

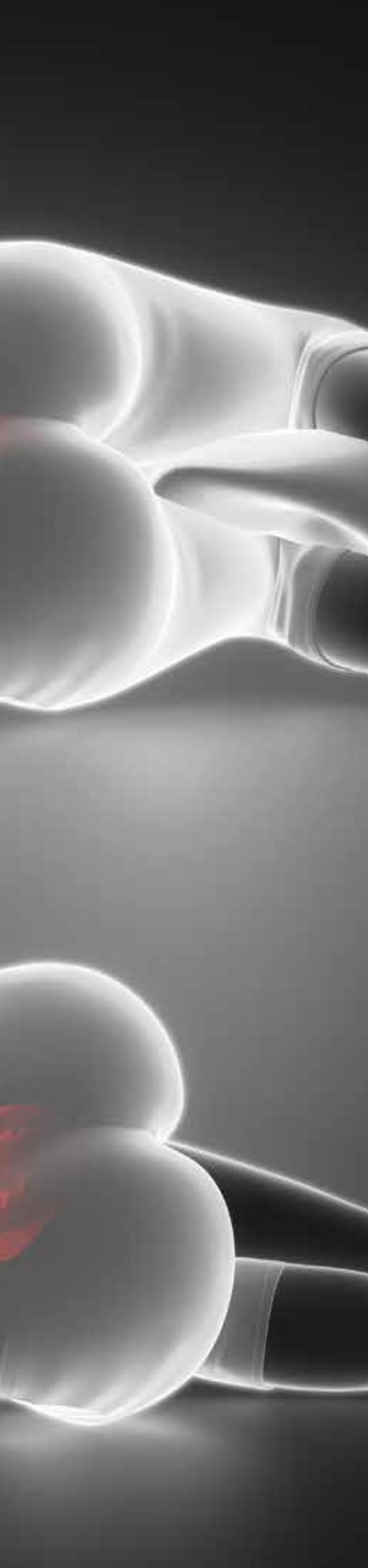


24-HOUR

POSTURE CARE MANAGEMENT

Sleep Positioning & Sleep Positioning Systems

WRITTEN BY: LEE ANN HOFFMAN, B. OCC.THER, MSC. REHABILITATION: POSTURE MANAGEMENT



CHANGE DOES NOT HAPPEN OVERNIGHT, IT HAPPENS AT NIGHT

OVERVIEW

The 24-hour posture care management approach encompasses all the postural orientations available to the individual; namely lying, sitting and standing over the 24-hour period of a day. The approach makes use of equipment and postural programs over the entire 24-hour period to support the individual.

In the complex rehabilitation industry, significant focus is placed on positioning an individual in a seating system, and if appropriate, a standing system. An area often neglected is positioning in lying. There is a strong link between lying and sitting postures, and it is counter-productive to provide no support for an individual with complex needs during the hours which are spent outside of the wheelchair-based seating system.

Posture management in lying is often referred to as 'night-time positioning' and 'sleep positioning.' The use of equipment such as sleep-positioning systems has largely been associated with children who have complex positioning needs, such as those with cerebral palsy who present on the Gross Motor Functional Classification Scale (GMFCS) at levels IV to V.

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Evidence supporting the use of sleep-positioning systems is gaining traction. In the United Kingdom (U.K.), this intervention and approach has evolved greatly and, consequently, has been included in policy, decision-making and practice.

