



SWEDISH NATIONAL CENTER
for RETT SYNDROME & RELATED DISORDERS

The Musement

Music/Motor function

“The Musement” – amusement with music and movement. A rhythmic movement class for children with Rett syndrome or any children who like to move to music.

Märith Bergström-Isacsson, Music therapist
and Gunilla Larsson, Physiotherapist

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*Rett Center Sweden is currently Swedish National Center for Rett Syndrome & Related Disorders

Introduction

THE MUSEMENT IS A MUSIC and movement programme developed by music therapist Märiith Bergström-Isacsson and physiotherapist Gunilla Larsson at the Swedish Rett Center, Frösön, Sweden. They have worked together for many years in an interdisciplinary team dedicated to Rett syndrome. The Rett Center is a national centre that provides specialist care and consulting services, and conducts research and development.

THE SONGS AND MOVEMENTS are intended for young children with or without disabilities. Working with body movements purposefully, beginning when children are small – small enough to sit on an adult's lap – can help prevent future problems. It is much

easier and more fun to do the movements if there is a reason for doing so. Movement is integral to these specially written songs, providing participants with an enjoyable experience. Otherwise, it is all too easy to become so focused on training that joy and happiness are forgotten.

MUSIC IN ITSELF IS MOVEMENT involving sound fluctuations that reach our ears and our body and that in turn generate movement. This is as good a reason as any to use music in conjunction with body movements. Experience has shown that music is a good path to communication and understanding for children with Rett syndrome and other disabilities.

THE BOOK YOU ARE holding contains a brief introduction to the authors and composer, as well as their thoughts about the book. The songs are arranged in the specific order to which they should be listened.

NATURALLY, YOU MAY CHOOSE to follow any order you wish, but this is our recommendation. Each song and movement is also accompanied by a brief description of how to perform the movements, and the objectives they are intended to achieve.

THE MATERIAL HAS BEEN carefully formulated and each exercise contains objectives both for music therapy and physiotherapy. Musement works with multiple senses, both from the inside out and the outside in.

THE MATERIAL INCLUDES an animated film created by the film team Tant-i-Loop Film to illustrate the exercises. The team includes award-winning Anna Erlandsson, who won a Guldbagge award in 2005 for her animated film “Glenn, the Great Runner”.

WE HOPE YOU WILL FIND both this book and the accompanying film to be helpful and inspirational in your work.

GOOD LUCK!!



SWEDISH NATIONAL CENTER
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Presentation

MÄRITH BERGSTRÖM-ISACSSON has worked for many years as a music tutor in such areas as early childhood music, special schools for children with learning disabilities, autism centres, paediatric rehabilitation, and as an instructor for preschool and school personnel in the subject of music. In the mid-1990s she began working as a music therapist at the Rett Center, continuing her studies at the Royal College of Music in Stockholm and in 2005 took her Master's degrees in music education with a focus on music therapy. She is now working on her doctorate at the Department of Communication and Psychology at Aalborg University in Denmark. Märith has composed many songs and lyrics often designed to achieve special goals. Her previously publis-

hed work includes "Musik från Topp till Tå" ("Music from Top to Toe") and "Mera Musik från Topp till Tå" ("More Music from Top to Toe"), both of which are educational material for children aged 0-8 years as well as children and adolescents with a special support needs.

GUNILLA LARSSON has worked as a physiotherapist for children and adolescents with physical disabilities in rehabilitation since 1978. In that year she also became interested in the disability which was later called Rett syndrome. Since the mid-1990s she has been the Rett Center's physiotherapist. She continued her studies at the Department of Community Medicine and Reha-

bilitation, in physiotherapy at Umeå University where she took her Master's degrees in 2003 with a thesis based on a survey about how Rett syndrome develops, using motor function as her basic premise. Gunilla is currently a doctoral student at Umeå University.

Comments from the authors

RETT SYNDROME IS A neurodevelopmental disability in which the child appears to be healthy at birth. Later these children present with the developmental delay, loss of communication and loss of both hand function and gross motor function associated with the condition. Research shows that while all parts of the brain are present in Rett syndrome fewer synapses form in the brain. The variability in severity is extensive in Rett syndrome. In the extremely young child the signs are

not as clear, but instability in the torso is often present, which causes the child to have problems when changing position and moving. This can be manifested in shakiness and fear.

THE CHILD SOLVES the problem by trying to find a physical position that feels secure and stable. This in turn leads to less variation in motor function and therefore decreased experience and perception. Tension in the feet makes it difficult to stand and walk; repeated, non-functional hand movements come at a rather early age. Somewhat older children often demonstrate asymmetry of the body with abnormal posturing of the torso. The characteristic repetitive hand movements can lock the child into a less functional body position, often with the head bent forward and shoulders and back rounded.

