

Banned from sleeping

Hi, I'm 15 years old.

Last October I suffered a huge ME relapse. I had been under the care of a clinic, but their advice seemed to make me worse.

I desperately try not to sleep through the day, as I was told by the clinic. I'm not sure if this is right, though. Should I try sleeping in the day, just a little?

I really need some advice I can trust. I have stopped trusting the clinic, as their advice just doesn't help me.

Hannah Barnes

Hi Hannah,

Rest assured, you are not alone in finding this advice counter-productive. We receive many such comments.

Sleep problems in classic ME have for many years been known to be caused by disturbance of the hypothalamus gland in the brain, which controls automatic functions of the body. One of the main problems appears to be that, like you, people with classic ME are often counselled not to sleep in the daytime even if their brain is telling them to fall asleep. This advice seems to be given out of a misunderstanding that they will not sleep at night if they have slept in the daytime. However, because of hypothalamic disturbance, they often can't sleep properly at night anyway, so they can then end up even more short of sleep.

Dr Darrel Ho-Yen once stated that patients who seem to do best are those who take naps. Consultant microbiologist Dr Elizabeth Dowsett, one of the

most knowledgeable authorities on ME (now retired) always talked of 'living within the rhythm of the brain' as it works to heal itself. That means following the brain's signals. Paediatrician and ME specialist Dr Alan Franklin maintained that it was downright cruel to wake children with ME when their brain had at last managed to sleep.

Although such a sleep pattern can be inconvenient, often necessitating a reorganisation of times spent studying and doing other activities, it does seem to assist the body to return to a more conventional sleep/waking cycle over time.

In *Mummies Aren't Supposed To Cry* (www.tymestrust.org/pdfs/mummiesarent.pdf) you can read an account by a mother describing how she and her son managed his difficulties sleeping. I heard from her recently with details of his substantial achievements and exciting life these days.

The worst thing can be the stress caused by worrying that one 'should' be asleep at night. I believe that the sleep police have a lot to answer for, using terms like 'sleep hygiene' as though one is dirty if one cannot sleep during the prescribed hours. Such stress prevents relaxation and makes it less likely that sleep will come. You will probably be amused by the poem about sleep that I once wrote, also in *Mummies Aren't Supposed To Cry*.

With best wishes,

Jane

Jane Colby FRSA
Former Head Teacher
Executive Director
The Young ME Sufferers Trust

Overleaf: Tara Mawer (www.youtube.com/watch?v=mSPTHzlaSao)



Dear Jane,

Thank you so much for your email!! I had tears of relief streaming down my face.

I have just read the publication you suggested, so much of it was so familiar.

I have only just started to respect my ME, after 2 years of following the clinic's advice.

Your poem is so funny, and yet so meaningful! It will help me get through tonight if I wake up.

Thank you so much for replying, you have no idea how much it has helped!

Hannah



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