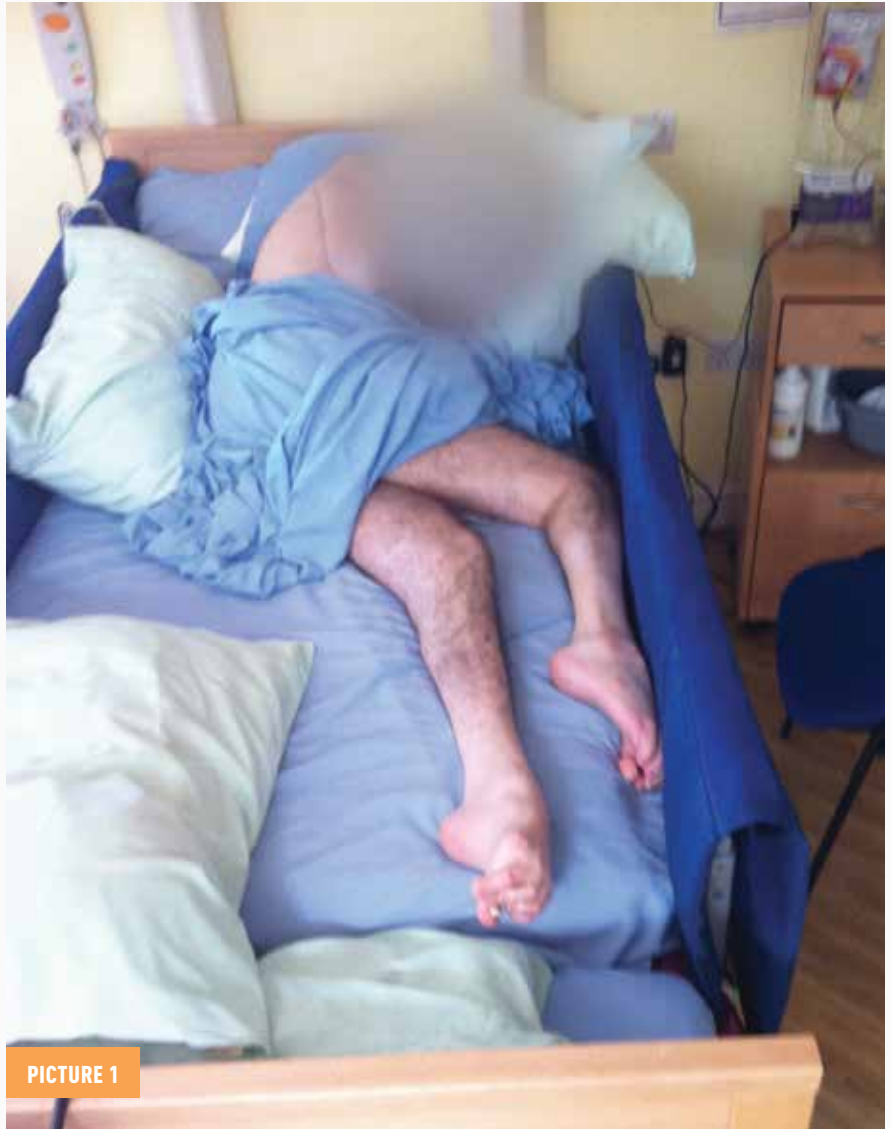
Sleep positioning and nighttime management of posture is applicable to all age groups, for those who are largely immobile and have difficulty independently changing their position in lying.

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INFLUENCERS ABROAD AND AT HOME

Many of the influencers of 24-hour posture care management have come from outside of the US. The U.K. and Europe have seen productive outcomes in relation to the intervention delivered and evolved to influence service provision by incorporating the approach into policy in certain geographical areas.

Posture management has origins in the U.K. and can be traced back to Fulford and Brown (Fulford et al, 1976) who noted the effect of gravity on children who were immobile and the resulting orthopedic asymmetries. The introduction of 24-hour posture care management thereafter was largely influenced by physiotherapists such as Hare, Pountney, Pope and Goldsmith.



PICTURE 1

Sleep positioning intervention from April 2013, without supports in lying.

Hare developed the Physical Ability Scale (PAS) in the 1970s and 1980s, which was used for the assessment of children with severe disabilities. The PAS formed the foundation for the Chailey Levels of Ability, created by Pountney, which described stages of motor development in children with motor impairments. The Chailey Levels of Ability have validity for children and youths with cerebral palsy.

