

THE SCOTTISH DEMENTIA ALUMNI

Dementia & Sleep Challenges

A peer to peer resource
researched and written by people living with dementia



The Scottish Dementia Alumni

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The Scottish Dementia Alumni is a group of people living in Scotland with collective lived experience of a diagnosis of a dementia of almost sixty years.

The group was created to inspire and support people with a new diagnosis of dementia but also campaigns for human rights.

Each member has contributed to and/or written publications, made videos and has been cited in many publications.

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Introduction

This booklet was researched and written by the Scottish Dementia Alumni, a group of people who have lived with diagnoses of different dementias for several years. We are experienced campaigners who actively fight for the rights of people living with dementia.

Over the past decade, we have gained a Churchill Fellowship Award, two MBEs, a BEM, an Honorary Doctorate from Strathclyde University, a BA and a BSc, written books and booklets, created and appeared in videos and have been referenced in many publications.

We set out with no funding to produce this booklet until The University of Exeter came on board with funding.



We have all experienced problems with sleep at some point in our lives. We have each experienced unsettled nights for various reasons and we noticed that people amongst our friends living with dementia are having problems, too.

We set out to discover which kinds of sleep problems that people living with dementia are experiencing, and what they do about it. We know that people who have dementia are resourceful, creative and resilient and that we have all kinds of solutions that we can share to support others living with dementia to get a good night's sleep.

Why We are Making this Booklet

'I have vivid nightmares'. 'I'm always tired these days.'
'I struggle to fall asleep' 'I sleep too much.'
'I worry a lot and this gives me a busy mind in the evening.'
'I feel too hot.' 'I can't get warm.'
'Sometimes, I feel like I'm falling. I then jerk awake.'
'I used to sweat and feel itchy at night.'
'I wake up and can't get back to sleep.' 'Pain keeps me up.'
'Every tiny noise wakes me up.' 'I just can't sleep at all.'
'I have tinnitus and it's really loud at night.'
'My dreams seem so real, clear, I can't tell if they are real.'

You can see from all of these real experiences, that there is a need for looking in to issues with sleep, which seem to go hand in hand with dementia.

We want to share our collective experiences, so that anyone experiencing sleep problems need not feel alone, and so that we can all benefit from our shared experiences and our work-arounds.

What this Booklet is For

This booklet is to gather together sleep experiences with dementia and the solutions that people have discovered to work for themselves. We have also researched how to access help with problematic sleeping and why a good night's sleep is important.

We hope that this booklet supports your personal journey to a good night's sleep.

This booklet is NOT offering any medical or legal advice. It is a general research - based guide to getting good quality sleep and accessing assistance where needed.

We researched this information in 2022. Change is inevitable. Please check with your GP, local services & Health Board for updates.

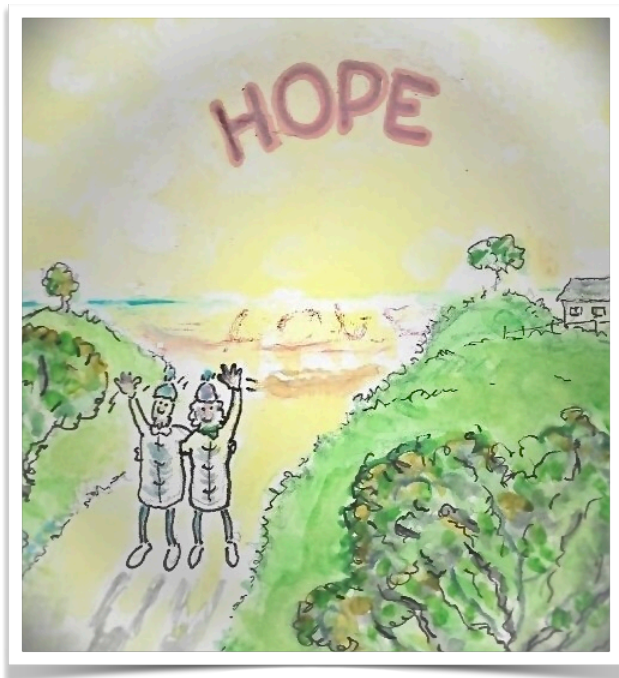


Who this Booklet is For

This booklet is for anybody who has dementia and has problems or challenges with aspects of sleeping.

