

## **INSOMNIA AMONG TERMINALLY ILL PATIENTS**

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Sleep is a complex function which is essential for our wellbeing. The pattern of when we wake up and when we go to sleep is part of the body's overall circadian (daily) rhythm. This sets the pattern for other essential functions including controlling temperature and hormone levels. Sleep problems are very common in people living with a terminal illness, though not everyone will be affected. Sleep problems can be distressing for people and their friends and families. There are things you can do to encourage good quality sleep. Sleeping problems are highly prevalent among people with advanced illness requiring palliative care. Sleep disturbance is a common and distressing problem in patients who are terminally ill. Poor sleep affects quality of life and can increase the intensity of symptoms such as pain, depression or anxiety. However both patients and clinicians often consider insomnia as an inevitable part of an advanced terminal illness. Sleeping problems (insomnia and poor quality sleep) are common in people requiring palliative care, and often have a significant impact on quality of life. They are particularly common in patients with COPD, patients with heart disease, end-stage renal disease, end-stage liver disease, AIDS, etc. As a consequence, many patients receive hypnotic medication on a long-term basis with often unclear benefit and little attention is paid to the underlying causes of patients' sleep disturbance. Clinical assessment should focus on modifiable factors which may contribute to sleeping problems and on prognosis to determine likely length of treatment. Sedative hypnotics, especially benzodiazepines, are frequently prescribed to palliative care patients. They are likely to be effective in the short term but there is limited evidence to support long term use or the choice of medication. Side effects of sedative hypnotics may include worsening cognition and daytime sleepiness.

### **Common sleep problems in terminal illness include:**

The quality and quantity of sleep can have a significant impact on a person's wellbeing and quality of life. Being tired and unable to sleep can make physical symptoms and difficult emotions harder to manage. Difficulty sleeping can also lead to low mood and anxiety.

- ❖ Insomnia – difficulty getting to sleep or staying asleep, or not feeling rested after sleep. This is often associated with feeling tired during the day.

- ❖ Disorders of the sleep-wake cycle – this can happen when someone's sleep at night is disrupted. It could be caused by interruptions in a noisy environment or be due to distressing symptoms or worries. Disrupted sleep at night can make people more tired during the day. Reduced activity in the daytime also contributes to not feeling sleepy at night and can cause a cycle of disturbed sleep.
- ❖ Excessive daytime sleepiness – when people have difficulty staying awake during the day and may fall asleep or become drowsy. This is different to the tiredness and fatigue which is common in people with a terminal illness.

### **Causes of sleep problems**

There are many reasons why someone may have sleep problems or a change in their sleep patterns, and there is often more than one contributing factor, including:

- ❖ uncontrolled pain
- ❖ nausea and vomiting
- ❖ restless legs syndrome – a common condition of the nervous system that causes an overwhelming urge to move the legs and is associated with many illnesses including anaemia, and chronic kidney disease.
- ❖ bladder or bowel symptoms – having to get up to go to the toilet or being incontinent
- ❖ depression
- ❖ anxiety, worries, spiritual concerns and distress
- ❖ reduced activity during the day
- ❖ delirium
- ❖ medication, such as steroids and some antidepressants
- ❖ respiratory problems, for example breathlessness, cough or obstructive sleep apnoea
- ❖ taking caffeine, nicotine or alcohol
- ❖ withdrawal from medicines or substances, such as nicotine or alcohol
- ❖ other uncontrolled symptoms, such as sweating and itching
- ❖ environmental conditions, such as noise and light levels, and visitors staying late.

Some people may already have had difficulty sleeping before they were diagnosed with a terminal illness. Many life-limiting conditions or the treatments associated with these conditions cause sleep problems. There are a number of potentially modifiable problems which may contribute to sleeplessness:

- Anxiety
- Pain
- Obstructive sleep apnoea, or other primary sleep disorder
- Dyspnoea, cough, pleural effusion
- Nausea, vomiting
- Movement disorders eg, restless legs, akathisia
- Night sweats
- Pruritis (itch)
- Environmental disruption, especially for in-patients
- Changed activity patterns
- Altered circadian rhythm
- Reduced bed mobility, and physical problems that limit comfortable sleeping position
- Medications eg, steroids
- Incontinence or nocturia.

There are a number of screening and assessment tools for sleep disturbances. One of the most common, validated tools used in the general population is the Pittsburgh Sleep Quality Index (PSQI). The Edmonton Symptom Assessment System (ESAS) was recently studied for its suitability to screen for sleeping problems in patients with advanced cancer. The authors found the ESAS was appropriate to use and recommended routine screening for patients in a palliative care setting.

### **Practice Implications**

Based on the available evidence, it is suggested that the clinical assessment of insomnia should focus on:

- ❖ reversible factors which may contribute to sleeping problems
- ❖ prognosis, which determines the length of time for which night sedation is likely to be needed, in order to minimise the use of long-term (greater than 8 weeks) sedative hypnotics.