In the 1980s, in a London adult residential care facility known today as the Royal Hospital for Neuro-disability, the rehabilitation team noted that it was not sufficient to only address postural problems during the daytime and that unsupported lying and sleeping positions were the source of many secondary complications (Pope, 2007). Based on the work undertaken by Hare and Pountney, Pope applied the PAS to assess posture and postural ability in individuals with severe physical disabilities, regardless of age and diagnosis, in the early 1990s. In 1992, Goldsmith developed an objective measure which was statistically validated to measure windswept tendency, and in 1996, the first



Implementation of the formal sleep positioning system during the early stages.



November 2013: formal sleep positioning system, regaining midline and symmetry. Ready for phase 2: custom molded seating.

formal sleep positioning system was created in the U.K. (Clayton et al, 2017).

From 2009 to 2011, further work was undertaken by Pope and colleagues to progress and modify the PAS, and the Posture and Postural Ability Scale (PPAS) was formulated. These scales have excellent interrater reliability and high internal consistency and construct validity (Rodby-Bousquet, 2014) for adults with cerebral palsy.

In 2014 in Canada, the Sunny Hill Health Centre for Children developed a tool to assist with promoting hip health and the prevention and management of hip displacement/dislocation in children. The tool is used for those who present at Gross Motor Function Classification

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System (GMFCS) levels IV-V and is specifically aimed at children with cerebral palsy. It is grouped for ages 0-2 years, 2-6 years, and from 6 years to skeletal maturity. Postural orientations of supine, sitting, standing and walking are encompassed.

Closer to home, much work and development has taken place. Inroads have been made in the US marketplace and several services provide postural management. One organization that is breaking exciting new ground is Posture 24/7 and the Montana Postural Care Project, headed up by an occupational therapist with a background in 24-hour posture care management. The Montana Project has been instrumental in introducing 24-hour posture care management as a viable approach in a large rural state with limited resources and services. “The Montana Project is funded by the Montana Council on Developmental Disabilities and is currently in its second year. The Project has served 50 individuals and trained more than 200 families, caregivers and professionals in systematic care for posture throughout the day and night. The Montana Project results for the first-year cohort of children and adults yielded exciting and encouraging results. Among those who followed through with the program, the six-month follow up showed that more than 80 percent exhibited improvement in body symmetry, while almost 80 percent experienced improved sleep, and more than 55 percent reported reduced pain (if pain was previously a problem). A second cohort, ages 1-17 years, is currently participating with follow up to occur after nine months” (Kittelson-Aldred, 2017).

HOW DOES IT WORK?

Round the clock posture care management requires a full and

comprehensive understanding of the individual’s postural needs over the 24-hour period of a day (Gericke, 2006; Pope, 2007; Pountney, et al, 2004). This approach is used predominantly with non-ambulant individuals. Specialized equipment is used in intervention and treatment over the 24-hour period. In the complex rehabilitation industry, great advances have been made in the management of posture with seating systems and standing equipment. Time spent outside of the wheelchair, where the individual is spending what could be up to a third of their day lying down can be “therapeutic or destructive.” (Kittelson-Aldred et al, 2015)

SECONDARY COMPLICATIONS FROM POOR POSTURE IN LYING

Neglect of positioning in the lying orientation and at nighttime can have a profound influence on postures adopted during the day (Goldsmith and Goldsmith, 1998) and influence outcomes in sitting. The 24-hour management of posture is essential in maintaining joint ranges and symmetry for the non-ambulant population presenting with significant movement and postural limitations.

When individuals who are immobile spend time in unsupported lying postures, the influence of gravity over time results in plastic adaptation of the musculoskeletal system. Muscle wastage and shortening of tissue leads to joint contracture and deformity, creating asymmetry. It is of vital importance to understand the biomechanical forces, how these distort body shape and the resulting complications (for further information, refer to the Medical Focus column in this issue).

