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Contents

Guidelines:Childhood Brain Tumour Leukaemia

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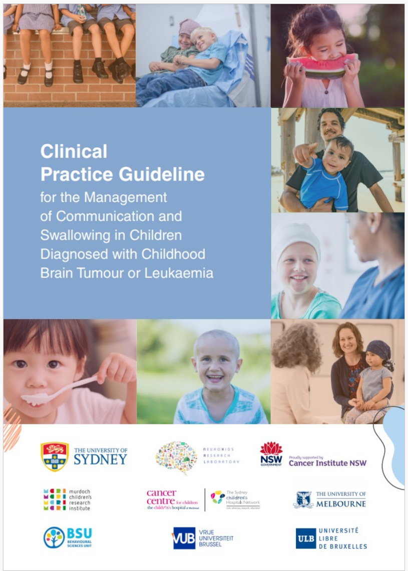

Clinical
Practice Guideline
for the Management
of Communication and
Swallowing in Children
Diagnosed with Childhood
Brain Tumour or Leukaemia

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Organisations involved in producing the guideline:

National Health and Medical Research Council

childhood brain tumour or leukaemia

What are the communication outcomes associated with childhood brain tumour or leukaemia?

Contents

Evidence-based recommendation

GRADE Recommendation?	Grade	Approval
Evidence-based Recommendation 1: Communication Communication assessment and intervention should be offered to children diagnosed with childhood brain tumour or leukaemia.	**Strong**	23-Nov-2020 – 22-Nov-2025

Key practice points

Practice point?

Assessment & Intervention

When to assess

- Communication assessment should occur at or as soon as possible after cancer diagnosis.
- Communication assessment should occur during the oncology treatment phase and oncology follow-up phase. Multiple assessments during these phases may be required if concerns are indicated by the oncology care team and/or family.
- Regular monitoring of the child’s communication development should continue throughout the survivorship phase until end of adolescence.

Practice point?

What to assess

- A comprehensive assessment of speech and language should be conducted. Assessment needs to be tailored to the age and developmental level of the child. Where appropriate, language assessment should include high-level language, discourse-level skills and literacy.
- Assessment should include a range of individualised assessment procedures such as norm-referenced assessments, criterion-referenced tools, care-giver report and clinical observations across environments.

When to intervene

- Children diagnosed with CBTL should be provided with early individualised intervention during the oncology treatment phase for identified communication difficulties.
- Children diagnosed with CBTL should be provided with timely individualised intervention for communication difficulties identified during the oncology follow-up and survivorship phases through until the end of adolescence.

Practice point?

Education

- Education about communication development and difficulties in CBTL should be provided to families at cancer diagnosis or as early as possible.
- Education about communication development and difficulties in CBTL should continue to be provided to families throughout the oncology treatment and follow-up phases.
- Education about potential long-term communication difficulties in CBTL should be provided to families and education professionals throughout the oncology follow-up and survivorship phases.

Practice point?

Care Team

- Speech Pathologists should be involved as integral members of the oncology care team from the point of cancer diagnosis and throughout the oncology treatment and follow-up phases.
- All members of the oncology care team should be informed about communication difficulties and involved in management throughout the oncology treatment and follow-up phases.
- Speech Pathologists should work in partnership with oncologists, family members and education professionals to monitor communication development throughout the survivorship phase until the end of adolescence.

Strength of communication recommendation

The strength of this recommendation was determined through the use of the GRADE Evidence to Decision (EtD) Framework. The EtD framework provided a structured approach to determine the strength of recommendation, integrating the systematic review findings with pre-specified criteria. The Steering Committee provided input throughout the process. Further detailed information about the EtD process and the complete EtD framework for communication can be found in the accompanying Administrative & Technical Report (Table 9).

Based on the results of the GRADE EtD Framework, this recommendation was rated as strong. This means that the Steering Committee was confident that the desirable effects of adherence to the recommendation outweighed the undesirable effects. The implications of a strong recommendation for patients, clinicians and policy makers as identified by GRADE[1] are:

- for patients — most people in your situation would want the recommended course of action and only a small proportion would not; request discussion if the intervention is not offered;
- for clinicians — most patients should receive the recommended course of action; and
- for policy makers — the recommendation can be adopted as a policy in most situations.

