

# MY PERSONALIZED DISCUSSION GUIDE

AGE 0-6 MONTHS

Use this discussion guide to help you prepare your conversation with your baby's doctor. The more information they have, they better equipped they will be in providing the best possible care for your baby.



## POOR HEAD CONTROL <sup>1</sup>

- When lying on their back or tummy, my baby struggles to move their head from side to side and lift their head up.<sup>3,4</sup>
- When on their back their head rests on one side of their body with little movement



Age when symptom was first noticed: ..... months

Notes .....

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## WEAK LEGS & ARMS <sup>1,2</sup>

- When lying on their back my baby does not move or lift their arms and legs very much, rarely kicking their legs or moving their arms away from their body <sup>3,5</sup>
- They struggle to reach for things



Age when symptom was first noticed: ..... months

Notes .....

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## FAST BELLY BREATHING <sup>3</sup>

- My baby's breathing is fast, even when they are resting
- When breathing, their belly moves up and down noticeably more than their chest <sup>3</sup>



Age when symptom was first noticed: ..... months

Notes .....

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## DIFFICULTY FEEDING/SWALLOWING <sup>3,5</sup>

- My baby struggles to suck or swallow during feeding <sup>3</sup>
- They are slow during feeding as they struggle to swallow <sup>4</sup>



Age when symptom was first noticed: ..... months

Notes .....

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## WEAK CRY & COUGH <sup>4</sup>

- My baby's cry is difficult to hear and seems weak
- Their cough sounds weak and they cough repeatedly <sup>4</sup>
- Their cough sounds 'chesty'



Age when symptom was first noticed: ..... months

Notes .....

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# MY PERSONALIZED DISCUSSION GUIDE

AGE 6-18 MONTHS

Use this discussion guide to help you prepare your conversation with your baby's doctor. The more information they have, they better equipped they will be in providing the best possible care for your baby.



## WEAK LEGS & ARMS<sup>2</sup>

- My baby's arms and legs are floppy and seem like they lack strength, this is more noticeable in the legs <sup>4,6</sup>
- They find it hard to support themselves using legs when held, and struggle to stand or walk <sup>4,6</sup>
- My baby struggles to reach out and grab or pick up toys



Age when symptom was first noticed: ..... months

Notes .....

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## STRUGGLES TO SIT UNSUPPORTED<sup>4,6</sup>

- When placed sitting upright, my baby struggles to sit still for long and leans forward or to one side <sup>3,4,6</sup>
- My baby finds sitting increasingly difficult and needs help <sup>6</sup>



Age when symptom was first noticed ..... months

Notes .....

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## CAN'T ROLL OVER<sup>6</sup>

- When lying on their back my baby rocks from side-to-side but struggles to roll on to their side, or onto their tummy <sup>6</sup>



Age when symptom was first noticed ..... months

Notes .....

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## SHAKING HANDS<sup>4</sup>

- When holding their arms out, they have minor tremors or shakes seen in their fingers or hands <sup>4</sup>



Age when symptom was first noticed: ..... months

Notes .....

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## SLOW OR LOST PHYSICAL DEVELOPMENT<sup>3,4</sup>

- They are slow to achieve developmental milestones such as sitting without support <sup>3,4,6</sup> and these skills may become more difficult over time <sup>3</sup>



Age when symptom was first noticed ..... months

Notes .....

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## ***ANY OTHER SYMPTOMS NOTICED***

## ***QUESTIONS OR CONCERNS TO ASK MY DOCTOR***

## ***CHECKLIST FOR CONSULTATION***

- Consultation booked
- Completed symptom checklist
- Videos or photos of symptoms to show doctor
- Questions listed for doctor

## ***NOTES DURING CONSULTATION***

### **References:**

1. Markowitz JA, et al. J Obstet Gynecol Neonatal Nurs. 2004;33:12-20.
2. Pera MC, et al. PLoS One. 2020;15(3):e0230677.
3. Kolb SJ and Kissel JT. Neurol Clin. 2015;33(4):831-46.
4. Wang CH, et al. J Child Neurol. 2007;22(8):1027-49.
5. Leyenaar J, et al. Paediatr Child Health. 2005;10(7):397-400.
6. Prior TW, Leach ME, Finanger E. Spinal Muscular Atrophy. 2000 Feb 24 [Updated 2019 Nov 14]. In: Adam MP, Ardinger HH, Pagon RA, et al., editors. GeneReviews® [Internet]. Seattle (WA): University of Washington, Seattle; 1993-2020