THE MONTANA PROJECT HAS BEEN INSTRUMENTAL IN INTRODUCING 24-HOUR POSTURE CARE MANAGEMENT AS A VIABLE APPROACH IN A LARGE RURAL STATE WITH LIMITED RESOURCES AND SERVICES. “THE MONTANA PROJECT IS FUNDED BY THE MONTANA COUNCIL ON DEVELOPMENTAL DISABILITIES AND IS CURRENTLY IN ITS SECOND YEAR.

Poor unsupported positioning in lying is often associated with secondary complications such as restricted breathing, pressure injuries, disrupted digestion, pain, discomfort, contracture and deformity resulting in body shape distortion. Tissue adaptation caused by poor positioning in lying has a significant influence on positioning and outcomes in sitting.

Pain and discomfort experienced in unsupported lying orientations may result in reduced sleep, which may in turn influence endurance and stamina levels in the daytime — amongst a long list of negative attributes associated with sleep deprivation on the brain and body. Witness how one’s own productivity, concentration and attention are affected due to reduced or disrupted sleep patterns.

AWARENESS, EDUCATION AND TRAINING

In the U.K., accredited training programs range in their duration. Some programs hold university accreditation toward Master of Science level qualifications, while

others are accredited through the Open College Network (Clayton et al, 2017).

In the USA, Posture 24/7 presents a two-day intensive course “24 Hour Posture Care: Supporting People with Motor Impairments.” The course is designed for those who are involved in the care of and/or work with individuals whose movement is impaired and are therefore at risk of body shape distortion and accompanying health problems. The course is accredited for 14 Continuing Education Units. Visit Posture 24/7’s website for details on course dates and locations.

Knowledge and empowerment of families and caregivers is an axiomatic key to success. Lack of proper assessment, education and follow-up will often result in poor tolerance, abandonment of the equipment and, consequently, poor outcomes.

Many manufacturers provide education and training for 24-hour posture care management and the effective use of their sleep-positioning systems (Polak, 2009). Most training programs are focused on education surrounding biomechanical principles, understanding the dynamics of the human body, the effects of gravity and the cumulative secondary complications resulting from poor posture and positioning. There are various assessment tools, such as the validated tools discussed earlier and associated resources and checklists, available from the manufacturers which may help in 1) identifying and determining the need and 2) determining the essential next steps in providing the appropriate 24-hour posture care management.

It is essential that the postural assessor is skilled in the evaluation of posture, the selection and implementation of an appropriate system, and the on-going review of postural care needs to ensure continued promotion of good sleeping posture through the adjusting of the system or program, as required. The role of the assessor is to assist with the identification of postural limitations, provide support of the family and caregivers, and create a structured plan which encompasses equipment selection, implementation, and review.

Posture care management for 24 hours a day is heavily reliant on a team approach. It is usually left to the family and caregivers to ensure the continued implementation of the determined positioning regimen. Families are largely the reason behind the success of the approach, and it has long been advocated that “family-led” intervention is an essential factor in the 24-hour posture care approach (Goldsmith, 2004).

The implementation of sleep positioning and a sleep-positioning system is not just about the equipment — it’s not a ‘plug and play’ style intervention. The approach is gentle, comfortable and caring, requiring on-going input from the therapy team and caregivers surrounding the individual with posture care needs.

OPTIONS FOR INTERVENTION AND FUNDING

The primary objectives, as identified by Pope, recognized the need to build a stable posture in lying by:

- providing support, directed toward aligning and stabilizing body segments relative to each other and their supporting surface
- controlling the forces acting on the body and avoiding sustained localized high forces
- providing a functional posture
- facilitating comfort

Pope (2007) advised it is always prudent to “try out the supported position, whether supine or side-lying, before prescribing or ordering purpose-made equipment.”

When considering intervention, Kittelson-Aldred (2017) states: “Supporting posture in lying is not unlike therapeutic positioning in sitting and standing, but has the advantage of eliminating gravity. Lying supports require different materials and both informal and formal supports can be highly effective, if used knowledgeably.” Conversely, lying supports will not necessarily be effective, or even tolerated, unless they are used appropriately by people with an understanding of the individual’s postural needs and goals, determined through assessment and readiness to commit to a long-term intervention.