THE RESULT CAN BE that the person perceives the body to be straight in this position – which could make it unpleasant to assume a truly straight position. Breathing problems are common and often lead to tension in the neck and shoulder muscles.

A SIGNIFICANT PART of the physical impairment in Rett syndrome is difficulty in initiating movements, known as dyspraxia. This could mean that the more the child wants to carry out an action, the more the body becomes “locked” and unmoving. In addition, children may have abilities they are unable to demonstrate. Structure, repetition and expectation make it easier for the child, providing the opportunity to develop and use more of their potential abilities, through both joy and positive reinforcement of the child as a person. Music

has proven to be a strong motivating factor and may help children to circumvent their dyspraxia. It has been noted that certain individuals with Rett syndrome have been able to retain some functions, to retrain a specific function and even to learn new abilities after the regression period.

THE EARLY LOSS OR CESSATION of speech makes it important for these children to develop alternative ways to show what they want or do not want, and to communicate with those around them. Both music and motor function can help in this effort. After working for many years with people with Rett syndrome and noting their difficulties and their possibilities, we started to ask ourselves the following questions: Could early intervention inhibit or delay the loss of gross motor function seen in Rett syndrome? Could this provide the person with

the opportunity for greater variation and joy in motor function or develop communication? In our experience, early intervention plays an important role and should be fun and motivating. The Musement can be one way of working with these questions and of introducing the exercises in a context that is clear for the child. Children can also experience joy and confidence in being able to use their bodies.

WHILE IT IS USUALLY obvious that motor function is movement, we do not always recognise the fact that music is also movement. Music in itself is sound waves and vibrations – in other words, movements – that we experience throughout our bodies. Different tempos affect us in different ways, which can be used, for example, when walking, dancing, running or swinging. In this material we have tried to combine our different professi-

onal disciplines and clinical experiences into something that we hope will become more than the individual parts separately.

CHILDREN WITH RETT SYNDROME are not the only ones who can enjoy and benefit from participating in the Musement. All children, regardless of whether or not they have physical disabilities, benefit from using their bodies, and feeling the enthusiasm and happiness of music and movement. The Musement exercises can of course be performed on one's own, but the pleasure of doing them together with others should not be ignored.

The Musement

General tips:

YOU CAN HOLD THE CHILD on your lap, either sitting on a chair or on the floor and turn to face the other children in the ring. In the latter case you can choose between having the child sit on or between your legs. If the child feels insecure it can be good at first to have the child facing you for support and to provide reassurance through eye contact.

AT FIRST THE CHILD MAY need clear and physical help in carrying out the movements, but you can gradually reduce how much you do. The goal is for the child to carry out the exercise independently or essentially independently.

The Musement song

(Text & Music Märith Bergström-Isacsson)

C G7 am F C G7 C (repr.G7) C7

//:Hello and welcome to the Musement. Hi and welcome to us.://

F C G7 C C7

//:We'll move our bodies a lot and sing. 1.We're gonna bend and stretch – there's no sitting still://

G7 C

2. There is no sitting still

Music therapy objective

This tells the children what is going to happen and that it's time to get started. It also provides a clear structure. In the opening song we also view the group as a whole entity.

Physiotherapy objective

This signals to the children that it's time to move their bodies. Move to the music.

Tip

Take off shoes and socks, and sway or hop up and down during the song.



So what's your name?

(Text & Music Märih Bergström-Isacsson)

F G7 F G7 F

So what's your name?.... Hi... So what's your name?.... Hi... So what's your name?...

G7 F G7 C

Hi... It's so nice to see you here!

Music therapy objective

This is a way to address everyone by name so everyone feels seen, feels part of the group, and feels an important part of what is happening in the room. This is important for both the individual and the group.

Physiotherapy objective

Having body contact, and physically touch the child, can strengthen the feeling that “now it’s my turn”. Eye contact also plays an important role in being ready.



Hi, hello

(Unknown composer)

A

E7

A

D

E7

A

I touch your lovely feet and I say hi, hello. Your feet then say to me: hey what's going on.

I touch your legs, tummy, hands, arms, cheeks, back, your body.

Music therapy objective

Here we use the music to help identify each part of the body and to give the experience that everything is inter-related. This strengthens the sense of self and the individual. The song also establishes contact and a sense of belonging with the person who touches the different parts of the body.

Physiotherapy objective

We know that asymmetry is common in Rett syndrome and other disabilities, but we usually cannot ask the children about his or her experience of body sensations. In this movement experience the child benefits from receiving as much stimulation as possible to the entire body.



Tip

The child should be touched in a way that is pleasant for the child and for certain children a firm touch can be more pleasant than a superficial one. Being physically close and touching will help the child to feel good. Don't forget the toes!

