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**Understanding and Managing Dementia-Related
Sleep Problems:
Community-Based Research with Older
New Zealanders**

A thesis presented in partial fulfilment of the requirements for
the degree of Doctor of Philosophy

at Massey University, Sleep/Wake Research Centre
Wellington, New Zealand

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Abstract

Sleep changes with ageing and people with dementia and their carers often have disturbed sleep, but information on the sleep of older New Zealanders is lacking. Four studies were conducted in order to address these factors. The first two used pre-existing survey data to understand the sleep health of older people, and to explore the relationship between caregiving and sleep. Sleep problems were reported by 20-32% of participants, prevalence decreased with increasing age. In those aged at least 79 years, sleep problems were associated more with health status rather than demographic factors. Older carers were more likely to report feeling tired than non-carers.

Dementia-related sleep problems are challenging for individuals and their carers, and poor sleep may exacerbate waking dementia symptoms. However, there is limited research with community-dwelling dyads of people with dementia (PWD) and their carers. Studies 3 and 4 were conducted to understand and treat dementia-related sleep problems. Focus groups with 12 dyads revealed the multifaceted nature of their sleep problems. Normalisation of sleep problems was common. In the final study, a five-week trial was piloted involving sleep education, light therapy and an exercise programme. Sleep of the dyads was monitored using actigraphy and standardised questionnaires. Questionnaires also measured cognitive functioning, quality of life, and dementia-related disruption, as well as carers' mental health and coping. Fifteen pairs participated, of whom nine completed the trial. Case studies revealed that five PWD had improvements to their subjective sleep ratings. These PWD also showed some improvements in wake time at night, cognitive functioning, and carer-rated quality of life. These changes did not always translate into improved sleep or mental health for carers. Many PWD's health deteriorated across the trial, masking the effects of the intervention.

Overall, these studies illustrate the importance and diverse nature of sleep with ageing, dementia, and caregiving. Non-pharmacological interventions can be used successfully by some community-dwelling dyads. It is recommended that these low-risk interventions are considered by healthcare professionals. Increased knowledge and options could empower individuals to manage their own symptoms, providing hope for improving the sleeping and waking experience of older people affected by dementia.

Dedication

During my time as an undergraduate student I worked as a care assistant for older people, the majority of whom had dementia. What I observed with regards to sleep and wake behaviours fascinated me. Some nursing home residents would behave in a polite, sociable manner whilst eating their breakfast; but by afternoon tea time would be paranoid, pacing, and requiring physical assistance. There were those who would be up in the night, walking the halls, seeking something out, or prematurely preparing for the day. In the nursing home environment there was a band of us care assistants and nurses who could take shifts in supporting our residents, guiding them back to bed at night, and taking the brunt of their sleep deprivation the following day.

Many people who have these symptoms live at home and are cared for by a family member, sometimes single-handedly. How these families managed with such disruptions to their sleep and wake intrigued me. For several months I worked as an assistant for Dorothy and Doreen, sisters aged over 80 years, one of whom had Alzheimers Disease. My job was to support them at the end of their day. To help Dorothy safely have her final cup of tea and cigarette, prepare for bed, read to her, listen to her, guide her back upstairs as many times as it would take, and to accompany Doreen while she waited for the sound of silence permitting her to go to bed. The tenacity of these sisters to remain together at home was overwhelming. They managed until Dorothy's dementia was such that she required overnight assistance to prevent accidents, and to allow Doreen sufficient rest. Ultimately both women had falls, leading to hospitalisation and institutionalised care. This experience stayed with me.

After graduating, I diverged into the fascinating world of sleep science, in a clinical and academic sense. Almost ten years on, it is a privilege to have the opportunity to present my research concerning the sleep of older people and people with dementia. I dedicate this thesis to all families affected by dementia, especially Dorothy and Doreen for inspiring me to take this journey.

Nights and Days¹

Aching limbs, tired eyes,

Silently weeping, pitiful cries,

All these things happen at night,

Never in daylight and out of sight,

How I wish my night was day,

Sunshine chasing my nightmares away,

Until then I continue to fight,

All these demons every night,

Just one thing I want to say,

For my Elaine will you please pray?

