

'SYMMETRISLEEP' TRIAL WITH ROCKY BAY CLIENTS

INTRODUCTION

Clients with neuromuscular conditions often have limited or no independent bed mobility. Many of the parents and carers of children at Rocky Bay report they have to turn their child several times each night in order for the child to get comfortable again and enable them to go back to sleep. Broken sleep is detrimental to the daytime functioning of the parents and the children.

Clients with neuromuscular conditions have difficulty maintaining good joint alignment due to muscular weakness and imbalance. This places the clients at risk of developing scoliosis and other joint deformity. A primary clinical goal of management of any neuromuscular condition is to maintain spinal symmetry and joint integrity by considering alignment in sitting, standing and during daily activities.

Reduced bed mobility results in the same posture being maintained for several hours. If the posture is asymmetrical it promotes development of scoliosis and other joint deformities. The majority of Rocky Bay clients sleep in side-lying, which is one of the worst positions in terms of maintaining skeletal symmetry. A tendency to favor one side exacerbates these problems. Symmetrical positioning during sleep would greatly assist in the maintenance of spinal alignment and joint integrity.

Spinal and thoracic deformity can result in compromised respiratory function. Clients with neuromuscular conditions often develop sleep apnea, which is known to contribute to night time waking. Maintaining postural alignment to promote optimal respiratory function can help reduce interruptions to sleep.

'SymmetriSleep' Night Time Positioning system uses supports to maintain a preferred position of alignment overnight. Components of the system include thoracic and pelvic positioners, a knee support and various cushions and pillows containing crumple foam. The system can be individually adjusted to meet the needs of each client.

The SymmetriSleep night time positioning system has predominantly been used with children with cerebral palsy, to our knowledge there is no information available about the use of the system with children with neuromuscular conditions.

Rocky Bay decided to trial the kit with their clients, the purpose of the trial of the night time positioning system was to determine the following:

SHORT TERM

1. Does the system allow the client to sleep more comfortably?
2. How long does it take to become used to the system.
3. What are the effects on client's sleeping patterns.
4. What if any, is the effect on parents or carers?
5. Does the system have an effect on behaviour or alertness the next day?

LONG TERM

6. Does the system contribute to maintaining spinal symmetry?
7. Does the system positively affect quality of sleep?
8. Does the system allow for maximal respiratory function?

LITERATURE REVIEW

No evidence regarding the use of night time positioning systems in a population of children with neuromuscular conditions could be found. The relationship between spinal deformity and pulmonary function has been described (Hart & McDonald 1998, Shapiro et al 1991). It is known that the sleep of people with disabilities is often disturbed (Kotagal, 1994). The relationship between compromised respiratory function and night time waking has also been described (Dubowitz, 1995). Little information could be found regarding optimal positioning for sleep apart from information pertaining to Sudden Infant Death Syndrome, and pregnancy.

"Abnormality of tone and movement causes individuals to lie in destructive postures for long periods at night and these habitual lying positions often become recognizable as the pattern of distortion of body shape as the person grows older." (Goldsmith, Goldsmith and Hill, 2001) The Goldsmiths (2001) go on to describe the immobile chest as a particularly vulnerable structure which distorts readily and predictably in response to internal pressures and asymmetric postures, compromising the basic physical well being of the individual.

For the proportion of the general population who have physical disabilities the Goldsmiths in their work on "postural care" advocate that "lying straight helps you sit straight, stand straight: stay straight" (Goldsmith et al, 1999). Postural care is defined as care that "provides comfortable, symmetrical support for people who are unable to move well" (Goldsmith et al, 1999) Goldsmith et al. suggest that "in the effort to protect body shape" postural care "supplements active movement and is needed during the day and night". In an "Introduction to Postural Care Family Workshops" held in November 2001 John and Liz Goldsmith stated the ideal "supported posture" to be supine.

PROCESS OF TRIAL - PARTICIPANT SELECTION

All Rocky Bay clients were potential candidates for the trial. Clients were excluded if they were not accessible due to geographical or time constraints, had a known respiratory illness, acute illness, or were users of night-time ventilation. Priority was given to families who indicated they were getting up many times during the night to turn their children.