It is researched in Scotland and some services might only be relevant to Scotland.

It might be helpful to everybody who has problems sleeping. We hope so. There is an often repeated phrase 'If you make things better for people living with dementia, you make things better for everyone.' This is our aim.



What Are We Experiencing?

Our questions:

- 1: Are you experiencing challenges with sleep?
- 2: What are the challenges?
- 3: What have you found to be helpful?

Not in any particular order, here is a list of some concerns of our survey respondents:

Responses from our call for experiences:

Every person, of the 76 who responded, replied 'yes' to question 1. Everyone experienced sleep challenges. While we can expect the people who felt it was important to respond to our questions to have sleep challenges, which motivated them to respond, it also appears, from our limited research, that sleep problems are common with dementia.

The range of challenges reported included :

- Getting to sleep or waking too early
- Emotional issues (worrying, thinking, stress)
- Environmental issues (heat, cold)
- Physical issues (itching, restless legs, pain)
- Being unwell in some way, or tinnitus
- Sensory issues (hallucinations, discomfort, nightwear)
- Issues with the sleep (waking, nightmares, sleep apnoea)
- Too much or too little sleep

Kim's Café Members' Discussion

Kim's Café members in Hampshire discussed sleep challenges.

'I am delighted that you are tackling sleep as, since you approached me, it has become apparent that this is a massive subject area. I will try and cover the issues we raised in the cafe succinctly.' Kim Badcock

Sleep appears to be a key trigger in people with dementia going into long term care, due to carer stress or patient safety. Live in carers will not always cover a night shift, thereby reducing care options if the person with dementia is awake all night.

TOO LITTLE SLEEP

Waking at night, day/night reversal, dreams or nightmares.
Does this matter?

Only if the person is troubled by it or the carer is finding it difficult to cope.

Or if behaviour seems to have changed coinciding with a change in sleep pattern indicating an unmet need.

Is there a risk to the person for example if they left the home during the night?

The following items need to be discussed:

What are the persons normal sleep habits?

What has been the normal bedtime routine and has this changed ?

Is the person sleeping during the day?

Is the person overstimulated or understimulated during the day?

Do they exercise and enjoy the outdoors regularly?

Kim's Café

Too Little Sleep, continued:

Consult an appropriate health professional if the normal bedtime routine is being observed and the person is taking exercise and getting out in the fresh air.

Expect a general review of health to include pain and illness. A review of medication which might help if dreams are an issue. If safety is compromised, it is appropriate to consider medication.

If domiciliary care is being considered - support will be needed to identify and implement the appropriate individualised care.

TOO MUCH SLEEP

This could be a normal progression of dementia but I love this quote "boredom is the pressure sore of the soul" and it is imperative that this is not the case as it will lead to increased rate of cognitive decline.

A situation raised at our café was from a daughter who provides excellent care and support for her Mum. She is concerned her Mum is sleeping too much and this is more evident on the days after she has been to day centre or out for lunch with her family.

She was particularly concerned it meant her Mum was not eating and drinking enough, as breakfast turned in to lunch and the evening meal was a sandwich and cake, with no time for dinner.

Kim's Café

Too Much Sleep, continued...

This is a real concern which could lead to an avoidable hospital admission.

We discussed care options & found Mum was under the financial threshold and therefore dependent on adult services care, which is inflexible and task orientated, and would therefore not meet her needs. We also felt it would be rejected as this lady is independent in her personal care. If people are self funding, a more bespoke person - centred care approach would have supported this lady.

The solution we came up with was a supporter (not a carer) to visit at a time chosen by the family that would best facilitate appropriate nutrition and hydration.

