Recommendations for Clinician Communication to Caregivers: The Hammersmith Infant Neurological Examination (HINE) and Cerebral Palsy Diagnosis

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Introducing the HINE:

> *"We want to make sure your child gets the best care. Because of (insert reason), we'd like to do a special check-up called the HINE. It's done by trained doctors and therapists and helps us see if your child might have trouble with learning or growing."*

Introducing the cerebral palsy (CP) Diagnosis:

1. Review the NICU course and any brain imaging results. When explaining these findings, use clear and specific language ("there was bleeding in the part of the brain that controls the left side").

2. Review the examination results at each visit using objective language.

3. Explore the caregiver's current understanding of the diagnosis. Ask about any concerns or expectations and provide resources as appropriate.

4. Suggest neurodevelopmental activities that caregivers can incorporate into daily routines (examples: pull to sitting after diaper changes to promote neck and trunk strengthening).

5. Review care goals with families, focusing on the 'F words': fun, function, family, fitness, friends, and future. Emphasize the importance of these areas in the child's development and well-being and encourage their integration into daily life and long-term plans.

6. Utilize an interdisciplinary approach. If other providers (therapists, social workers, etc.) are not available during the initial discussion, guide caregivers in establishing care and encourage them to ask questions.

7. Ensure the diagnosis is shared with the primary provider (as well as the community-based therapy team if applicable). The primary provider may not have detected the neurological concerns, so this discussion could allow for ongoing education and collaboration.

8. Share evidence-based, trustworthy resources and caution families about possible misinformation found on the internet. Offer counseling and peer mentoring opportunities.

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9. Remain open to discussion of alternative treatment approaches. Providing education on the concept of evidence-based living allows families to identify goals, values, and evaluate their individual resources as it relates to alternative approaches. Evidence-based living instructs families to consider possible interventions, cost associated, goals in the context of family values and resources. This approach allows families to explore options that they may deem important, navigating their own variables of resources and values as it relates to any reported efficacy.

10. Understand that caregivers may display an array of feelings during the conversation. When possible, establish an appropriate way for ongoing communication after the meeting.

Other Considerations:

- Timing: Research has shown that caregivers prefer early diagnoses. In situations where a patient lacks one of the essential components of CP diagnosis but has others, caregivers are also open to the possibility of the “high risk for CP” designation. The evidence suggests that delayed diagnosis increases caregiver frustration and decreases satisfaction.
- Environment: Caregivers report a preference for a private, quiet area. Whenever possible, both caregivers should be present for the conversation, or in the case of a single caregiver, encouraging the presence of another trusted adult for support, but allowing for caregiver preference whether to wait for additional support or not. It is recommended that the messaging comes from a single provider, with time set aside for caregivers to ask questions.
- Content: The literature recommends that the information provided is direct and specific. Caregivers report increased satisfaction when more information is provided, and their specific concerns are addressed. Their satisfaction also increases when the provider is hopeful and supportive.