

Aquatic Rehabilitation in Rett Syndrome

By Meir Lotan, PT and Merav Hadar-Frumer, PT, Beit Issie Shapiro School, Ranana, Israel

The following excerpts come from a new IRSA publication. It has been written by therapists who have treated many girls with with Rett Syndrome with endless love and support within water and outside of it. With summer weather coming soon and program-planning for next year in sight, it is hoped that this information will be helpful.

The range of problems experienced by a girl with Rett Syndrome is wide and unique; her ability to control her body is minimal. Spending time in a pool situates her in a normative, "normal" place, which almost every child gets to experience in his or her lifetime. Water provides the girl with new and exciting experiences. It enables her to function in ways she cannot achieve outside the water. It also enables her to express her lost and sometimes latent motor skills.

The Value of Activity in Water

Since nine RS girls are enrolled at "Beit Issie Shapiro," a center for rehabilitation and aquatic therapy and also the national Israeli Rett Syndrome Center, it allows us to identify some important treatment areas worthy of attention. Swimming is a major part of the child's physical learning process. The values of swimming are survival, fitness and joy (Elkington, 1978). These values are the same for those with limitations: integrating the child with limitations into normal life is part of our aim as hydrotherapists. Activity in water is perceived by the child, her family and surroundings as a "normal" children's activity, thus reinforcing the perceptions regarding her ability to participate in as normal a life as possible. This feeling improves self-esteem and self-confidence.

The value of activity in water has been well known for years but only recently, we have found more and more material indicating the importance of this treatment for children with developmental disabilities.

Our goal is to encourage the disabled girl to reach the highest level of independence she can, to teach her to be involved in society, to keep her physically fit (as a tool for independence and maintaining her general health), and to improve her quality of life. A great deal of research on this subject shows that a person's limitation in movement diminishes his or her world of experience and delays her development in all areas. This is due to her limited sensory exposure and the lack of perceiving normal everyday life as it is experienced by children of her own age.

Researchers who have studied the connection between motor skills and perceptual development (Rosenbloom, 1975; Held, 1965) have found that limitations in physical activity limit perceptual development, including spatial orientation and self-esteem. Internalizing the outside world can only be achieved through the child's active experience and her senses in her own environment. Girls who lack movement and have apraxia and ataxia experience the world around them in such a minimal way that it is not surprising that their development in all areas is extremely limited.

Most children approach water as a joyful experience. In the water, movement is easier and freer and allows the girl to understand and to become aware of her body's movements. This awareness improves the girl's movement out of the water as well, and helps change her negative attitude toward movement. When the girl learns to move freely in water, and sometimes even swim, she can join a swimming group, or other in-water activity groups and thus improve her social abilities. As a result, success in the ability to make movements and use her body freely can give her great satisfaction and joy that may raise her self-esteem and improve her self-confidence (Campion, 1991).

All the equipment used to assist the girl in her everyday life, such as wheelchairs and walkers, is not required in the water, thus freeing her from the trap of her physical limitations and using equipment all day long. Free movement in water is the right way to build strong and healthy body awareness. Getting used to the water is also important and allows her to participate more freely in her family's activities, such as going to the beach and swimming pool.

Objectives of treating girls with Rett syndrome include:

1. Decrease of pain
2. Decrease of spasticity
3. Relaxation
4. Preserving and improving joint range of motion
5. Re-exercising weak muscles
6. Strengthening muscles and developing stamina.
7. Improvement of walking.
8. Improvement of circulation and skin condition.
9. Improvement of morale and self-esteem.
10. Socialization

Principles of Treatment in RS

Of the various treatment plans implemented nowadays when treating RS in the water, most focus on achieving independence in water. Hydrotherapists, physiotherapists, volunteers, family members, teachers and caregivers who assist in bringing the girl to the pool, prepare her before treatment and activate her in the water.

Since the water has advantages of its own, it would be wrong to duplicate the same exercises practiced out of the water and execute them in the pool. It is important to remember that girls with apraxia have difficulty learning new skills. Skills that have been first learned in water will not easily transfer out of the water, simply because of the distinct differences of both environments and the lack of generalization by the apractic child. Thus, it is important to build a common plan with goals that serve both environments, in and out of the water, and work together on improving the girl's activities of daily living and quality of life.

