

Aquatic rehabilitation and the medically fragile child with life threatening illness: A Case Study of Niemann-Pick Disease, Type A

Children with life threatening illnesses, such as the following case study of a child with Niemann-Pick Disease, Type A (NPA), can benefit from aquatic rehabilitation. Children born with NPA are missing the enzyme acid sphingomyelinase (ASM). This enzyme deficiency results in progressive neurological impairment, profound developmental delay, progressive spasticity, epilepsy, enlarged liver/spleen, muscular weakness, feeding difficulties, loss of motor skills, abdominal distention, hypersensitivity to movement, and skin with a yellowish brownish discoloration.

Baby Sophia

Case Study: Niemann-Pick Disease, Type A

Sophia Herzog Sachs began aquatic therapy at 14 months. Our goal is to improve Sophia's quality of life while her parents pursue life saving treatment that prolongs her life.

Due to her lack of head, neck, and postural control, and the requirement of a continuous indwelling nasal gastric tube, Sophia requires 2 experienced aquatic practitioners to achieve an effective 30-minute aquatic session.

Sophia is hypersensitive to movement and must be positioned carefully. She tolerates some massage but joint movement is painful and Sophia does not like to have her limbs stroked. Instead she likes to have a hand gently placed on her in one place.

When her abdomen is more distended than usual and her face more jaundiced, Choubabko will place one hand over her liver while the other arm cradles her head and upper torso.

Meanwhile, Azevedo holds the disconnected indwelling nasal gastric tube out of the water with one hand, monitors her breathing, and leads Sophia in gentle range of motion and extension exercises.

Rhythmic singing, our aquatic handling, and Sophia's suspended movement through the water allows for increased sensory input and allows her brain and body to work together

Palliative care in Warm Water Pools

It is important to note that palliative care is NOT limited to people thought to be dying and can be provided concurrently with life-prolonging treatments. For Sophia, we are providing palliative care in the aquatic environments that specifically addresses pain management, assistance in breathing and bowel functioning, and progressive muscle relaxation. Aquatic therapy improves Sophia's quality of life by making her feel better while her parents pursue potentially life saving experimental treatments.

Conclusions

In summary, bringing a medically fragile child into the pool environment requires a great deal of effort and coordination. Providing pediatric palliative care in the aquatic environment is possible, a worthwhile endeavor, medically beneficial, morally justified, a community building enterprise, and an important opportunity for staff learning. It is our hope that this case study will inspire other practitioners to provide aquatic therapy for children with life threatening illness.

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Benefits of Aquatic Therapy

- * Muscle relaxation
- * Reduction in pain.
- * Increase in flexibility.
- * Cognitive, visual, and auditory stimulation.
- * Social interaction.
- * Aquatic session promote deeper sleep.
- * Sophia cries less after an aquatic session.
- * Sophia is better able to tolerate blood draws after an aquatic session.