A flower

(Text & Music Märith Bergström-Isacsson)

C am dm7 G7 am7 F dm7 G7 C dm7

As a warm sun rises, the flower starts to bloom. And as evening falls, its petals all curl up.

C am dm7 G7 am7 F dm7 G7 Cmaj7

First you are so tiny, and then you stretch out. By curling up you turn into a little ball. (3x)

Music therapy objective

The song includes the experience of external and internal structures that provide both an opening up and sense of freedom, but also the feeling of holding the body and the “self” together. In the beginning it is important to go slowly since not everyone feels secure enough to open up and be vulnerable.

Physiotherapy objective

This exercise prepares the body for the other movements and helps it to loosen up. Help the child to gently stretch out! This gives a pronounced and physical sense of the difference between big and small, and between a curled up body and stretched out body.



For children with physical disabilities it can be important to begin with small movements and then gradually make larger movements.

Sit & look

(Text & Music Märith Bergström-Isacsson)

dm

A7

You can twist your head to the right. Turn and twist and look and see if something happens.

F

gm7

dm

A7

dm

Use your hand and wave upwards, towards the roof with your hand, - yes, with your hand.

You can twist your head to the left...

(x2)

The purpose here is to help the child to turn his/her upper body.

Music therapy objective

This provides communication, eye contact, encouragement and playfulness. It can be fun to meet each other's eyes, wave and maybe make silly faces. The song provides the experience of seeing and being seen.

Physiotherapy objective

Turning the upper body can relax the body, and maintains mobility. This is often difficult for children who feel unsteady and can cause apprehension. This exercise works best if you hold firmly, encourage the child and help him or her to experience joy. Gradually reduce the support you provide.



The boat

(Text & Music Märith Bergström-Isacsson)

Dmaj7 D7 Cmaj7 D7 Dmaj7 D7 Cmaj7 bm7

You sit on my knees - it's like the ocean. You're like a boat following the waves. (x3-4)

Music therapy objective

Here we give the child a sense of relaxation, with calm and close contact. Sharing the movement provides a feeling of togetherness, openness and security.

Physiotherapy objective

This movement exercises balance and torso mobility to the sides. Experience, feel and gradually control the movement – feel what happens in the body and what it does to straighten up again.

Tip

Try to do the full range of movement equally to both sides. Start with small movements and gradually increase the range as the child allows. With some children you can do large movements for fun, but not too fast –



the child should have time to feel and understand what is happening in the body. It is preferable if the child sits freely but with a secure base for support.

Behind the back

(Text & Music Märith Bergström-Isacsson)

C /h /a /g F C G7

1. Twist and look behind you - what's behind your back. Is it a mouse, or a duck saying quack?

C C7 F dm7 C am G7 C

Look very carefully, twist a little more. Maybe there's an elephant or a dinosaur!

2. Look the other way now, is anyone there? Maybe there's a cake or a little bear. Look very carefully, twist a little more. Maybe there's some candy for you down on the floor. (x2)

The purpose here is to help the child to turn his/her head, to look over his/her own shoulder.

Music therapy objective

The nature and lyrics of the song motivate and encourage the child to interact, establish contact and carry out the movement of the song.

Physiotherapy objective

Common hand movements and breathing problems in Rett syndrome cause tense muscles in the neck and shoulders. Doing these movements regularly in a playful way can help prevent muscle tension.

Tip

Perform slowly and wait for the child to take part. Encourage the child to gradually do the movements independently. Support the child's hips or as far down as possible.



The hand

(Text & Music Märith Bergström-Isacsson)

D

A

A7

D

1- 2 //: Here is your hand. You can feel when I touch it, feel it when I touch you in your hand.

bm

A

A7

D

Here is your hand, and you can feel it when I tickle, feel it when I tickle in your hand. ://

3 Here are your hands, you can feel them when they clap. Feel them when you're clapping with your hands. Here are your hands, you can feel when they clap. Feel them when you're clapping with your hands. (2x)

Music therapy objective

Touching the palm of the hand helps the child to stop its typical hand movements and if possible, to relax for a while. The song can also create opportunities for contact and a quiet conversation.

Physiotherapy objective

You stimulate sensation in the hand and provide new experiences that differ from those that the child gets from his or her typical movements. Even children with disabilities other than Rett syndrome can be inactive with their hands and they receive too little sensation or too limited and monotonous sensations from them.



Tip

Many children may need help with opening their hands and turning their palms upwards.

In verses 1 and 2 the palm is turned upwards.

