

Communicating the diagnosis of cerebral palsy or high risk of cerebral palsy

Informing parents and carers of the diagnosis of cerebral palsy or high-risk of cerebral palsy is a difficult process. It is imperative that it is completed in the most sensitive, compassionate and well planned way to optimise outcomes for both parents and children.

The process of parental acceptance of a cerebral palsy diagnosis, grieving, coping and resiliency is ongoing, cyclical and requires a continuum of supports from diagnosticians^{1,2}.

Parents experience grief and loss at the time of diagnosis, or when they are told their infant is at 'high-risk of cerebral palsy'. Emotional experiences at the time of diagnosis can be intense and contradictory, and include anger, fear, relief, confusion, guilt, despair and denial^{1,2}.

For parents, the learning processes inherent in receiving information on the diagnosis can be impacted by various factors including experiential avoidance strategies, actively blocking the recall of bad news in order to cope and processing large quantities of new and complex information^{1,4}. The communication of high-risk cerebral palsy to a family should be conveyed through a series of well-planned and compassionate conversations, rather than a one-time event.

Qualitative evidence indicates many parents are dissatisfied with the diagnostic process³. Common criticisms include the amount of information received at diagnosis; lack of discussion about the likely impact on their child and family; information was unclear and conveyed a pessimistic outlook for the future^{3,5}.

1. Whittingham, Koa, Wee, Diana, Sanders, Matthew R. and Boyd, Roslyn (2013) Sorrow, coping and resiliency: parents of children with cerebral palsy share their experiences. *Disability and Rehabilitation*, 35 17: 1447-1452.
2. Ahmann E. Review and commentary: Two studies regarding giving "bad news". *Pediatric Nursing*. 1998;24(6):554.
3. Baird G, McConachie H, Scrutton D. Parents' perceptions of disclosure of the diagnosis of cerebral palsy. *Arch Dis Child* 2000; 83: 475-80.
4. Jedlicka-Kohler I, Gotz M, Eichler I. Parent's recollection of the initial communication of the diagnosis of cystic fibrosis. *Pediatrics* 1996;97:204.
5. Hummenlinck, A., & Pollock, K. (2006). Parents' information needs about the treatment of their chronically ill child: A qualitative study. *Patient Education and Counseling*, 62(2), 228-234.

Communicating with parents

Best evidence-based communication strategies are recommended when communicating the diagnosis of cerebral palsy or the news about high-risk of cerebral palsy. Data from qualitative interviews suggests the following:

- Provide at least two face-to-face diagnostic information sharing sessions to facilitate comprehension, recall and acceptance.
- Ensure both parents and the infant are present to promote acceptance of the infant.
- Use a quiet, private office.
- Provide the most honest, transparent and specific information about the diagnosis and prognosis as possible and explain the likely impact on the family.
- Use simple, direct and jargon free language.
- Use a hopeful, empathic and supportive tone.
- Tailor the information to the individual infant and the family communication style.
- Provide written information to allow absorption at a later stage.
- Provide information about the child's strengths as well as limitations, to promote development of an optimistic outlook.
- Invite questions.
- Invite discussion about feelings, as this promotes confidence in the parent's ability to cope and increases satisfaction.
- Recommend parent-to-parent and family support; parents indicate this facilitates long-term coping.
- Arrange a debriefing to help parents gather information and navigate service entry.
- Arrange early intervention, preferably initially at higher intensity to help parents come to terms with what is required of them.