

## 24-HOUR POSTURAL CARE – THE QUEST FOR OBJECTIVE DATA

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Considerable time and effort is invested in the management of posture for people who present with skeletal deformities, ranging from complex seating and mobility systems to surgery for spinal instrumentation. From a therapist's perspective, we understand that lengthy periods of time spent in destructive postures counteract those efforts. The concept of 24-hour postural care is being embraced as a strategy for the prevention, maintenance and correction of skeletal deformities. Liz and John Goldsmith, from England are pioneers in establishing the therapeutic benefits in night time positioning and measuring body symmetry. Increasingly, products are available on the market to specifically address bed comfort and positioning both in the commercial market and in the durable medical equipment market. However, translating theory into practice can be daunting when funding and compliance are at issue. Funding agencies like to see objective data before committing dollars to equipment, and people like to see immediate results from interventions.

Posture of people with severe skeletal deformities is very difficult to quantify and changes are expected to be very gradual. Existing measurement tools for quantifying skeletal deformity either rely on x-ray, or are tools that cannot be used effectively when severe deformities are present.

A long-term study is currently underway with five individuals who are in their mid twenties, and present with moderate to severe skeletal deformities. All participants live in group homes and have had family identify concerns related to their posture, breathing, future ability to be seated and resulting of quality of life, as none are considered surgical candidates. The purpose of the study is to track postural presentation before and after the introduction of night time positioning. Each participant was set up with an individualized position utilizing SymmetriSleep components. Physical measurements are taken at six month intervals, as well as nightly tracking of sleep, positioning, and acceptance of the equipment by the individuals. Training on posture, sleep, use of equipment and data collection was provided to care staff in the group homes and family members that chose to attend.

The initial expectation was to be able to collect objective data regarding physical changes in the individuals. Initial measurements were a uniform set of points over all individuals: ziphoid process to the mat bilaterally, ziphoid process to ASIS bilaterally, bottom rib to ASIS bilaterally, and ASIS to the mat bilaterally. However, questions arose as to whether these were the critical measures or if they should be more individual, whether they should be in the corrected or uncorrected posture, and influence of the environment on the individual. Measures were refined and developed for each individual, as well as a protocol for data collection to ensure consistency of the data collected.

While the physical measures have not changed significantly, what has emerged, however, has been powerful subjective data; changes in sleep patterns, decreases in waking tone, ease in handling, increased tolerance to range, decreased pressure issues over bony prominences, increased participation in daytime activities and acceptance by clients.

Challenges continue to exist in implementing the program; staff compliance and turnover being the greatest. Participants who are seeing the greatest benefits however, are becoming their own advocates for use of the equipment where care workers appear less than enthusiastic. Accuracy of data collection also continues to present a challenge resulting in simplification of data collected by care staff. The homes where the greatest resistance to participation by staff is present is also reflective of larger systemic issues in those individual homes.

It is recognized that physical deformities do not develop over a short period of time, and non-invasive interventions will also require extended periods of time to show any result. The subjective changes that have become evident have certainly influenced other families to look at night time positioning as an adjunct to therapies. It is hoped that as the study progresses, the objective data will be able to show results, and ultimately be able to be used to influence decision makers and funders.

### **Speaker Bios**

Lyndel is an Occupational Therapist who has worked for 36 years with children and young adults who have severe developmental disabilities in school systems, special centres and in the community. For the past 26 years she has been consulting and teaching physical management within group homes in the community. Lyndel can be reached at [lyndel\\_hill@hotmail.com](mailto:lyndel_hill@hotmail.com).

Stefanie Laurence is an Occupational Therapist who has been working with people with special needs in a variety of settings and roles for over 25 years; the last 18 as an Occupational Therapist. While the terms wheelchair lady, commode queen, seating specialist and equipment geek have all been used as worthy descriptors, she is actually the Education Manager for the Motion Group of VGM Canada, based out of Motion Specialties in Toronto. Stefanie can be reached at [slaurence@themotiongroup.com](mailto:slaurence@themotiongroup.com).