Parents were first approached verbally and then written consent was obtained for their child to participate in the project. A letter of consent was also gained from the children's General Practitioners indicating to us that the child would not be compromised medically if positioned in the supine position to sleep.

Parents and carers were informed that all names would be omitted from the final presentation and all information would be treated confidentially. They were also informed that they could withdraw from the trial at any point.

QUESTIONNAIRE DEVELOPMENT

A basic questionnaire was developed to administer with clients and their family or carer's pre and post trial. The aim of the questionnaire was to identify the client's present sleeping pattern including the position they most commonly slept in, how many times they required assistance during the night and whether or not they experienced any discomfort or pain during the night. The effect this was having on the parent or carer's quality and quantity of sleep was included. The questionnaire allowed provision of subjective information from families/carers.

Therapists practiced together to ensure each administered the questionnaire in the same manner. A prompt sheet was included so that standard responses could be given to families and scales could be explained in a consistent manner. The same questionnaire was administered at the end of the trial.

Immediately prior to and during the trial, parents or carer's completed a "Daily Sleep Record" for a 2 week period. This was a checklist including how long the child slept, whether or not the child experienced any discomfort, and how many times they needed to be attended to during the night.

THE PROCESS

A therapist met with each client and family to complete the questionnaire and set up the system. The components used for each client was at the discretion of their therapist. Parents were shown how to position the child correctly for sleep. A follow-up telephone call was made after the first night to address any

immediate concerns, and further adjustments were made during the trial period as required.

DISCUSSION

The results of the pre and post trial questionnaires and the sleep records were analysed in relation to the initial study questions.

SHORT TERM

1. Does the system allow the client to sleep more comfortably?
2. How long does it take to become used to the system?
3. What are the effects on client's sleeping patterns?
4. What if any, is the effect on parents or carers?
5. Does the system have an effect on behaviour or alertness the next day?

LONG TERM

6. Does the system contribute to maintaining spinal symmetry?
7. Does the system positively effect quality of sleep?
8. Does the system allow for maximal respiratory function?

1. Does the system allow the client to sleep more comfortably?

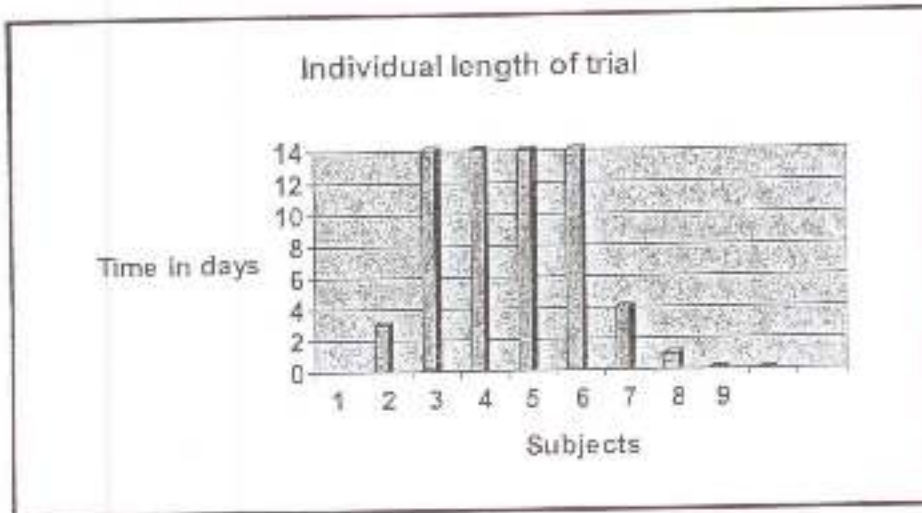
Pre trial, four out of six clients reported pain. Pain was reported in the hips, thighs, groin, lower back and ankle. While using the system one out of four reported pain. This pain was due to a bracket causing pressure on the thigh as opposed to a change in sleeping posture.