The transdisciplinary approach is preferred for disabled population. In an approach such as this the girl has only a few very specific treatment goals agreed upon by the para-professionals, teachers, parents caregivers and hydrotherapists, and all take part in achieving those goals.

Adapting to the water

Adapting to the water is one of the first goals of aquatic therapy. In order to ensure that the child feels secure and enjoys being in water, it is important to gradually introduce her to the water and to the therapist. The difficulty of adaptation to water primarily derives from the fact that humans are not aquatic creatures and water is considered a new and different element for them.

If we bear in mind that the girl's movements are impaired due to ataxia and her difficulty in regulating and balancing her body's muscles, one can understand why changing environments can be most frightening for her. Apraxia is another factor that delays adaptation to new situations, especially when a change in existing physical execution is required. Thus, it is very important to make sure that the girl goes through a gradual and protected transition from land to water. Another problem common to RS females is diminished equilibrium and a distorted sensory system. Once all these barriers are surmounted with the loving care of the team and over a long process, the child will gladly come to the pool and find it hard to wait her turn to get into the water.

Adaptation to water is achieved during the first few meetings and is accomplished by using various fun and games activities. Since girls with RS are sometimes sensitive in the facial area, one must avoid splashing water at their face, especially in the first few sessions.

On the other hand there are girls who lack any fear of water. This situation is extremely risky, far more than the previous one mentioned (Reid-Campion, 1991, p. 248), and should be well prepared for in advance or avoided through constant monitoring of the child around the pool area.

If possible, it is helpful if the person who goes into the water with the girl in the first sessions, or the person accompanying her from outside the pool, is someone she trusts and knows: her caregiver, teacher or a parent. When the girl shows signs of fear or anxiety, it is important to calm her verbally. Speak to her softly and clearly and even whisper in her ear (girls with Rett Syndrome like that and pay extra attention to the person who whispers), phrases like "Don't worry," "I'm here to protect you," "The water is fun," and so forth.

The therapist must present him- or herself skillfully and convey trust since the child is sensitive enough to read the therapist. Constant eye contact should be maintained with the girl at most instances.

If the girl uses a communication board, she should be equipped with a small, sealed version of it for the pool so she will be able to express herself. If she knows she can be understood, she will be more relaxed and react positively and calmly to the new experience in the water.

Breathing control

Breathing control is important for all water activities (Campion, 1991), but is specifically significant for girls with RS who display various forms of breathing irregularities. Most children who come to aquatic therapy do not know how to breathe correctly in the water and the common mistake made by most children is inhalation instead of exhalation in the water, which eventually leads to coughing and a feeling of suffocation (Styer-Acevedo, 1995). This unpleasant feeling can cause her to be afraid of the water and to refuse to enter it again. In order to avoid this situation, it is important to work with her on gradually immersing her head in the water and teaching her how to breathe correctly underwater. Correct breathing enables a feeling of control and promotes the girl's independence in the pool. This takes a long time to achieve, but our experience has shown that it can be done with most RS females.

Head control

Head control is the fundamental basis for development of motor functions. Failure to elevate her head against gravity will prevent the girl from developing qualitative eye-hand coordination (Rosenbloom, 1975). Head control, is of great importance especially in the water: in the water, the head leads the body and the body follows the head's lead.

Buoyancy negates a large part of the force of gravity. When a child enters the water, she uses a set of motions against the force of gravity, specifically using the balance reaction of the legs. Since the body tends to float in the water and the legs have no solid support from the ground, the child must learn to control her responses and reactions in a new way - using her head.

Sometimes the ability to control the head can become a treatment goal in itself, especially in girls with severe hypotonia. In the water, one can identify the place where the patient cannot control her head and work with her, improving from that particular point onwards. Each small movement of the head will change the body position. Good control over the head's movements will lead to better control over the whole body's movement in the water, and thus to independence.

Controlling Rotational Movements

The human body is not completely symmetrical and neither is the body of a girl with RS (Budden, 1995). Instead of the concepts of mass and weight that usually fit the world outside the pool, in the water we use concepts of shape and volume. This means that every change in the capacity or shape of the child who enters the water will lead to a rotational reaction of her body. This movement will stop only when the body returns to a state of balance. To be able to reach this balance, the child who enters the pool must learn how to correctly react in the water: the reaction should be slow and in the opposite direction to the rotation.