I am sure there are many more issues and I would be happy to discuss this further.

Kind regards,

Kim

Kim Badcock RGN, SCM, BSc Hons, QN
Havant and Waterlooville Primary Care Network

What Helps Us? Our Responses

Responses from our call for experiences
Every person, of the 76 respondents, offered ideas.

- Keeping a sleep diary to track changes and issues
- Using tech (sleep trackers & 'calm' app)
- Keeping a notepad by the bed to note concerns
- A bedtime routine
- Not using screens in the evening
- Music - a relaxing playlist
- Calling a relative or friend, before bed
- Keeping physically active during the day
- Keeping mentally stimulated
- Aromatherapy
- Herbal tea etc
- Massage
- Mindfulness
- Yoga
- Napping
- Tweaking diet (nutrition & avoiding problem foods)
- Telephone call with GP's dementia nurse
- Talking over sleep issues with friends or family
- Online movement classes
- Walking group
- iPad class - helps indirectly by keeping connected
- Altering bedding or nightwear
- Pharmacist discussion - side effects of medication etc.
- GP to discuss medication
- Adjusting temperature in bedroom
- Using techniques to fall asleep (military I)
- Self Directed Support

Self Help Experiences

I keep a notebook by the bed to write down my worries

Aromatherapy

I swapped to cotton bedding

I had to give up cheese snacks at night

A night time routine

I visited my GP for a medication

I go to yoga online

A dog walker

Music - a playlist

I nap

My walking group - keeping active

Chamomile tea

I phone my daughter before bed

I saw the dementia nurse

My GP helped with sleep apnoea

How We Manage Our Sleep Challenges

There were some common responses amongst the questionnaires, listed above and there were some individual responses, offering some personalised discoveries for coping with sleep challenges.

One person uses a herbal remedy

Nightwear was just too uncomfortable for one person

Keeping the cat out of the bedroom

A dog walker was employed to relax an older active dog

Earplugs helped to dull the noise of a busy road

Water by the bedside helped with a dry mouth

Two couples decided to sleep separately

One person met the continence nurse for night support

One person bought washable incontinence underwear

Two people put a commode chair by the bed

Putting night time medication on the nightstand

A touch lamp - no more fumbling for the light switch

Smart lightbulbs - Alexa, turn on the light!

One person moved house to be nearer family/less stress

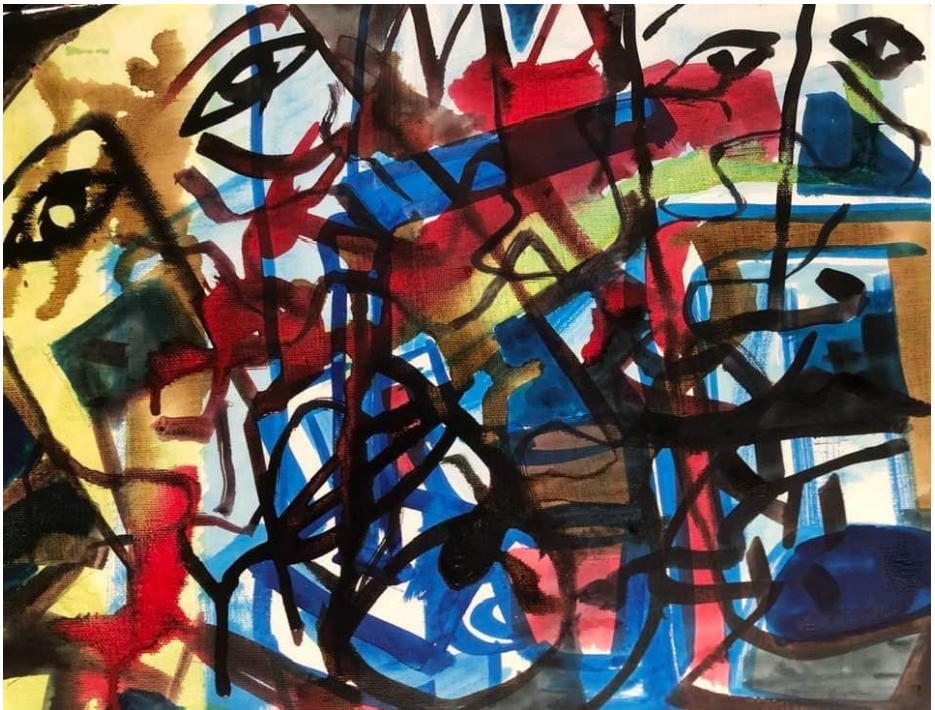
One person moved into town to be nearer services

