



# Insomnia in Alzheimer's disease

A Science Policy Paper

This paper summarises the discussions that took place at the Policy Roundtable entitled *"Tackling Insomnia in Alzheimer's disease: A Wake-Up Call"*. This was the fourth in the series of "What if" Roundtables on Alzheimer's disease, supported by MSD. This event was held at the European Parliament in Brussels on 3<sup>rd</sup> December 2019 under the auspices of **MEP Tomislav Sokol**.

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"More than 70% of people with Alzheimer's disease have disturbed sleep or insomnia."

Prof. Markku Partinen, Helsinki Sleep Clinic,  
3<sup>rd</sup> December 2019<sup>4,7</sup>



# Introduction

Around 10.5 million people in Europe are living with dementia – this number is similar to or greater than the populations of two-thirds of EU member states and is expected to almost double every twenty years.<sup>1</sup> Dementia confers enormous costs on society – estimated globally at \$818 billion in 2015, an increase of 35% since 2010.<sup>2</sup> Alzheimer’s disease is the most common form of dementia and may make up 60–70% of cases.<sup>3</sup>

Insomnia in people with Alzheimer’s disease is increasingly recognised as a common problem that contributes to the disease burden, and worsens with disease progression,<sup>4</sup> yet so far it has received little attention at the policy level.

The **“Tackling Insomnia in Alzheimer’s disease: A Wake-Up Call”** roundtable was a unique opportunity for around thirty stakeholders, including Members of the European Parliament, patients, carers, clinicians and other healthcare professionals, researchers, and industry representatives, to focus on this important issue.

The panel comprised Tomislav Sokol MEP, Joke Jaarmsa (European Federation of Neurological Associations [EFNA] and European Brain Council [EBC]), Dr Jina Swartz (MSD), Tineke Mollema (GAMIAN-Europe), Professor Chantal Van Audenhove (LUCAS KU Leuven) and Professor Markku Partinen (Helsinki Sleep Clinic, Helsinki, Finland).

The purpose of the roundtable was to:

- ▶ Raise awareness of the major burden insomnia imposes on people with Alzheimer’s disease, carers, health systems and economies
- ▶ Shed light on the latest evidence for insomnia as a risk factor for Alzheimer’s disease progression
- ▶ Identify priorities for EU-level policies and actions.



“Patients with Alzheimer’s disease are prone to severe sleep disturbances that impair their condition even further. However, they have limited tools to manage this issue.”

Dr Jina Swartz, MSD





“EU actions should focus on:

1. Building awareness
2. Improving insomnia care
3. Supporting patients and carers
4. Fostering research”

Joke Jaarsma, EFNA, EBC

## Opening remarks

Event host MEP Tomislav Sokol stressed that Alzheimer’s disease is one of the most important healthcare issues facing Europe. People suffering from Alzheimer’s disease also face critical co-morbidities, including sleep disorders. Crucially, the **EU has regulatory and financial instruments** to help address both Alzheimer’s disease and such co-morbidities.

For instance, the Horizon 2020 and future **Horizon Europe programme should be used to increase the research** which would help improve the assessment and treatment of insomnia and Alzheimer’s disease. Also, MEP Tomislav Sokol encouraged **putting insomnia in Alzheimer’s disease higher up the EU’s health policy initiatives**, as this would further raise awareness of the difficulties which persons with Alzheimer’s disease and their families face.

The EU has regulatory and financial instruments to address Alzheimer’s disease and its co-morbidities.



# Insomnia and Alzheimer's disease are closely linked

Dr Jina Swartz (Executive Medical Director Neuroscience, European Clinical Development, MSD) presented the latest scientific knowledge on the link between AD and disordered sleep.

Dr Swartz highlighted that:

- Alzheimer's disease is a very **complex neurodegenerative disorder** that represents a huge burden at the global level.
- Given the lack of treatment to address directly Alzheimer's disease, **therapies to treat its symptoms** are also a focus of research, both in academia and the pharmaceutical industry.
- **Accumulating evidence demonstrates that there is a cross link between Alzheimer's disease and insomnia:**
  - ▶ Alzheimer's disease causes changes that result in severe sleep disturbances, in conjunction with functional, cognitive and behavioural decline – in other words, "dementia". Insomnia further aggravates the condition by causing night-time agitation and daytime somnolence;
  - ▶ Insomnia is also a significant risk factor contributing to the pathogenesis and progression of Alzheimer's disease.<sup>4,5</sup> **Good sleep hygiene** could therefore help to prevent the progression of Alzheimer's disease.
- Current treatment options for insomnia are unsatisfactory, owing to side effects and **limited evidence** of effectiveness. This leaves patients, carers and doctors with limited tools to manage this issue.
- Therefore, more needs to be done both pharmacologically and non-pharmacologically to address the significant unmet need in insomnia avoidance and treatment. Good sleep should be an important prerequisite for optimal disease management.



"Alzheimer's disease patients are prone to severe sleep disturbances which impairs their condition even further. However, they have limited tools to manage this issue."

Dr Jina Swartz, MSD

Accumulating evidence demonstrates that there is a bi-directional link between Alzheimer's disease and insomnia.



# The burden of insomnia in Alzheimer's disease

The Roundtable offered an opportunity to explore the issue of insomnia in Alzheimer's disease from the perspective of different stakeholders. These contributions clearly illustrate the **significant toll that insomnia takes on patients, families, carers, healthcare systems and economies** as a whole.