Knowledge and empowerment of families and caregivers is an axiomatic key to success. Lack of proper assessment, education and follow-up will often result in poor tolerance, abandonment of the equipment and consequently, poor outcomes. To reduce abandonment of equipment, a comprehensive assessment is required before trialing and purchasing supports or formal equipment (Pope, 2007). It is important to assess and review each individual to determine compatibility/suitability and to determine potential risk factors regarding sleep position, as well as any items placed in the bed.

In any intervention, risk factors should be a prime consideration. Among those requiring further investigation are overheating and risk of seizure; respiratory status;

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skin integrity; incorrect or inappropriate use of equipment; reflux and risk of aspiration; active movement which may result in injury (Harvard, 2010), entrapment, or falling; thermo-regulation (Goldsmith et al, 2004); and potential risk of suffocation.

Once the assessment is complete and needs have been identified, it is important to determine which intervention pathway and which funding sources can be accessed. Training and support is of vital importance for the implementation and success of any sleep-positioning system to ensure its correct use to meet current and changing client needs. Guidelines and materials can support ease of application and arranging review visits will help to promote communication and achieve postural outcomes.

The therapeutic intervention of a sleep-positioning system will not rapidly correct the individual's asymmetric posture. Consider that the asymmetric posture developed over time and that this is a gradual intervention which should be gentle and comfortable while making use of supporting surfaces and gravity in a positive way.

INFORMAL SUPPORTS: The support provided in lying does not necessarily need to be a 'formal' manufacturer-made sleep-positioning system. The use of pillows, blankets, towels and soft toys can be used to achieve the support required (Pope, 2007; Bower, 2008; Harvard, 2010). "Informal supports are improvised or 'homemade' items used in unique ways to position a person comfortably while lying. Supports can include rolled towels, stuffed [toy] animals and cushions of various shapes and carved foam pieces. These can be secured beneath a fitted sheet in various ways; on their own, wrapping them with Coban® to

make them 'sticky,' placing them between layers of non-slip mesh, and rolling them into a draw sheet beneath the person. These can be augmented with reasonably-priced commercially available products to help support the lower extremities in alignment; if they are inadequate, custom foam supports can be made. Informal supports provide a large advantage from the standpoint of funding. A lying support system can be obtained at very low cost using creativity and easily-obtained items. Depending on needs of the individual, a simple but functional support system can cost less than \$100. A more involved system could cost up to \$500. Using informal supports for trial during the assessment process is an excellent way to establish what the person needs or does not need — and can tolerate — prior to seeking funding for a formal system. If funding is a challenge, the low-cost informal supports can be used long-term" (Kittelsohn-Aldred, 2017).

FORMAL SUPPORTS: formal supports can be purchased readymade from companies specializing in positioning equipment. In the USA, several products are currently available, however there is less variety than in other countries where the use of lying supports have established acceptance and funding. These sleep-positioning systems range from complete sleep positioning devices to modular systems which can be placed on any mattress.

Funding for this equipment can be challenging. To get the latest information, I asked Tamara Kittelsohn-Aldred for further information:

"Most formal systems have various pieces that can be ordered according to individual need and cost between \$1,500 – \$5,000 when ordered as a unit or with multiple pieces, although some can be ordered piece-by-piece gradually over time to spread out the cost. This can also work well in combination with informal supports – for instance, ordering a formal leg support piece to combine with a homemade system. Funding for lying support systems varies greatly according to geographical location and funding source. Some state Medicaid programs have funded lying-support systems (Colorado, for example) and some insurance companies will approve funding if medical necessity is demonstrated. Other funding sources include Medicaid Waiver programs, private foundations, personal funds and fundraisers" (Kittelsohn-Aldred, 2017).

