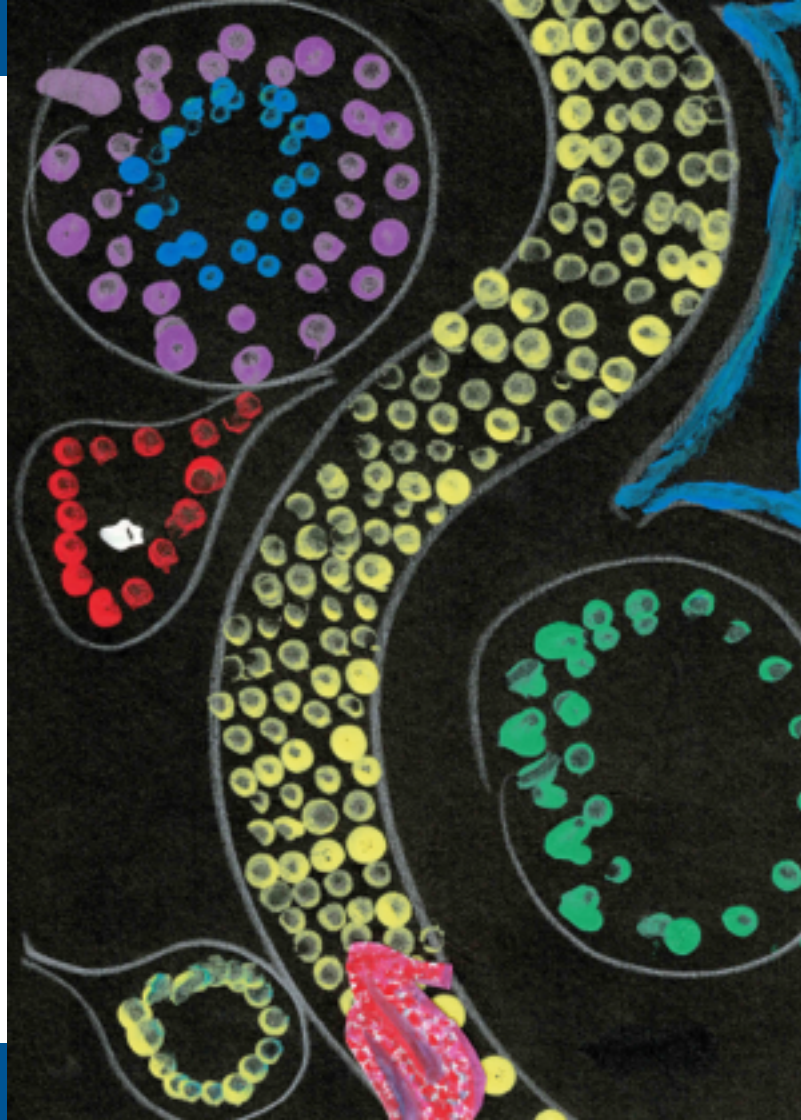
*I'm finding at the moment that, actually, I don't want to go to sleep and I will be up in bed till 3am, either watching my tablet or reading. It's kinda the only time I get to myself!*



*We all have that sixth sense. You're definitely tuned in. It's rather like having a very big child.*



*If she wakes me at night and can't sleep, I just do my jobs then because I know I won't have the energy the next day.*





*I have so much to do tomorrow.*

*Shall I get up and do the ironing?*

*I shouldn't have shouted at Joe today.*

*Goodness! The grandchildren are round tomorrow!*

*Milk, bread, vegs... now what else was it I needed? Oh, I need to call the chiropodist tomorrow. Washing powder, that was it.*





*My body clock is in a mess.*

*My body clock is in a mess too.*





*You have to go without sleep, it's the life of a carer.*



*Your body clock is just in a mess.*



*When caring for my father I struggled to sleep as I found I was often too anxious. That's how it affects us carers.*



*The early hours of the morning!  
The whirling dervishes! It helps to know my friends are in the same storm.*





*I am too frightened. If I sleep, I may never wake up again. I don't know where I am.*



*I like doing things and there is nothing to do. No cooking, cleaning. So I go to bed.*



*As soon as I go to bed I start to think about the future. How will the family manage without me?*