Conclusion

We know that people living with dementia experience a variety of challenges with sleeping. We also know that people living with dementia are incredibly resourceful and are keen to share their resources to help each other.

People living with dementia from all over the UK got in touch with us about their sleep challenges and shared sometimes surprising work-arounds. We also researched widely to find resources to share. We hope that you find our discussions, films, research and resources helpful in your own sleep routines.

The Nightmare - Willy Gilder



Our Campaign

What we will campaign for as a result of our research:

We would like to see:

- Further research into the sleep challenges that happen alongside dementia.
- Support specifically for our sleep challenges.
- A named nurse for dementia at all GP surgeries.
- To have sleep challenges included in our annual dementia review.
- Some areas offer free incontinence products but not all areas. This should be available nationally.

Human Rights Approach

It is our right to receive quality services for our dementia. These rights need to be upheld, not as a 'should' or 'could', but as a quality standard that we can expect.

We have the right to life.

We have the right to liberty.

We have the right to a family life.

We have the right to live free from discrimination.

We have the right to reasonable adjustments to services.

Nancy's Experience

While the overwhelming collective experience is of sleep challenges, one person is not currently experiencing sleep challenges and we thought it might be good to share how to 'live like Nancy', as one of the group joked. Over to Nancy!

I go to my walking group.

I have a grand time on holiday with my family.

I grow my own veggies, I'm boiling some 'pink fir apple' potatoes for my dinner, on the stove, now.

I'm learning Alexa. I'd like to know things like when the bus is coming to the bottom of my lane. I'm going to ask her to read me a story, next.

I go to my iPad class. It's difficult because I don't always know what I want to know! But I'm learning and that's good.

I have chamomile tea, at night, I find it's really good for sleeping.

And mindfulness. That's important.

I'm going to the conference in Dundee on Monday. I think that if there are train strikes or travel problems, we won't be the only ones having trouble. Lots of people will be. That's helpful to know.

I try not to worry too much, about sleep.

Our Own Research

[Sleep Problems and Insomnia Self Help Guide NHS](#)

[Dementia UK Sleep Resource](#)

[Sundowning Resource from Alzheimer's Society](#)

[Dementia Together Online - Sleep Resource & Activities](#)

<https://www.nhs.uk/conditions/sleep-apnoea/>

[Sleep Hygiene](#)

[Agnes Houston's work - Talking Sense](#)

Quote

I thought I'd never dream of using incontinence products but it was playing on my mind, if I would wake up in time. I sleep deeply. It worried me so much that I daren't go to sleep, especially away from home. But I found these brilliant washable knickers. I'd recommend them to anyone!

(Link in resources section)

Helpful Resources - Click Links

NHS SLEEP SELF HELP GUIDE

<https://www.nhsinform.scot/illnesses-and-conditions/mental-health/mental-health-self-help-guides/sleep-problems-and-insomnia-self-help-guide>

NAPPING - Chest Heart & Stroke Scotland Blog

<https://www.chss.org.uk/health-defence-blog/napping-at-work/>

[A Personal Recommendation from a lady - helpful nightwear](#)

Incontinence Products (other companies are available)

Herbal teas (again, other brands are available!)

