



**Dying Without a Voice –**  
*Communication when a child can no longer speak*

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# Dying without a voice

Interviewed 14 families whose child (aged 4 - 16, died 6 mo - 3 yrs prior) lost communicative abilities due to a brain tumour. Asked about:

- ❧ Communication experiences;
- ❧ Suggestions for design of a communication aid;
- ❧ Suggestions for other families and staff.

Team: Physician, Social Worker, Child Life, Speech Language Pathology & Rehabilitation Engineer.

# Handbook: Table of contents

- ❧ Introduction & Quick Tips
- ❧ Communication
  - ❧ Preparing for the unexpected
  - ❧ Different ways to ask questions
  - ❧ *How* to communicate
- ❧ Communication Strategies
  - ❧ Tools, Techniques, Challenges
  - ❧ Deciding what to try, When to introduce/change strategies
- ❧ Communication Topics
  - ❧ Physical; Medical; Emotions; Activities; People & pets; Future, spirituality & death.
- ❧ Supporting children, supporting yourselves
  - ❧ Common struggles; Supporting siblings; Challenges parents faced; Support from others
- ❧ Tools

# When and how to help families?

To acknowledge and prepare, families need us to:

- ☞ Discuss potential loss of function as soon as we know it's possible;
- ☞ Tell them what to look for as signs that the child's abilities are changing;
- ☞ Show them when we see these signs, help them find strategies they can practice even before these strategies are needed, and;
- ☞ help them adapt strategies as needs change.