Not so easy

(Text & Music Märith Bergström-Isacsson)

D bm G em D A7 D

//: It isn't so easy to sit up straight when the whole world leans this way.://

G D bm em7 A7 D (D7)

//: It's a good thing I have a hand that I can lean against as we sway. (Yes) :// (x2)

Music therapy objective

It can make it easier if you know what to do. This makes the child feel secure and trust you. It's important to be able to trust the person on whom you are dependent. These lyrics describe leaning against your own hand and that it is also good to have another hand as support.

Physiotherapy objective

The ability to support oneself on one's arms is functional and practical for situations such as moving from one position to another and for rising to a standing position. This exercise also exercises the muscles in the arms and shoulders. Children with Rett syndrome seldom spontaneously support themselves with their hands or place their weight on their hands, arms or

shoulders. If they do, they do so to a lesser degree than others because of the typical hand movements caused by the syndrome.

Tip

Do the movements calmly, one side at a time. Feel the body leaning and the weight on the hand. Try "shaking" the child gently or sway a little bit. It can also be done against the adult's hand or leg, or against the floor.



The push

(Text & Music Märith Bergström-Isacsson)

G7 C G7 C

//: Now I'm pushing you. That is all I do. And if you follow me, here comes number three.

G7 C G7

Oops, something must be wrong. With counting in this song. But that is not too bad.

C

We're having fun and I am glad. :// (x2)

Music therapy objective

The song builds up expectation. The child knows that somewhat is going to happen and is prepared for the little push that comes. It's fun and easy to understand.

Physiotherapy objective

This is a way to stimulate protective reflexes and balance reactions. This is important for most children who have some form of disability and it is a fun game for all children.

Tip

Start with a little push forward, then push to the sides. Children develop the reflex to resist backwards last. It is important to recognize how far each child has developed so the game is secure, fun – and challenging.



Jumping song

(Text & Music Märiith Bergström-Isacsson)

E7

am

E7

//: It's time for jumping, jumping, jumping, jumping - stopping. It's time for jumping, jumping,

am

dm

Cmaj7

dm

jumping, jumping - stopping. Hey you, come here. Come close to me. Are you ready?

am

dm

Cmaj7

dm

am

Let's go again. ://(last time) Hey you, Come here. Come close to me, time to relax and end this song.

(x3)

Music therapy objective

The song generates a clear expectation and contact. It also provides a clear experience of rhythm, tempo and change of pace. The rhythm carries the movement and the changes in pace clarify the difference between action and rest.

Physiotherapy objective

Here the children put their weight on their legs and feet during a fun game. Bearing weight in itself stimulates sensors in joints and muscles and gives impulses to the children to stretch their bodies. Impulses and impressions from vision and the inner ear are also used in this exercise.



Tip

Really young children can jump on the adult's lap, while a somewhat older child can be held in front of the adult on the floor. For children who cannot support themselves on their feet, the movement can be done with the child sitting astride the adult's lap. Follow along with the changes in musical tempo even if the starting position changes.

The airplane

(Text & Music Märith Bergström-Isacsson)

C am dm7 G7 F G7 F

Imagine you are an airplane, flying high in the big blue sky. Playing with all the birds, and flying

G7 C am dm7 G7 C

through the clouds. Imagine you are an airplane. If I am nice maybe I can let you come along. (x2)

Music therapy objective

The song says what is going to happen, which provides reassurance in the exercise. The character and calmness of the melody “carry” the movement and the experience of the movement.

Physiotherapy objective

This exercise strengthens and stretches the back, and counters slouching positions. The risk of developing asymmetry, crookedness, or weakness in the back muscles is not limited to Rett syndrome. All children could use this movement to help them stretch in ways they normally do not do.

Tip

The movement can be done in many ways. On a chair: The child lies on his or her stomach on the adult’s lap, facing the oth-



ers, supported by the adult’s thighs and hands under the stomach/chest. The child is encouraged to look up. On the floor: The child lies across the adult’s lap and is encouraged to hold up his or her head. The adult can also lie on her/his back with the child on their lower legs/soles of feet. This position allows good eye contact between child and adult. It is important that the assistant understands the goal – the child should stretch his/her back, lift the head and have fun.

The end

(Text & Music Märith Bergström-Isacsson)

D bm A D G A D bm

Now we have finished our work for today, you have done very well.

G A D G A D

The Musement is finished for today. Yes the Musement is finished for today. (x2-3)

Goal

This clearly signals that this activity is over, which helps create structure. It is also a song with a clear rhythm that encourages activity and the desire to move.



For your inspiration

This is literature we find inspiring and worth reading.

The books, articles, papers and DVD include songs, exercises, clinical observations as well as scientific articles about music therapy and physiotherapy. Some literature is written in Swedish and some in English.

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Rett syndrom – Hur ser det ut och vad kan man göra?
Östersund: Svenskt Rett Center

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