To be able to achieve control over the body's rotation, hard work is required. Only those who can maintain a stable position in the water will be able to be completely independent in the pool and achieve higher abilities such as swimming.

It is well known that girls with RS, including those who are able to walk, have a tendency to asymmetry (Budden, 1995). The difficulty of maintaining balance can cause a lack of security, which in turn will lead to stress and stereotyped hand movements that eventually prevent all functioning or control. A good way to help the girl achieve balance in the water is through play and enjoyment.

Disabled people have difficulty maintaining a stable position in the water because of the difficulty in controlling different parts of their body (Reid-Campion, 1991). Thus, working on controlling body rotation is in itself a valid goal. It can lead to better control of the body, improving stability and balance reactions out of the water.

Relaxation

Relaxation is extremely important to activity in the water and to all activities in life in general. Stress, fear, anxiety and pain increase spasticity and cause tension (Mitchell, 1977, in Campion, 1991). When the girl feels relaxed, her movements in the water will become freer.

Relaxation can be achieved through:

1. Feeling secure and free of any supporting devices (used on land) once the child adapts to the water.
2. The support given to the body by the water's hydrostatic pressure (Duffield, 1976, in Campion, 1991).
3. Feeling weightless due to buoyancy (Harris & McInnes, 1963).
4. The therapist's support - There must be enough support to provide a sense of security, avoiding unpleasant pressure or a tight grasp. The amount of pressure the therapist applies is dependent on the child's reaction and should be carefully monitored by the hydrotherapist.
5. The warmth of the water - relaxes and reduces pain (Harris & McInnes, 1963).
6. Slow, rhythmic, passive bilateral and rotational movements (like Watsu), which increase relaxation (Sullivan, Markos & Minor, 1982).
7. Early introduction - It is highly recommended that the therapist finds the time to meet the RS girl in a friendly and familiar environment in order to try and create a relationship based on trust and understanding before meeting in the pool. Also, time should be taken in the first few classes in the pool to let the girl decide on the activity and the pace of entering the water.

The space in the therapeutic pool allows the girl to learn about different spatial dimensions and therefore helps her understand and be more aware of her body and her limbs' place in space.

The change in body posture during activity in the pool and the ability to use the different rotations has been proven to encourage the development of the body scheme. The encouragement of the body scheme is essential for girls with RS who suffer from a deficient body scheme and, as a result, apraxia.

Ataxia and Apraxia

Due to objective limitations, even when trying to perform different tasks, the girl's precision will be far from perfect. It is important to remember this and support the girl in every act she does, and even reinforce her willingness to work (Lindberg, 1988). It is recommended to start with simple tasks that bring immediate success. After building rapport with the girl, the therapist can raise the level of difficulty of the exercises.

Reaction Time

The reaction time of girls with RS is long (several minutes can elapse between request and performance). Thus, when asking the girl to execute a certain exercise, she should be allowed all the time she needs (Lindberg, 1988). It is important to wait for the girl's active performance, since it is the only way the brain can process and assimilate the body's movement. At a later time, these memories become a movement scheme enabling the child to initiate and execute future motor acts (Ayers, 1994).

After Treatment

When leaving the pool, the girl's body-heat mechanism starts working on regaining the body's temperature and bringing it back to normal. The chief mechanism is perspiration, which causes considerable fluid loss. In order to encourage perspiration and prevent fast body cooling, it is recommended to wrap the girl in a towel as soon as she leaves the pool, and an appropriate quantity of liquids should be given to the child.

Likewise, one should dedicate time to rest. Resting right after leaving the pool enables the girl to keep losing heat through perspiration and thus the blood vessels, heart and respiratory system will gradually return to normal.

Summary

Aquatic therapy is a new and efficient treatment for people with various limitations and girls with RS can enjoy and benefit from this treatment. The pool is perceived as part of the healthy people's world and is very different from the surroundings of most conventional treatments. This combination motivates the patients, young and old alike, to take part in the treatment and improve their mental and physical condition-an improvement that eventually enhances their daily functions in all areas of life. This is the basic aim of aquatic therapy and should be the guideline of every hydrotherapist.

Tomado de: <http://www.rettsyndrome.org/main/aquatic-rehab.htm>