Every night she puts up with this,

Yet with a warm embrace,

And a gentle kiss,

She brings me round,

And I awake,

Safe in her arms,

No more to take

¹ Poem by Norman McNamara, who has lewy body dementia and is the founder of the Torbay Dementia Action Alliance (<http://tdaa.co.uk/poems/>)

PREFACE

Overview

Sleep changes with ageing. As we grow older the likelihood of having sleep disturbances increases. These include changes to sleep timing, primary sleep disorders (e.g., sleep disordered breathing or insomnia), as well as daytime sleepiness or a general dissatisfaction with sleep. Previous international studies show that sleep disturbances are associated with the neurophysiological ageing process as well as with psycho-social factors, demographic status and comorbidities. However there is limited information concerning the sleep of older New Zealanders (aged ≥ 60 years) and the factors that affect it.

Dementia is a progressive brain disease which manifests as cognitive impairment, disruptive behaviours, as well as changes to mood and personality. Dementia is more common with ageing and involves accelerated neuropathological deterioration to the areas of the brain responsible for sleep timing and maintenance. This causes increased sleep disturbances for older people with dementia (PWD, used interchangeably to include “person with dementia”), which can be associated with exacerbated waking symptoms. Previous research has identified that sleep problems are considered by carers as among the most disruptive dementia-related symptoms.

Life expectancy is increasing and the prevalence of dementia is also rising. With the increased pressure on residential care facilities, there is an increased need and desire for PWD to be cared for within their homes, resulting in more individuals in our communities affected by dementia and requiring support. People with dementia are often cared for informally by a family member. Due to the nature of the disease, carers for PWD are often older themselves and are already predisposed to age-related changes to sleep. Carers’ sleep is further disrupted due to being woken by the person in their care, as well as by the physical and mental burden of the caregiver role. Previous research has shown that when the sleep of both PWD and their carer is disturbed, there is increased risk of accidents or injury. Such situations have also been identified as contributing to the decision to institutionalise PWD. Therefore understanding and treating the sleep problems of both PWD and their carers is of importance.

Rationale for Thesis

The sleep of older people affected by dementia is an area with many current research gaps and a growing research need. Through reviewing the literature, it became apparent that there were three key areas which required attention in order to address the sleep of older PWD living in Aotearoa, New Zealand (NZ). Firstly, better understanding is needed of the distribution and prevalence of reported sleep problems among older New Zealanders, as well as the factors associated with reporting a sleep problem, including mental health and caregiving status. Secondly, this research field is moving into a more *person-centred* approach. However there is still a lack of qualitative, first-person reports regarding the sleep experience of PWD, and what PWD and their carers do to try and improve their sleep. In this thesis, three studies were undertaken to address these areas, to provide a basis for designing and conducting a final pilot study to address the third issue, that there is a lack of community-based trials of non-pharmaceutical interventions to improve the sleep of PWD (“community” and “community-dwelling” are used to refer to people living in their own homes, as opposed to institutions). If successful, such interventions could have positive effects on carers’ sleep and for the waking symptoms of dementia, thus potentially benefiting both the PWD and their family carers. The ultimate goals of the research are to raise awareness about the importance of sleep health for older people and those affected by dementia, leading to better options for improving the sleep and quality of life of PWD and their family carers.

Organisation of Thesis

This thesis includes four research studies. *Figure 0.1* gives an outline of the topics covered and the progression between the studies to reach the final research question and aims. Studies 1-3 are presented as research papers, two of which have been published in peer-reviewed journals and the other has been submitted for review (see Appendix 1 for statement of contribution forms). These have been reformatted to maintain the style of the thesis. The references are incorporated into the full reference list at the end of the thesis. Study 4 is presented in traditional thesis form.

Studies 1-2 analyse data from two pre-existing cohorts, one of New Zealanders of advanced age (≥ 79 years), the other of retirees. Both cohorts included large samples of Māori participants allowing

equal explanatory power, which made it possible to investigate the factors contributing to self-reported sleep problems of older Māori (the indigenous people of NZ, comprising 14% of the total population, Statistics New Zealand, 2006a). The third study contributed vital information for a person-centred approach for the intervention pilot study (Study 4), through the use of focus groups conducted with PWD and their carers. The focus groups sought to improve understanding of their experience of sleep problems, their beliefs and attitudes towards sleep, and the methods they had in place for managing sleep problems.