- ❖ The Edmonton Symptom Assessment System (ESAS) can be recommended for use in palliative care.
- ❖ If the patient has a prognosis of several months, non-pharmacological options for treatment should also be considered.
- ❖ Non-pharmacological interventions have limited evidence in the palliative care population, but in primary insomnia it may be beneficial to review environmental issues and sleep hygiene (including avoidance of napping and sleeping in where possible), behaviour therapies, and relaxation techniques.
- ❖ Medications which have sedating properties may contribute to night sedation (eg, tricyclic or other sedating antidepressants, antihistamines, or antipsychotics) but should be carefully assessed with regard to their side effect profile, and are likely to be best used where there is a specific indication.

## **Treatment**

A number of systematic reviews have examined both pharmacological and non-pharmacological interventions for sleep disturbances. A meta-analysis was unable to identify sufficient evidence to draw conclusions about the use of benzodiazepines in palliative care. Agents that were included in the meta-analysis were all benzodiazepines, as well as zolpidem, zopiclone and zaleplon. Midazolam is the most commonly used benzodiazepam in palliative care, although it is rarely used specifically for sleeping problems and there is no evidence to support its use for sleep. Melatonin has been used in a number of populations to assist with sleep. It has been studied in advanced cancer with limited efficacy.

Non-pharmacological interventions, such as Guided imagery technique, exercise, sleep hygiene, mind-body practices and changes to the environment have been examined for efficacy at improving sleep. There are practical things you can do to support someone to get good quality sleep. If you are concerned about uncontrolled symptoms, or if simple measures are not improving sleep, speak to the person's GP or specialist nurse who can arrange further assessment and treatment. The person might also benefit from emotional support and relaxation therapies.

## **Practical Tips**

During the day:

- Encourage the person to go to bed and get up around the same times each day.
  
- If possible, avoid napping during the day.

- If appropriate, encourage physical activity during the day.

#### Managing symptoms:

- Check that the patient is comfortable and that pain and other symptoms are wellcontrolled.
- Speak to the person's GP or specialist nurse if you're concerned about any symptoms.

#### Preparing for bed:

- Help the person to feel relaxed before going to bed. Listening to music or trying relaxation techniques such as deep breathing might help. Some people find a bath helpful if they have enough energy.
- Encourage the person not to have caffeine, nicotine or alcohol before they go to bed. Some people will be able to drink tea and coffee earlier in the day without it affecting their sleep, but it's best to avoid it in the evenings.
- Ask visitors not to stay too late. If the person is finding it tiring having visitors, then you may need to ask them to leave. Some patients find it difficult to sleep if their partner or family member is in the room, so you may need to be mindfulofthis.

#### Sleeping environment:

- Set up their sleeping environment to be quiet, calm and at a comfortable temperature.
- Use earplugs and eye masks if noise and light levels could be disruptive.
- Encourage them to avoid electronic devices such as tablets and smartphones before wanting to sleep.
- If someone can't sleep because of worries and concerns, it can help to have a pen and paper beside their bed so they can write things down and deal with them in the morning.

### **Talking and wellbeing**

Encourage the person to talk about any worries or fears they have that are keeping them awake. They might benefit from talking to a professional such as a psychologist, counsellor, faith leader or spiritual advisor. Cognitive behavioural therapy (CBT) can be effective if it's available in their area. They may be able to access these services from their local hospice or through their GP.

You could suggest free sleep apps or podcasts that are designed to help people fall asleep.

Wellbeing therapies such as aromatherapy, massage or hypnotherapy might also be helpful.

### **Medical management**

If you think that the patient may need medication to help them manage sleep problems, speak to their GP, district nurse or specialist nurse. They can review any medicines, such as steroids, that might be contributing to sleep problems and make sure that the person's other symptoms are being managed as well as possible. They may arrange further assessment or prescribe medicines including:

- short-acting benzodiazepines such as lorazepam or temazepam
- hypnotics such as zopiclone or zolpidem.

### **Sleep changes at the end of life**

People often become more drowsy and sleep more towards the end of life. This is one of many signs that a person may have when they are in their last few days and hours of life, but not everyone will experience this. Everyone is different. This may be concerning for family and friends as it can make communicating with their loved one more difficult.

Management of sleep problems will change at this stage. It might not be appropriate to encourage someone to be active or to avoid sleeping during the day.

Encourage the patient's family to keep talking to them, to let them know they're close by. The patient may still be able to hear what is said, so it can be comforting to them if family and friends carry on talking to them. Remind them not to say anything that they wouldn't want the patient to hear.

## **CONCLUSION**

Sleep problems are very common in people who are suffering with a terminal illness. It will not affect patients sleeping pattern only but also family members and friends.

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