Evidence for communication recommendation

The communication recommendation made in this guideline calls for communication assessment and intervention to be offered to children diagnosed with childhood brain tumour or leukaemia (CBTL). This is required because communication difficulties are frequently reported in children diagnosed with CBTL (see Summary of Findings – Communication; Administrative & Technical Report, Table 8). Communication difficulties may be present for some children at the time of cancer diagnosis (e.g. Chieffo et al;[2] Mei & Morgan[3]) and/or during the cancer treatment phase (e.g. Brannon-Morris et al;[4] Taylor et al[5]). However, communication difficulties may also be seen in the longer-term, months or years after the completion of cancer treatment (e.g. Docking et al;[6] Levy et al[7]).

Communication difficulties have been shown across the areas of both speech and language (see Summary of Findings − Communication; Administrative & Technical Report, Table 8). Dysarthria or specific speech difficulties have been reported in this population such as prosodic problems,[8][2][9][10][11] poor articulation/ speech intelligibility,[8][2][12][10][11][13] slow rate,[8][12][9][13] and voice problems.[8][5][12][10][11][13][14][15][16] Fluency difficulties have also been identified.[2][15][17] Mutism and/or dysarthria following surgery for cerebellar tumours surgery are well documented as part of post-operative cerebellar mutism syndrome (pCMS)[8][3][12][4][9][10] [11][13][14][15][16] [17][18][19][20][21][22][23][24][25][26][27][28][29][30][31][32][33] For some children, mutism may resolve to dysarthria and/or language difficulties.[3][9][13][16][20][25][29][31][32] In the leukaemia population, specific speech difficulties have not been identified, but general difficulties in speech have been reported.[5][7]

For language, a range of difficulties have been identified including general oral language skills,[34][8][5][2][35][6][7][9][6][20][21][22] [24][31][32][36][37][38][39][40] problems with word-finding,[9][20][37] narrative (story-telling) skills[41] and high-level language skills (such as inferencing, metaphors, jokes, and problem solving).[41][42][6][38][39][40][43] Literacy difficulties (pre-literacy skills, reading, writing, spelling) have also been reported.[8][42][6][6][44][45][46]

A strength of the literature evidence is that it unambiguously demonstrated the existence of communication difficulties in this population. However, there are a number of distinct limitations related to this body of evidence. First, there has been a reliance on descriptive study designs with small sample sizes. Second, heterogeneity across the literature in study design, participant factors, outcome measures and timing of assessment makes it impossible to determine the prevalence of communication difficulties in this population. Third, there is limited evidence related specifically to children with leukaemia.

In addition to literature evidence, the need for communication assessment and intervention in children diagnosed with CBTL was recognised in evidence systematically gathered from experts, health professionals and consumers. Communication skills were identified as foundational with significant impacts on quality-of-life and related outcomes such as academics, social connectedness and mental health. The potential for cascading effects into adulthood with implications for employment and participation in society was also highlighted.

This source of evidence also emphasised the need to consider diversity in the CBTL population when providing communication management. In the Health Professional and Consumer survey, consideration of risk factors was seen to be particularly important. Identified risk factors included child factors (e.g. age, socio-economic background, hospital stay), tumour properties (e.g. cancer location, brain tumour size) and cancer treatment (e.g. treatment type/combination, frequency) (see Administrative & Technical Report, Box C). Given the inherent diversity in this population, communication assessment and intervention should be offered to all children diagnosed with CBTL in the context of an individualised approach to management.

The desirable effects of providing communication assessment and intervention were rated by the Steering Committee (panel of experts) as large. The desirable effects focused on the improved communication outcomes that could be achieved if assessment and intervention was routinely offered to all children and the downstream benefits on quality-of-life, particularly for social and academic participation. The undesirable effects were rated as small. These related to feelings of stress, worry or frustration that could be experienced by the child or family in relation to testing and communication being “just one more thing to worry about”. Desirable effects were overwhelmingly rated as outweighing undesirable effects.