Study 4, the central research project for this thesis, was a pilot study trialling non-pharmaceutical interventions with a small sample of PWD and their carers. The methods and results presented in Chapters 4 and 5 relate to Study 4, which is presented as a series of case studies to illustrate the common and the couple-specific effects of the intervention. The final discussion chapter addresses the results, implications and limitations of the pilot study, drawing on the conclusions from the three introductory papers. Overarching the entire thesis are the ethical and methodological considerations involved in conducting research with PWD. The symptoms, stages, and nature of dementia can make this a sensitive and complicated field, and relevant literature is included and revisited throughout the thesis.

The scope of this work crosses several disciplines including psychology, public health, sleep science, and sociology. The Publication Manual of the American Psychological Association (American Psychological Association, 2010) was used to guide many aspects of the presentation of this thesis. However, the style used was also informed by the conventions of the other disciplines listed.

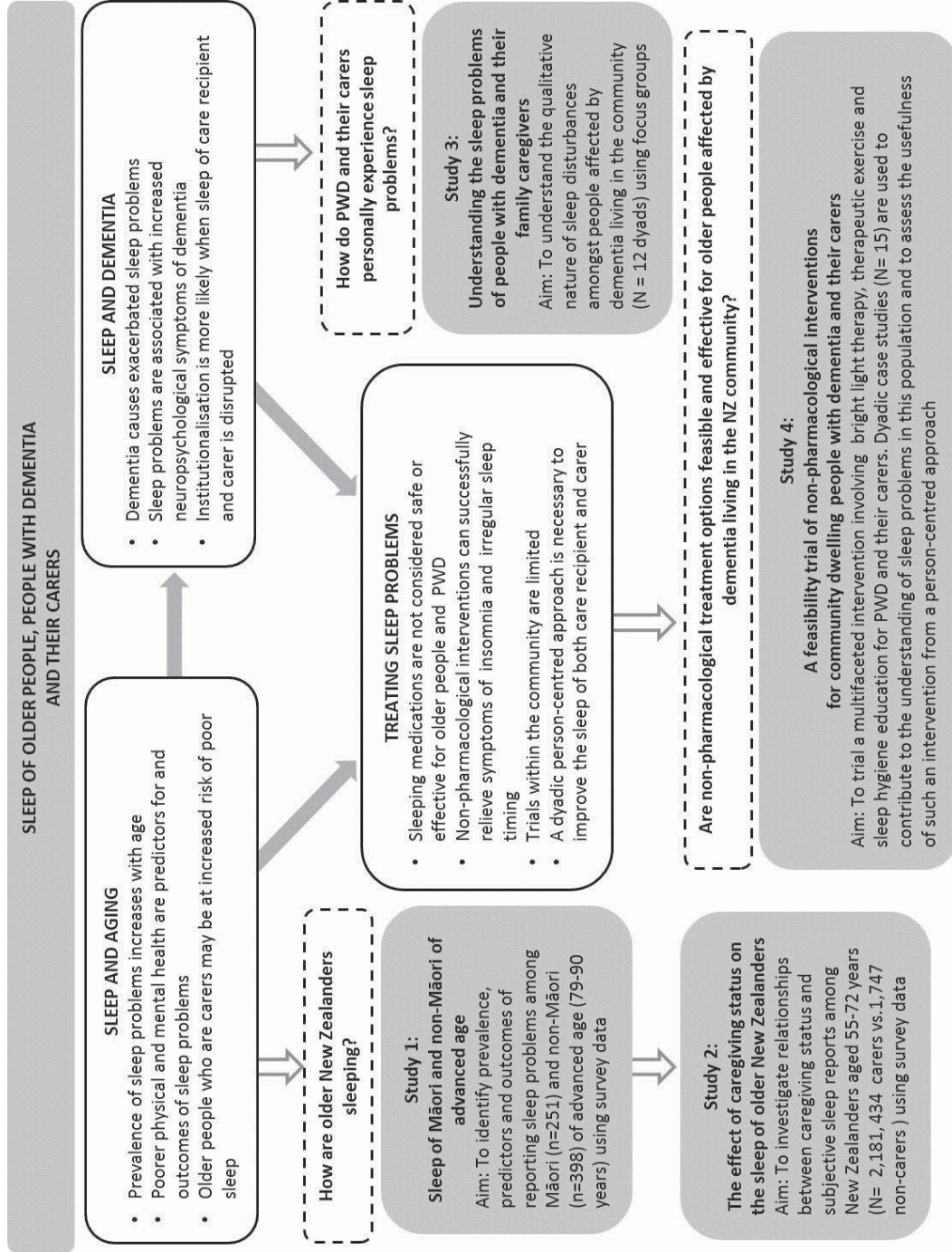


Figure 0.1. Outline of key thesis topics, questions and research studies.

Acknowledgements

I'd like to acknowledge all of the people who took part in the research presented here. I am particularly grateful for the participants who were affected by dementia. I'm aware that, for some of you, incorporating home visits, sleep monitoring, as well as interventions into the daily routine was a lot to take on. *Thank you* for being open to taking part, experiencing something new, and contributing to greater knowledge. I hope you feel that you benefited. Your contributions will help make a difference for other families affected by dementia.

I was only able to reach these participants through the generous support of those assisting me with recruitment. Invaluable support was provided by local support workers, healthcare professionals, and retirement village management who took the time to support this research regarding recruitment and advocacy. I'd especially like to acknowledge the team at Alzheimers Wellington. Thank you Liz O'Hare, Nigel Heard, and Verna Schofield for taking the time to help me design and conduct this research, and having faith in me to work closely with your members. Also to the wider team at Alzheimer's Wellington (Catherine Timms, Trish Howard, Annie Manning, and Leonie Crawshaw) for assisting with advertising, encouraging people to take part, inviting me to promote my study at your support groups, and assisting with conducting focus groups – *Thank you!*

