



EARLY ACTION, EARLY TREATMENT, SAVES LIVES.

Infant 0 - 6 months \*

## DOES YOUR BABY SHOW SIGNS OF A MOTOR DELAY? EARLY DIAGNOSIS AND EARLY TREATMENT ARE KEY

Developmental delays can be early signs of a serious medical condition. Don't delay. **If you notice any regression or see any signs of a motor delay, *make an appointment with your child's doctor.***

Early diagnosis could mean more life-saving treatment options available to your child. Talk to your pediatrician about your concerns. ***Be persistent with your questions.***

### REGRESSION IS A RED FLAG

If your child suddenly develops any of these signs, please contact your child's pediatrician immediately:

- ▶ Regression: loss of the ability to do things he/she was previously able to do
- ▶ Rarely moves arms and legs
- ▶ Seems excessively loose in the limbs, or floppy
- ▶ See-saw, rattly or wheezy breathing

### TRUST YOUR INSTINCTS

If you feel like something is not quite right with your baby's developmental progress, do not wait to voice your concerns. According to the American Academy of Pediatrics, the overwhelming majority of parental concerns are ***correct and accurate.***

### IS YOUR BABY "BRIGHT EYED?"

Babies with SMA are frequently described as being very bright eyed, engaged and smiling. They appear comfortable, at ease, showing few signs of being upset. This may be even more evident when a baby is fully dressed, covering up some of the physical limitations associated with the disease.

\* Please note, if your child was born prematurely, use his/her adjusted age to ensure that you are using the correct checklist. To calculate the adjusted age, first convert your child's current age to weeks. Next, subtract the number of weeks your child was premature from the current age in weeks. For example, if your child is 20 weeks old, and born 5 weeks prematurely, the adjusted age is 15 weeks.

## CHECK FOR EARLY SIGNS OF MOTOR DELAY

If your baby exhibits one or more of these signs, it may indicate that he/she has a motor delay. Use this checklist to guide your conversation with your pediatrician. **Check all that apply to your child:**

Breathing is very fast; only the belly moves, especially when he/she is lying on his/her back.

Cry is weak (hard to hear his/her cry).

Does not kick his/her legs.

Does not lift his/her legs when lying on his/her back. (No anti-gravity movement).

Unable to independently extend legs, and/or his/her legs often remain in a frog-like position.

Has a bell-shaped chest.

Does not move his/her head from side to side when lying on back.

It takes a long time to complete his/her feedings.

After feeding, breathing sounds rattly or wheezy.

Has trouble lifting his/her head when lying on stomach during tummy time (floppy baby).

When I pick up my child, it feels like he/she will slip out of my hands.

Does not squirm.

Does not move his/her hands to mouth

Does not reach for toys placed in front of him/her.

Seems smaller than other children his/her age and is not gaining weight appropriately.

Has lost the ability to do things he/she was able to do before.

I have concerns regarding my child's movement and development.

Bring your checklist to your next pediatrician visit and discuss what you have observed. If your next appointment is several weeks off, contact the office to make an earlier appointment.

All children develop at their own rate. A positive finding does not mean your child has a motor delay. That said, early diagnosis and early treatment are key. Always consult your pediatrician.

### Visit **SMARtMoves.CureSMA.org**

Watch instructional videos, gain a better understanding of motor delays, hear personal stories of families with SMA and insights from healthcare professionals.

### Questions or concerns?

Contact us at [earlydiagnosis@curesma.org](mailto:earlydiagnosis@curesma.org)

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