Evidence for key practice points

Assessment & intervention

When to assess

Assessment of communication needs to occur when a child is first diagnosed with brain tumour or leukaemia, during their cancer treatment and during oncology follow-up. Continued close monitoring by family and health professionals that have regular contact with the child should continue throughout during the survivorship years. This is because children diagnosed with CBTL may experience communication difficulties at one or more points in time across their oncology care and/or during the survivorship years (see Administrative & Technical Report, p. 20–21). Mutism and speech difficulties have mostly been studied and reported on in the shorter-term, while language difficulties have primarily been studied and reported on in the longer-term.

The importance of assessing regularly over time was also supported by the evidence collected from the experts, health professionals and consumers. In the Health Professional and Consumer survey, the need for regular communication assessment at crucial points across childhood was identified (see Administrative & Technical Report, p. 68–69). A clear message seen in both the survey of health professionals and consumers and Steering Committee (panel of experts) comments was that communication outcomes would likely be improved and deleterious effects minimised if assessment and monitoring over time was routinely implemented. In Figure 5, the key practice points regarding assessment timing are embedded in the ‘timing and setting framework’, illustrating direct communication assessment across the first three phases and close monitoring and referral to Speech Pathology services if needed during the survivorship phase.

What to assess

A broad range of communication difficulties may be experienced by children diagnosed with CBTL, across speech and language (see Summary of Findings − Communication; Administrative & Technical Report, Table 8). Therefore, it is crucial that comprehensive communication assessment is provided, taking into consideration the developmental level of the child, functional needs and family priorities. The literature evidence highlighted that a variety of assessment tools such as norm-referenced, criterion-referenced, care-giver report and observation across environments could be beneficial in understanding the nature of difficulties in this population (see Administrative & Technical Report, p. 20). The importance of comprehensive assessment was reflected in the health professional and consumer survey evidence where it was rated as very or extremely important by the majority of respondents (see Administrative & Technical Report, p. 68). Figure 6 outlines areas of communication that may need to be considered by the Speech Pathologist when planning a comprehensive communication assessment. This, of course, is dependent on the age of the child and priorities for the child /family.

Figure 5 When to assess and when to monitor communication skills in CBTL

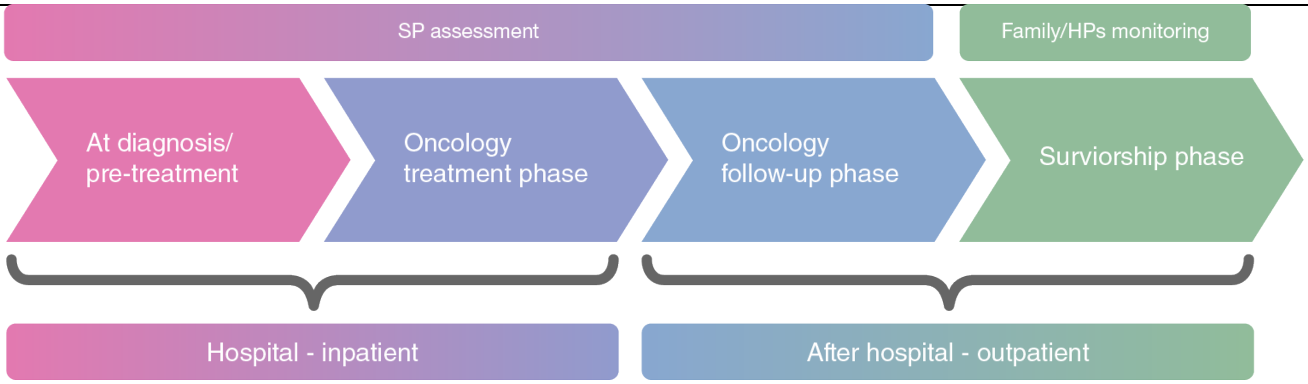
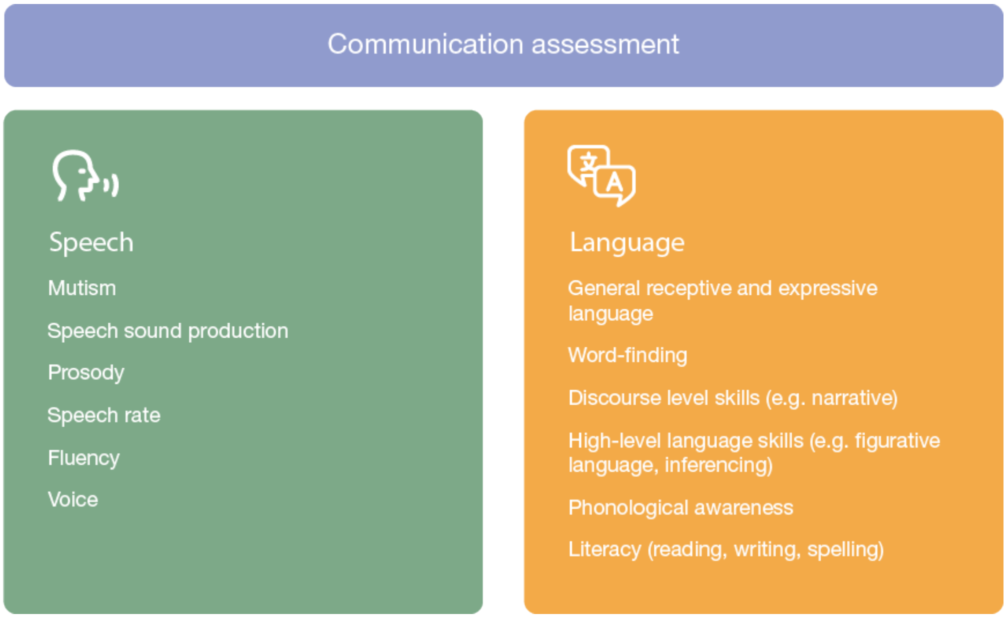