When developing the documents for Study 4, Cass Alexander of Alzheimers New Zealand offered friendly and supportive advice regarding the appropriate use of language and style. Cass introduced me to Nigel and Tania Wynn, who also reviewed the materials for the intervention study. Having somebody with dementia and their partner give feedback on the study design and documents, particularly the sleep education booklet, was invaluable during the early stages of this study. Thank you all for your interest, time, and support.

During the initial stages of this thesis I co-wrote and applied for funding grants to make the dementia-related studies possible. Funding was secured from the Massey Doctorial Scholarships Committee, the Health Research Council (feasibility grant, 11/562), the Maurice and Phyllis Paykel Trust (project and equipment grant, 2010), and the Alzheimer's Charitable Trust (small project grant, 2010).

This funding helped to support me during this journey, and allowed for the purchase of equipment necessary for an intervention and the objective recording of sleep. It also allowed for additional time, and travel expenses deemed necessary for the recruitment and conduct of this community-based project. Without such support this project would have been limited and I am extremely grateful for the opportunity these agencies provided me.

The preliminary studies presented in this thesis were made possible via collaboration with two other research groups: the Life and Living in Advanced Age team at Auckland University, especially Professor Ngaire Kerse; and the Health Work and Retirement team at Massey University, especially Professor Fiona Alpass. Thank you for sharing and trusting me with your valuable data, and contributing to my production of papers regarding the sleep of older New Zealanders. I am grateful to all of the participants of these studies, and the funders of these projects (acknowledged within their relevant chapters). These analyses allowed for the sleep health of older New Zealanders to be described for the first time.

I have been extremely fortunate to have such a supportive group of supervisors during my PhD journey. Linda Jones – your knowledge in health psychology and working with people with dementia helped me to conduct and present my research in an appropriate manner, and your attention to detail is much appreciated. Tony Dowell – you always brought a considered view concerning the conduct and interpretation of my research, and with regards to the bigger picture and clinical framework. Your pragmatic advice and guidance helped to keep me and these projects grounded in what matters, the people. To my primary supervisor, Philippa Gander, thank you for supporting me in my second postgraduate thesis. You are a sucker for punishment! Thank you for providing me with the opportunity to undertake a piece of work in an area that I was, and still am, passionate about. Your enthusiastic, pragmatic, and respectful approach to me and my research facilitated an encouraging and supportive environment for my journey.