2. How long does it take to become used to the system?

Nine pre trial questionnaires were completed. Two children didn't proceed to trialing the kit due to illness and access difficulties. Of the remaining seven children, four completed the full two week trial. Three children discontinued the trial early. Two of these children had good bed mobility and didn't tolerate their mobility being restricted by the kit. The remaining child had previously been sleeping on a ROHO mattress and had concern that the overmante wouldn't provide adequate pressure management.

Two of the children who didn't complete the trial reported negative attitudes towards the kit prior to the trial commencing. The third child was three years old and did not tolerate a change to her sleeping routine.

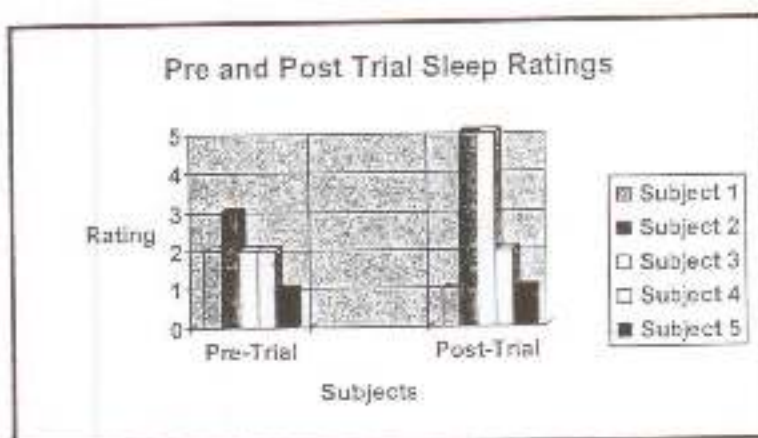
Of the four children who successfully completed the trial, all had very limited bed mobility and had a positive attitude towards the kit. These children tolerated full postural support, with the exception of the use of the knee cosy which was discontinued early in the trial. This information is represented in the graph below.



3. What are the effects on client's sleeping patterns?

Parents rated their child's sleep on a scale from very good to very poor. Three children's sleeping went from being rated by their parents as satisfactory to very good while using the kit. One child's sleeping rating did not change and three children's rating deteriorated and they did not continue with trial.

For those who completed the trial, total hours of sleep remained relatively unchanged before and during the trial. Two children had to be attended to more often during the night when using the kit. This was largely due to discomfort with the knee cosy. One child's attendance needs remained the same and one child was teething so accurate data could not be obtained.



Key

1	Very Poor
2	Poor
3	Satisfactory
4	Good
5	Very Good

4. What, if any is the effect on parents or carers?

information to determine the effect on parents and carers was insufficient.

5. Does the system have an effect on behaviour or alertness the next day?

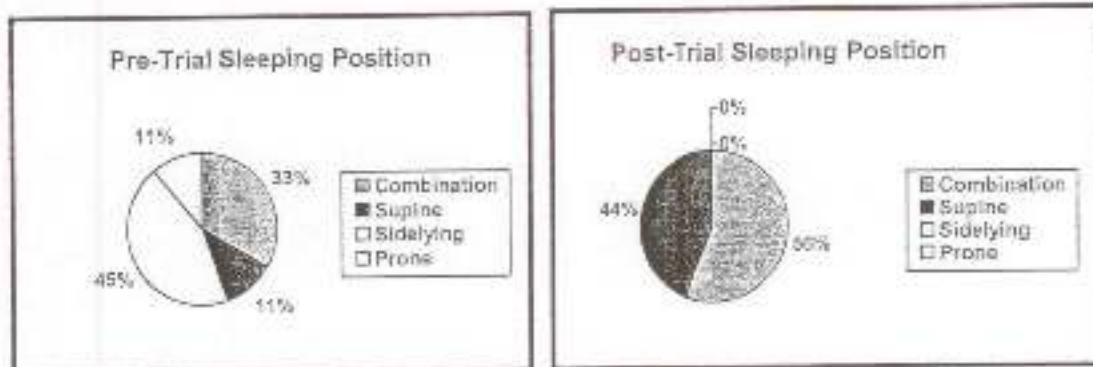
Out of six families who responded to this question in the pre-trial questionnaire, four reported that they believed that night-time waking was impacting negatively on their child's behaviour. Adjectives used included; "grumpy, reduced concentration in the afternoon, long time to wake in the morning and floppy in the morning".