Figure 6 Areas of communication to be considered for assessment in CBTL



When to intervene

Timely individualised intervention is crucial for children diagnosed with CBTL with identified communication difficulties. Given the broad range of speech and/ or language difficulties that may be encountered across oncology phases (see Summary of Findings – Communication; Administrative & Technical Report, Table 8), intervention services need to be accessible across oncology care and into survivorship. Regular comprehensive communication assessment and monitoring across phases in the ‘timing and setting framework’ can ensure that timely intervention is provided to those children with identified difficulties. The importance of intervention as required was supported by the health professional and consumer evidence (see Administrative & Technical Report, p. 69). In particular, early intervention, that is, intervention soon after cancer treatment, was raised as crucial in improving communication outcomes. Moreover, ensuring availability of intervention services across oncology phases, including for those children who may have milder difficulties, was discussed.

Care team

Communication difficulties are likely to be experienced by children with CBTL over time (see Administrative & Technical Report, p. 20–21) and therefore Speech Pathologists, as experts in communication development and disorders, are crucial members of the oncology care team both acutely and into the longer-term. The importance of the Speech Pathologist in the care team was reinforced by the health professional and consumer group evidence (see Administrative & Technical Report, p. 69, & Table 11). Overwhelmingly, Speech Pathologists were identified as the health professional most commonly involved in the management of communication difficulties, recognised for their direct role in assessment and intervention.

Multidisciplinary care teams were highlighted by health professionals and consumers as essential for the successful management of communication in children diagnosed with CBTL (see Administrative & Technical Report, p. 69, Table 11). A range of multidisciplinary team (MDT) members were identified as serving in the management of communication disorders. The most commonly identified team members included Speech Pathologists, Occupational Therapists, Education professionals, Neuropsychologists, Psychologists, Medical staff, Paediatricians, Nurses, Physiotherapists, Child Life Therapists, Oncologists, as well as families. The roles of each member were varied and included collaboration with the Speech Pathologist, implementing recommendations from the Speech Pathologist, consulting with the Speech Pathologist and family about related factors that may underlie or affect communication, facilitating and guiding overall rehabilitation as well as monitoring skills and advocating for the needs of the child.