Philippa is not only an internationally acclaimed expert in sleep science, she is also the director of a wonderful and inspiring group of researchers at the Sleep/Wake Research Centre. Being a member of this group provided me with immeasurable support throughout my post graduate journey. Philippa and co-

director, Leigh Signal welcomed me as a Masters student in 2008. I was an international student from England on a one-year scholarship to conduct research regarding the factors affecting infant sleep. Six years have passed and somehow I have comfortably become a part of the furniture and written another thesis concerning the other end of the life-span. This is down to the incredibly open, friendly, and supportive environment and people that constitute Sleep/Wake. I'd especially like to acknowledge Bronwyn Sweeney, office buddy extraordinaire, who has been my thesis writing companion throughout. I cannot wait to graduate and celebrate with you! Sarah-Jane Paine, you have been a fantastic mentor and friend, always there for a coffee with fantastic statistical and writing advice. Kanch Pathirana, thank you for your assistance with data entry and double scoring, I miss your bubbly presence around the lab. Karyn O'Keefe, you are a fountain of knowledge, thank you for being there and sharing your ideas! And to my new PhD buddies: Dee Muller, Margo van den berg, and Jen Zaslona; thank you for your words of enthusiasm, coffee dates, and companionship. It makes such a difference having friends like you to share the journey with.

I'd also like to dedicate this work to my families, the Gibsons and my new in-laws, the Mouldeys. Mum and dad, thank you for believing in me and encouraging me, even if it did mean living on the other side of the world. And Noel and Beryl, thank you for taking me in and helping me to achieve my goals. I think I've almost made it, next stop a glass of wine and a game!

Finally, I am indebted to my husband Gavin, who has stood by me through three degrees, listening to my woes, reading my work, and having faith in me all of the way. You are my rock. Thank you for all of the sacrifices you have made for the sake of my career. I am so lucky to have you as my life partner, as Piglet said to Winnie the Pooh: "If you live to be 100, I hope I live to be 100 minus one day, so I never have to live without you".

My baby, Lyla, came and provided an intermission for me during this research project. Thank you, my love, for sleeping so beautifully and giving me the opportunity to write. Thank you for your warm cuddles and laughter that have motivated me to get this job done so I can spend more time with you. Gavin and Lyla, if I ever have the misfortune of losing you in my mind, you will always, *always* be in my heart.

Glossary and Abbreviations

Actigraphy	A method of assessing rest and activity, using a small wrist-worn device over a period of days or weeks
Advanced age	Individuals aged more than 79 years
AChEI	Acetylcholinesterase inhibitors
AD	Alzheimer's disease
ApoE	Apolipoprotein E gene
ARAS	Ascending reticular activating system
BLT	Bright light therapy
BZD	Benzodiazepine
Carer/caregiver	Used interchangeably to describe someone who provides care or support for someone with a disability
Circadian dysrhythmia	Changes in sleep timing and fragmentation of the sleep/wake pattern
CBT-I	Cognitive behaviour therapy for insomnia
CI	Confidence interval
CME	Continuing medical education
Community-dwelling	Used to refer to people living in their own homes (as opposed to institutions)
Constant routine	Protocol using a controlled environment with the absence of external time cues in order to accurately measure markers of circadian regulation
COPE index	Carers of Older People in Europe index
CSA	Central sleep apnoea
Declarative memory	Explicit knowledge, e.g., what something is
DMH	Dorsomedial nucleus of the hypothalamus
DRBs	Dementia-related behaviours
Dx	Diagnosis
Dyadic approach	Refer to the act of considering the experience of the carer and care recipient at the same time in order to more reliably and ethically inform understanding and treatment
EEG	Electroencephalography
FDA	Food and drug administration
GABA	Gamma-aminobutyric acid
GDS	Geriatric Depression Scale
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
CHDEC	Central Health and Disability Ethics Committee
HWR	Health work and retirement
ID	Identification
Informal carer/family carer/whānau carer	Used interchangeably to refer to those providing unpaid care, usually to a family member or friend
Institution	Used to refer to residential or nursing homes or hospitals
Interdaily stability	A figure calculated from actigraphic data to represent the stability of day-to-day circadian timing
Intradaily variability	A figure calculated from actigraphic data to represent the variability in the amount of sleep and wake per hour across the 24-hour day
Koha	Māori term meaning donation/gift
LiLACSNZ	Life and living in advanced age: A cohort study in NZ
LBD	Lewy body dementia