<https://www.bettersleep.com/blog/fall-asleep-in-two-minutes-with-the-military-method/> (from an app website - there are a few sleep apps you might want to try if you have a smartphone but some will not be free or might offer a free trial).

[Social Prescribing](#)

[A day to night \(orientation\) clock](#)

Our Method

- We asked a set of **three questions** of people living with dementia across the UK. 1: Are you experiencing sleep challenges? 2: If yes, what kind of challenges? 3: What helps?
- We **advertised this questionnaire** widely through the DEEP network and other UK networks.
- People responded by video, voice, email, letter, telephone, completed forms and via discussion within their peer support group.
- When the 76 **responses** came in, we looked through them and looked for **patterns, similarities and common themes**.
- We noted that every respondent **WAS** experiencing sleep challenges. **We listed the kinds of challenges** that they told us about. We also **listed the helpful support and self help** that people told us about.
- We asked one peer support group to discuss the questions a little more deeply, as a **case study**. We have included their responses.
- All of this information is shared here in this **booklet**.

Further Reading

You will find more of the Scottish Dementia Alumni's resources on our web page for the DEEP network:

<https://www.dementiavoices.org.uk/group/dementia-alumni-glasgow/>

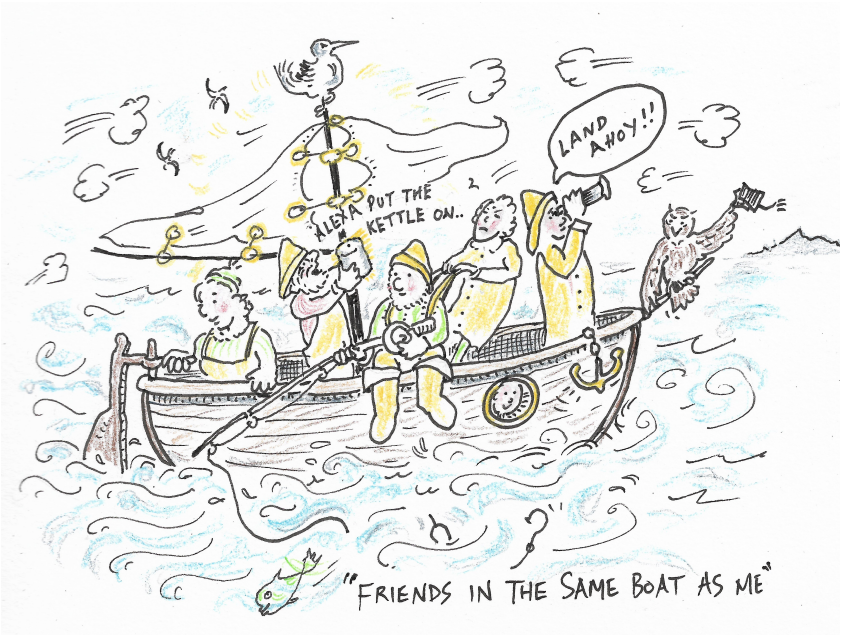
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Innovations in Dementia.

Everyone who contributed.
Our friends at Kim's Café.
Our friend and Artist Paul Thomas.
Our friend and Artist Willy Gilder.
Our Facilitator Paula Brown.



Handy List For Calls



Your GP Surgery:.....



Your phone number:.....



Your mobile phone number:.....

Your date of birth:.....

Your email address:.....

Do you have any allergies?.....

What 3 Words home:.....

Medications:

Glossary and Common Acronyms

BA - Bachelor of Arts (degree)

BEM - British Empire Medal

BSc - Bachelor of Science (degree)

MBE - Member of the British Empire

DEEP - UK Network of Dementia Voices

GP - General Practitioner

NHS - National Health Service

S some

L late

E evening

E exercises

P promote

S sleeping (James McKillop owns the last laugh!)

DNR - Do Not Resuscitate

DNAR - Do not attempt resuscitation

DNACPR - do not attempt cardiopulmonary resuscitation

deep

The UK Network
of Dementia Voices