RESOURCES AND TOOLS

In 2009, the U.K.'s National Health Service (NHS) "Buyer's guide for night-time postural management equipment for children" was released. This resource, albeit relevant and applicable to adults and the elderly, has a list of "operational considerations" for the application and use of this equipment that is still relevant today. Many of the sleep-positioning system manufacturers include this list or similar sets of criteria on their websites. These considerations are relevant when identifying and selecting a sleep-positioning system and include child and caregivers needs, spatial constraints, functional level, safe client handling and transportability, adjustability and ease of use, aesthetics, safety, training and support, thermo-regulation, and cleaning (Polak, 2009).

Manufacturers' resource pages often have practical everyday methods, advice and items which may help one provide solutions for individuals with complex positioning needs in lying. Resources and tools can be found or sourced from

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manufacturers' websites, literature, testimonials, YouTube videos, and quite often, free training and education materials. YouTube serves as a great visual aid when explaining concepts such as the set-up and use of various supports, the effects of body shape distortion, and success stories. Manufacturers also carry their own assessment tools, such as measurement kits, which range from basic equipment to specific devices. These all vary in price point.

Several case studies can be found on manufacturers' websites and resource pages. It is both wonderful and encouraging to see so many positive outcomes achieved with a variety of sleep positioning equipment.

As an occupational therapist not affiliated with any one sleep-positioning system manufacturer, I have assisted individuals and their families in experiencing great success with several different sleep-positioning systems. An important, practical lesson that I learned early on was ensuring that the informal/formal system was meeting the needs of both the individual and their families. Through experience, I have discovered a specific sleep positioning system may work well for one client – due to having specific features and characteristics which may be suited to one particular setting – but may not be applicable or meet another client's needs due to the set-up or arrangement of the system. We are indeed most fortunate to have such a wide choice of equipment.

The ability to select the appropriate form of intervention based on the individual's specific needs highlights the value and importance of a comprehensive assessment. It is crucial to ensure that the system, whether it

is informal or formal, will successfully meet the needs of the individual, family and caregivers within their unique setting now and in the future.

A 24-HOUR POSTURE CARE JOURNEY

Twenty years ago, Alan experienced an anoxic brain injury requiring complex rehabilitation intervention. He received a manual wheelchair and seating system, and his home was adapted to promote and maximize his residual abilities and independence. He was largely dependent on his caregivers. One day, Alan expressed discomfort in his seating system and requested to be placed in his bed. There Alan remained for the next 20 years, during which time he sustained a cerebral vascular accident which significantly impaired his remaining function.

When I met Alan, he was a resident in a long-term care facility with a referral for the provision of a wheelchair and seating system. He was 'confined' to his bed. Not a word that I like to use – but an appropriate description for Alan's situation. Alan was lying in almost a fully prone position, and over 20 years' time, this had resulted in contractures, distortions and asymmetries. His position left him facing a pillow and a bed-rail with a protector cover, leaving him very little visual or other form of stimulus (See Picture 1). As a result, it was more difficult to communicate with Alan. It was clear to fulfill the request for the provision of a wheelchair and a seating system, restorative and reparative work in the lying position had to be the starting point.

SLEEP POSITIONING INTERVENTION, BE IT IN THE HOME OR A CARE-FACILITY ENVIRONMENT, IS CONTINUOUS, CLIENT FOCUSED, FAMILY LED, AND REQUIRES MULTIDISCIPLINARY INPUT TO ASSIST WITH SUPPORT AND MONITORING WITH THE AIM OF ACHIEVING POSITIVE OUTCOMES.

Following an in-depth assessment, an action plan was established with Alan's sister and the occupational therapist at the unit. This plan included the care staff at the facility, as the success of the plan was largely dependent on the therapist and the care staff who were relentless in implementing the 24-hour approach established for Alan.

The first step in the intervention plan was to gradually move Alan from the current three-quarter prone position to a supine orientation. Staff was requested to regularly check Alan's vitals and ensure he was not in distress or experiencing any adverse effects due to the change in orientation. Informal supports were used to provide a stable base of support in lying. Staff training and guidelines for implementation were part of the careful review and monitoring undertaken by the therapist and care team to ensure the positioning supports were placed correctly, and that Alan was continuing to show no signs of distress.