Of the four families who responded to this question in the post-trial questionnaire, two families recorded an improvement in daytime activity and behaviour and two families reported no change.

OBSERVATIONS

- After all trials had been completed, therapists worked together to review the pre and post trial questionnaires and daily sleep records. From this, outcomes trends and observations were noted.

As is indicated by the graphs below, a change in sleeping position was recorded post trial. Children who previously slept in prone or side lying only, now sleep in supine or a combination of supine and side lying.



- The project found that children who were more dependent for bed mobility tasks had a more successful outcome while trialing the kit. Children who were able to change their position in bed reported feeling too restricted by the positioners.

- Children and families who had positive attitudes towards the trial generally had a more positive outcome. The more positive the child and family's attitude before the trial, the better the outcome
- Due to the limited timeframe with which the families had to become used to the sleeping system, an increase in night-time waking was reported. Given that there is an obvious 'settling in' period in adjusting to the system this increase in nighttime waking was not unexpected. Since the trial, four children have been supplied with SymmetriKit and according to families, nighttime waking has been reduced.
- It was determined that the age of the client was also important in terms of introducing the system. Very young children i.e. <18months adjusted better than children aged between 3-5 years. Children who were older (11-15years) had an even better outcome as they were educated about what the system was and how it could be beneficial to them.
- When the 'Knee cosy' was used with clients it was reported to us that this was the piece of positioning equipment most often complained about. Several children were unable to tolerate the 'knee cosy' for the whole night which led the family to remove it. Reports of discomfort were reported from children who had Ilio-Tibial Band tightness.
- Families who had a good understanding of the 24 hour positioning concept had a very positive attitude toward the SymmetriSleep system.
- All children who participated in the trial were able to be positioned symmetrically.
- All children tolerated sleeping flat/supine without any reported respiratory difficulties.
- Clinicians noted that following the trial Parents were more aware of; the importance/implications of their child's sleeping position. This was regardless of the whether SymmetriSleep systems were prescribed or not.
- Toileting was not included as a reason for waking in the sleep record, however several parents reported that this occurs quite frequently, and this, rather than discomfort, was responsible for the night-time waking.
- The study demonstrated that the trial period of two weeks is too short for most children to become accustomed to a new sleeping position.

RECOMMENDATIONS

- Before issuing a kit for trial, provide families with detailed information and education about 24 hour positioning and the importance of maintaining a symmetrical position. If the child is old enough, include them in the education process.
- Components of the kit need to be introduced gradually over a period of time so that the child and family can adjust. If clients are not used to lying in supine, it may be beneficial if they try and get used to the position gradually before the kit is even introduced.
- Children with neuromuscular conditions quite often have Ilio-Tibial Band tightness. It is recommended that the client's hip abduction should first be restricted by thigh brackets, before the knee cosy is introduced, if at all. The use of the thigh brackets will hopefully lead to an increase in length of the Ilio-Tibial Band. Cylindrical cushions can be placed under the knees to accommodate any knee flexion contractures or shortening.
- Families require ongoing encouragement and support to assist them in working the system into their regular routine.
- The concept of 24 hour positioning should be introduced to families early in the child's management. This includes standing, seating and lying postures.

LIMITATIONS

- The two week trial period was too short to determine the kit's usefulness.
- The subject group was small. Out of nine subjects to commence the trial, only four completed it.
- Subject selection. Some of the subjects were not suitable due to various factors including, developmental level and bed mobility.

FURTHER PROJECTS

1. Institute routine measurement of chest dome, sterno-spinal line & Goldsmith index for inclusion in annual physiotherapy assessments.

2. Measure respiratory function using pulse oximetry in various sleep positions (so as to ascertain respiratory impact of changing sleep position).
3. Collect longitudinal data to ascertain whether or not the SymmetriSleep system has a positive influence on joint range and muscle length.
4. Collect photographic evidence of body posture of those using the kit compared to those who have not used the kit.
5. Investigate long term impact of using the system on scoliosis development.

CHILDREN SERVICES TEAM
Rocky Bay
May 2002