LTD	Light therapy device
Lux	Units of measure for light intensity
Māori	The indigenous population of NZ
MCI	Mild cognitive impairment
MMSE	Mini Mental State Exam
NEAC	National ethics advisory committee
N	Sample size
NBZ	Non benzodiazepine
Non declarative memory	Implicit knowledge, e.g., knowing how to perform a task
NREM	Non-rapid eye movement
NZ	Aotearoa/New Zealand
NZDep	NZ Deprivation index
Older	Typically used to refer to individuals aged ≥ 60 years
OR	Odds ratio
OSA	Obstructive sleep apnoea
PASE	Physical Activity Scale for the Elderly
PLMS	Periodic limb movements of sleep
PMS	Pearlin Mastery Scale
Polypharmacy	Taking ≥ 5 medications
Polysomnography	A method of measuring sleep using direct physiological measures, usually in a laboratory setting
PSQI	Pittsburgh Sleep Quality Index
PWD	Used interchangeably for “people with dementia” or “person with dementia”
QOL-AD	Quality Of Life in Alzheimer’s Disease
RCT	Randomised controlled trial
REM	Rapid eye movement
RHT	Retino-hypothalamic tract
RLS	Restless legs syndrome
RMBPC	Revised Memory and Behaviour Problem Checklist
SCN	Suprachiasmatic nuclei
SD	Standard deviation
SDI	Sleep Disorders Inventory
SF-12	Short Form 12 item survey
Sleep hygiene	An individual's behaviours and environment that can influence sleep
SPZ	Supraventricular zone of the hypothalamus
SWRC	Sleep/Wake Research Centre
SWS	Slow wave sleep
UK	United Kingdom
USA	United States of America
VaD	Vascular dementia
VLPO	Ventrolateral preoptic nucleus
Whānau	Māori term meaning family including extended family and community
Young old	Individuals aged between 60-79 years

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1 SLEEP AND AGEING

In order to understand how sleep changes with dementia it is important to be aware of the changes that occur in healthy ageing without dementia. Increased sleep disturbances with ageing have been associated with several factors including neurophysiological changes affecting the timing and quality of sleep, changes to the type and intensity of circadian time cues that individuals are exposed to, and the exacerbation of pre-existing sleep disorders. The likelihood of having disturbed sleep also varies with demographic factors, physical and mental comorbidities, as well as changes to expectations around sleeping, and caregiving status. This chapter gives an overview of sleep and its changes with age.

1.1 Defining Sleep

1.1.1 Sleep Architecture and Changes with Ageing

Sleep is not simply a passive state opposing the active state of wake. The advent of the electroencephalogram (EEG) in the 1930s allowed scientists to record and view electrical activity from the cortex (Loomis, Harvey, & Hobart, 1937). These early studies showed that the brain clearly remains active during sleep. The term *sleep architecture* refers to sleep stages and depth defined by the EEG. Eye movements and muscle tone are also recorded through electrodes, these attached around the eyes and chin to help define particular stages of sleep. The process of measuring sleep in this way is called *polysomnography*. Polysomnography typically takes place in a laboratory setting and it is considered the gold standard for measuring sleep (Collop, 2006). Additional channels measuring airflow, oxygen saturation and limb movements can also be included to diagnose particular sleep disorders (see section 1.3).

Studies using polysomnography identify five sleep stages within two distinctly different sleep states: non-rapid eye movement sleep (NREM) and rapid eye movement sleep (REM). The four stages of NREM sleep are on a continuum of depth and threshold for arousal (from the lightest, Stage 1, to the deepest, Stage 4). Sleep is entered through NREM stage one, often accompanied by slow rolling eye movements. Stage 2 is a light stage of sleep characterised by EEG phenomena known as sleep spindles and K-complexes. Slow wave sleep (SWS) consists of stages 3 and 4. Slow wave sleep is characterised by slow frequency and high amplitude delta waves (≤ 2 hertz). It is the deepest stage of sleep, therefore being