In addition to the challenges of implementing a sleep positioning system, Alan had not worn any clothing nor experienced a vertical orientation for the 20-year period which he had spent lying horizontal in bed. Review and monitoring of his tactile and vestibular systems, along with his seizure status were documented, ensuring holistic intervention. Following the success of the informal sleep positioning

system, it was decided that a trial-assessment with a formal sleep positioning system would benefit Alan and be more appropriate for the multifaceted care intervention he was receiving. The introduction of a formal sleep positioning system (See Picture 2) would also comply with the infection control requirements of the rehabilitation unit.

The formal sleep positioning system properties needed to meet Alan's identified needs, namely intelligent fabric which promoted heat dissipation and airflow, supports which provided gentle positioning, the availability of additional components which could be purchased at a later stage, if required, as well as the essential ancillary features including ease-of-use, set-up, laundering, compatibility with the current equipment care regimen, and, very importantly, good support from both the manufacturer concerned and their local area representative.

The formal sleep-positioning system was successfully trialed for a short period before it was purchased. The ability and flexibility to 'try-before-you-buy' is most essential, as it can help in determining if the system will be a 'good fit' for the individual in their environment and also meet their support team's expectations. Following further success, graded steps were taken to introduce periods where the head of the bed was raised and the support surface of the bed was altered by raising the knee break, to ensure stability with good positioning in the supine orientation and decreasing the risk of shear and friction due to sliding down in the bed. Adjustments to the system were made, and gains were steadily achieved over a six-month period of 24-hour posture care intervention in the lying orientation (See Picture 3). Not only had Alan achieved tactile and vestibular milestones, he had regained some degree of symmetry and midline orientation. The building blocks for a seated postural orientation had been achieved, and we started work on creating a custom-molded seating system for Alan.

Sleep positioning intervention, be it in the home or a care-facility environment, is continuous, client-focused, family-led, and requires multidisciplinary input to assist with support and monitoring with the aim of achieving positive outcomes.

CONCLUSION

While the Cochran review of sleep-positioning systems (2015) found there is no evidence (such as randomized control trials) for use of sleep positioning systems, I am aware of many other interventions, just like this case study with Alan, where major successes and significant improvements have been achieved and documented (for an additional case study, refer to the Rehab Case Study in this issue).

Further research and work in this field will always be a requirement, as befits an ever-growing and rapidly-developing field. The effects and outcomes are encouraging evidence that postural distortion can be avoided through preventative positioning to preserve and protect body shape, as well as corrected.

A paradigm shift away from the purely hierarchical evidence-based standpoint toward an evidence-informed practice framework is greatly needed in health care. Evidence-informed practice is a term used to describe the merging and weaving together of experience, expertise and the best available evidence-based research data. Evidence can be numerical, statistically-analyzed data (quantitative) or descriptive data that has been gathered from interviews, focus groups and open-ended questions (qualitative).

Evidence can also be a mixture of both methodologies, encompassing qualitative and quantitative data (Dodd et al, 2016; Miles, 2017).

With this kaleidoscope approach, the best use of the available information (evidence-based and informed-practice) can be used to identify the potential hazards, risks, benefits, challenges, opportunities and economic implications of any intervention.

In this inclusive evidence-informed reference framework, sensitivity is vital. We must understand a single approach, which may work in one cultural setting and context, may not be suitable nor viable in another cultural setting and context. Individual needs must lead intervention.

THE TIME FOR CHANGE IS NOW.

Join the call to action and address postural needs in lying with the 24-hour approach. By addressing postural needs in lying, you are not only working toward better postural outcomes and success for the individual in their seating system and standing frame, you are working toward improving their quality of life.

Will you join the fight against gravity?

CONTACT THE AUTHOR

Lee Ann Hoffman may be reached at lehoffman@invacare.com.

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