

## Reflection on some problems in motor development in children with EB.

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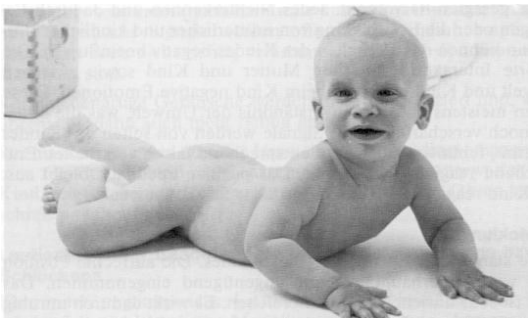
Physiotherapy is still often associated with mobilisation and avoiding of contractures. This is certainly a task for the physiotherapist, especially if we are talking about older children and adults.

For babies other goals can be more important and often aren't taken into consideration. Babies with EB should be helped with their motor development and their parents should be coached.

Babies with EB will be confronted with several problems influencing their motor development. The pain they resent can give them fear to move. This will give them less chance to experiment and to discover their body. Parents often have fear to touch their children and often also fear that movement will hurt their baby.

This can result in a motor development that will be too static and gives not enough experience in a dynamic motricity. This means that the child will be put on his back, later on he will be brought in the sitting position and at the end in a standing position. But the transitions from one position to another might not be sufficiently trained.

It is important for any baby to exercise the prone position. If they like to be on the tummy they will be willing to learn to turn over and to move without help from one position to another. A child that learned to move on his tummy will learn to creep. If they can come in a creeping position they will learn to come to a sitting position without help earlier than children who only lies on their back. The development in prone is important:



- to exercise mobility in different joints
- to train strength in shoulders, arms, trunk
- to develop the right coordination between the different parts of the body
- to train the equilibrium reactions in safer condition than sitting or standing
- to prepare the hands for manipulation: mobility, strength and coordination

In children with EB we often remark that:

- **Supine** is the preferred position in the first months and they use a lot of extension when they move. This increases the risk to develop a preference for head rotation to one side and to develop an asymmetrical posture and motricity.
- **Prone** is often disliked and avoided when awake. The prone position requires much energy and doesn't give much satisfaction at the beginning. It isn't easy to raise and to find the different coordination's needed to enjoy looking around and playing in this situation.

- **Sitting** is often the position of preference when awake, but they often develop a static way of sitting. They mostly don't exercise weight bearing on the hands and trunk rotation which are necessary for the transitions to other positions.
- **Standing** will not give problems of weight bearing on the legs unless there are often blisters and pain in the feet. They will rather experience difficulties with dynamic weight bearing: necessary for safe equilibrium. The danger is that some children will like too soon to be put in the standing position without being enough prepared for it. This results in a longer dependency on adults.
- **Walking** : some children will like to "walk" with adults or to be put in walking toys without being sufficiently prepared for it. The danger for this is that they rely on the help of the adult and that they are afraid to let it go. As they rely on the adult they haven't sufficiently trained their equilibrium and support reactions and they don't have sufficiently self-confidence.

We must be aware that the prone development and the crawling are very important to prepare independent walking. Even the use of the hands and fine manipulations will be affected by prone development.

Many parents are afraid of prone because the risk of blisters is present. Of course the individual child must be evaluated but often the risks can be diminished by using good protections like cloth, gloves, knee protectors or bandages.

One also should consider that children who learn to walk will fall and be confronted with injuries. So it might be better to give them the opportunities to exercise the skills they will need the rest of their life's at the right time and in circumstances as controlled as possible. Coaching the parents and giving them advices how to care and play with their baby's can be more efficient than every day physiotherapy and mobilisations.

### What must we learn the parents and the children?

**In supine:**

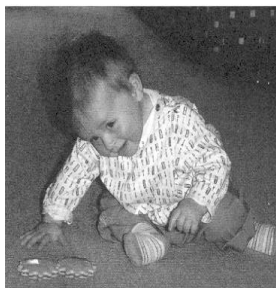
- finding the midline
- promoting the head and trunk control
- stimulating rolling

**In prone:**

- explaining to the parents the need of prone development
- inform why the prone is difficult for a baby
- giving playing advice
- promoting crawling

**In sitting:**

- explain the difference between a static sitting and a dynamic sitting which enables more enjoying playing
- stimulating changing of position by using weight shifts and weight bearing on the hands



- In standing:**
- explain the difference between standing and walking with and without support
  - insisting on the importance of developing good equilibrium and supporting reactions
  - giving advice about the use of walking aids
  - warning about promoting walking to early without the child being ready for it



This can be very enjoyable for the baby but is of no use to teach him walking independently. He doesn't learn to put his weight on his feet and he isn't challenged to use his equilibrium reactions.

It also gives a false idea of safety. Many accidents do happen with this type of walking toy.

Searching with the parents for safe alternatives adapted at the age and the needs of the child is important.



Living with EB isn't an easy task. Babies have a long way to go when they are born. Finding a way in motor development is surely not an easy task for an EB baby and his parents. As therapists our role isn't finished with tonification and mobilisation. Searching together with the parents to comply with the individual needs is a challenge.