*If I go into care who will pay? I have talked to friends at the dementia group, it's a big worry for all of us.*











## TOP TIPS from Carers

These are some of the things that have helped us:




-  *I put on headphones and listen to music or an audio book for a short while before turning out the light.*
-  *I try to sleep when my husband does, even if it's in the middle of the day.*
-  *I do something I like to do when he sleeps.*
-  *Don't give too much notice of places you're going.*
-  *What might be worth a try (and you can only try) is putting a note up saying it's his day off when he starts to get up.*
-  *I've put a dementia clock in his room, another one downstairs. It tells you the day, the time, the month, on one screen. What it did for my dad was he stopped asking me what day it was, and what the time was, from one minute to the next.*
-  *If you can't sleep do something – bake a cake, stay awake well.*
-  *Get a watch that talks.*
-  *Get an alarm for the front door.*

## ***TOP TIPS from the Cared For***

**These are some of the things that have helped us:**

-  *My wife complains I wake her up but I think I sleep fine. If you do get up, try not to disturb the mrs!!*
-  *Don't tell me about an appointment or somewhere we are going the next day, I will be worried all night.*
-  *I am up and down all night for the loo, I try not to drink too much just before bed.*
-  *I have terrible dreams sometimes, since I started on those tablets. Be careful what you watch just before bed, I sometimes dream about it and I am in the story, it feels so real.*
-  *Try not to nap during the day.*
-  *I usually read for a shortwhile, turn the light out and I am asleep straight away.*

## ***TOP TIPS from Health Care Professionals***

-  Toddler clocks (night and day clocks) can be very helpful. These don't have numbers or a clock face which can be tricky to make sense of when you have dementia. Instead they glow with a sun in the day and a moon at night. So a quick look in the night can make it clear its still bedtime.
-  Sensor lights are a great investment. These light up when they detect movement. You can even get some that are fitted inside the toilet bowl. It means you don't have to switch the big light on if you get up the night or hunt for the switch and so you don't have to wake up fully and so its easier to fall back to sleep.
-  Make sure to go to the toilet before bed and if you wear continence aids make sure they are night time ones and that they are fitted comfortably.

## ***Sleep Changes in Dementia - what the research tells us***

Changes to sleep patterns are a very common experience for people living with dementia. These changes can occur for lots of different reasons and look different for each person.

- For some people with dementia their sleep-wake cycle flips completely and they feel wide awake at night and want to sleep in the day. A complete change like this can be caused by damage to the part of the brain that controls our sleep hormones.
- Often people need a lot more rest and sleep because their brain is working very hard (just as you would need to rest more if you were walking around with a broken leg) and lots of people benefit from a nap in the

afternoon to rest their brain. As dementia progresses and the brain works even harder, it's common for people to sleep more.

- Some people nap a lot during the day because they are bored, perhaps because they struggle to take part in hobbies they once enjoyed or because they get left out of conversations or activities. If you sleep a lot in the day then you might be awake in the night.
- Some people struggle to sleep because they feel worried or frightened. Anxiety is a very common experience for people with dementia, the world can seem a strange and uncertain place at times and worry can keep us all awake. Sometimes people feel like

they should be somewhere or they are not sure what's happening next so it's hard to relax and switch off.

- Another common reason people struggle to sleep is that their body feels restless or twitchy and keeps them awake.
- Nightmares, night terrors and vivid dreams can also keep people awake. Some people with dementia have said their dreams feel very real and frightening.

The other thing to remember is that dementia rarely travels alone, lots of people living with dementia also have multiple other health conditions that might affect sleep.

Pain is a common reason people struggle to sleep.

Sometimes the side-effects of medication

can make it hard to sleep (especially if they mean that you are up and down to the loo all night).

If you are struggling to sleep the first step is to try and work out what's causing it. A sleep diary can help with this. A good routine at night is also really important- doing the same things in the same order each night helps your body to recognize its time to sleep.

Speak to your doctor for more advice.



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Find out more Top Tips by checking the website.

You can also share your own tips and coping strategies, we'd love to hear from you!

[www.butterflies.org.uk](http://www.butterflies.org.uk)