## Patient's perspective

Tineke Mollema (GAMIAN-Europe)

- Sleep is an important problem in all neurodegenerative and mental health disorders.
- Insomnia is a vicious cycle: lack of sleep can cause day-time problems such as memory loss, inability to focus, clumsiness, anxiety, agitation and difficulties in learning new things. This in turn impacts cognitive function.
- Education about sleep hygiene is critical to reduce comorbidities and costs on healthcare systems.

## Carer's perspective:

Professor Chantal Van Audenhove (LUCAS KU Leuven)

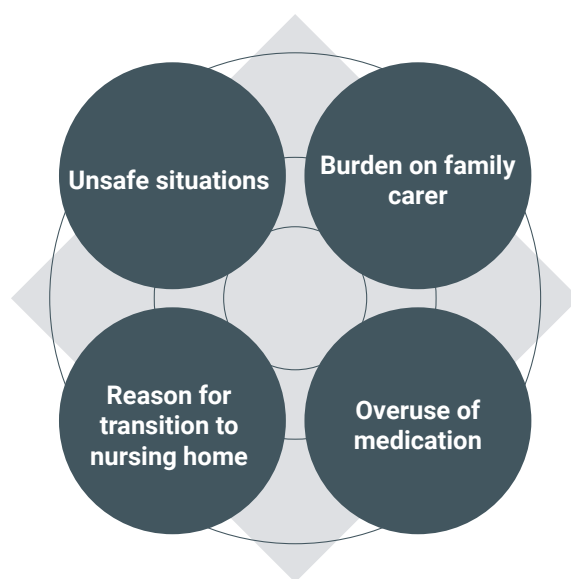
- Insomnia and night-time agitation have many faces: difficulties falling asleep, getting-up at night, walking around at night aimlessly, pacing or engaging in unusual activities, waking-up others, etc.
- Very often these problems cause the sudden necessity of a transition of the person with dementia to a nursing home.
- Stress and night-time agitation are also problematic in nursing homes, and this can lead to the overuse of hypnotic medications.<sup>6</sup>
- Besides causes related to dementia (such as disorientation) social factors (such as the organisation of the day-night rhythm on a ward) and environmental factors (such as noise, light and temperature), are potential triggers of insomnia and should be addressed when caring for people with Alzheimer's disease.



“Insomnia is a big problem for those living with neurological diseases and with mental health problems. The nights can be very long.”

Tineke Mollema, GAMIAN-Europe

Insomnia takes a significant toll on patients, families, carers and healthcare systems.



- Non-pharmacological solutions should be developed to better support and improve the quality of life of patients and carers, both during home care and in nursing homes.

## Health economics' perspective:

Professor Markku Partinen (Helsinki Sleep Clinic)

- Sleep is critical to rebuild energy in the brain, and also “clean the dirt” that accumulates in the brain. Sleep can be called “the brain’s washing machine.” Therefore, lack of sleep can be compared to living in the same clothes for months, if not years.
- More than 70% of people with Alzheimer’s disease have insomnia, which may not always be recognized by the patients with dementia. If we include poor sleep, then we are at 100%.<sup>4,7</sup>
- Recent research demonstrates that **insomnia is the most common risk factor** for Alzheimer’s disease.
- Addressing sleep disturbances is therefore important, as it could help slow down disease progression, even in patients with advanced dementia.
- In addition to improving patient’s and carer’s quality of life, effective early treatment of insomnia in people with Alzheimer’s disease could also reduce comorbidity (e.g. from falls caused by night-time agitation), help patients live longer at home, and reduce the enormous costs of Alzheimer’s disease care.
- Indeed, treatments that reduce the progression of Alzheimer’s disease, including by improving sleep, **could help save at least €300 billion in direct and indirect costs across the EU over the next 60 years.**<sup>8</sup>



“Sleep is the washing machine of the brain. It cleanses the brain of accumulated toxins. Addressing sleep problems could help slow down the progression of the disease and ultimately save €300 billions.”<sup>8</sup>

Prof Markku Partinen

Family carers  
have to wake  
up at night to  
support their  
family member  
suffering from  
insomnia.

# Overall conclusions & policy recommendations

To ensure that the issue of sleep disturbances in people with Alzheimer's disease is properly addressed, **concerted and timely actions at EU level should include:**

- Promoting the funding and development of patient and carer-centred research to help improve the assessment and management of insomnia in people with Alzheimer's disease;
- Inclusion of insomnia in Alzheimer's disease and dementia as a priority issue in upcoming EU health and research initiatives;
- Developing initiatives that address insomnia among people with Alzheimer's disease holistically and which also further **support family caregivers** whose sleep is disrupted;
- **Raising awareness of the environmental risk factors of Alzheimer's disease**, with sleep disturbances being a major one, and of the importance of healthy living (food and sleep hygiene) as a means to prevent cognitive decline;
- Promoting the harmonisation of summertime and wintertime in Europe;
- Developing pharmacological and non-pharmacological solutions to empower and support patients and carers.



“Concerted and timely actions at EU level are vital to improve insomnia prevention and care which can potentially help reduce the progression of Alzheimer's disease.”

MEP Tomislav Sokol

Raising awareness of the environmental risk factors of dementia.

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Lack of sleep prevents cleansing of the brain



7 out of 10 people with Alzheimer's disease suffer from sleep disturbances

### Bi-directional link between Alzheimer's disease and insomnia



Accumulated brain toxins can lead to brain decline and early Alzheimer's disease



## Lack of support, information and treatment options



### Impact on patients

- Night-time agitation
- Daytime impairment
- Reduced quality of life



### Impact on families and carers

- Disturbed sleep
- Hampers daytime care
- Distress and reduced quality of life



### Burden on healthcare systems

- Greater co-morbidity (including falls)
- Early institutionalization in nursing home



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