Education

Communication difficulties in children diagnosed with CBTL are complex. A wide range of difficulties may be experienced from trouble with producing clear speech, to difficulties with reading and writing (see Summary of Findings − Communication; Administrative & Technical Report, Table 8). The functional impacts of such difficulties may also present in varied ways such as finding it hard to make friends or keep up with schoolwork. An additional complicating factor is that difficulties may be experienced across oncology phases (see Administrative & Technical Report, p. 20–21). Given this multi-layered complexity, education for families is crucial. This education needs to be provided early and continued over time. It needs to cover the common communication difficulties that may be experienced by children with CBTL and the potential for communication difficulties to continue or arise in the longer-term. This will provide families and teachers greater awareness and knowledge allowing them to identify communication needs that may arise, make referrals and advocate for the needs of the child, whether it be weeks after their cancer treatment or many years later. Evidence from the experts, health professionals and consumers also underscored the importance of education for families. The Steering Committee (panel of experts) identified that the value placed on communication by families may differ depending on the education/information they have received from health professionals. Families need to be informed about the importance of communication and the potential for communication difficulties as a consequence of CBTL. This will support them to make informed decisions and advocate for the needs of their child. In the survey, families as well as education professionals were identified as key members of the care team with particularly important roles related to day-to-day communication as well as monitoring and advocating (see Administrative & Technical Report, Table 11). However, in order to successfully take on these roles, it is essential that they receive appropriate education regarding communication development and disorders and their impact on academic and social skills.

Implications for clinical practice

There are important considerations in planning for the adoption of this guideline. In addition to guiding the process from research to recommendation, the GRADE EtD provided valuable context about the likely impact of this recommendation on clinical practice. As part of the GRADE EtD framework, the Steering Committee (panel of experts) considered five factors that weigh the risk versus benefit of recommendations. Specifically, these considerations included: resources required, cost effectiveness, equity, acceptability and feasibility. The implications on clinical practice described in Table 2 are based upon the detailed information provided in the GRADE EtD framework (see Administrative & Technical Report, Table 9).

Table 2 Implications of communication recommendation for clinical practice

Implications for clinical practice	Summary of judgements and comments from GRADE EtD Framework
Resources Required	**Costs and Savings** The Steering Committee determined it is likely that there would be both costs and savings related to offering communication assessment/intervention to all children diagnosed with CBTL. Possible costs in the short-term may relate to the employment and upskilling of staff. However, there are potential long-term savings for the health sector, disability sector, education sector and families due to reduced impact of communication difficulties long-term.
Cost Effectiveness	**Favours providing assessment/intervention** The Steering Committee determined that communication assessment/intervention would be more cost effective compared to no communication assessment/intervention. The short-term costs of offering communication/intervention are likely to be small compared to long-term costs of treating more established disorders later in development. The cost benefits also extend to psychological, educational and employment outcomes.
Equity	**Increased** The Steering Committee determined that equity would be likely to be increased if communication assessment/intervention was offered to children diagnosed with CBTL. If the recommended minimum standard via a national guideline was implemented, communication assessment/intervention would become routine. This would allow greater access to communication assessment/intervention, regardless of factors such as cultural and linguistic diversity, non-English speaking backgrounds, socio-economic status, geographical location and education levels.
Acceptability	**Yes** The Steering Committee determined that offering communication assessment/intervention would be acceptable to the majority of stakeholders, including families and health professionals.

Feasibility	**Yes** The Steering Committee determined that offering communication assessment/intervention would be feasible to incorporate into current services. There are few issues with regards to feasibility, except for funding and staffing resources. Note: Feasibility was considered by the Steering Committee prior to COVID-19. It is acknowledged that the financial impacts of this pandemic may last several years. However, it has since been considered that implementing this recommendation from a cost perspective within the current climate remains feasible.

Future research directions

There is a clear need for larger-scale studies with prospective-longitudinal research designs examining communication outcomes and intervention in children diagnosed with CBTL.[47] In particular, additional research focusing on communication outcomes in children diagnosed with leukaemia is warranted. This includes further examination of communication difficulties longitudinally across all timepoints and settings (e.g. diagnosis, during oncology treatment, oncology-follow-up and survivorship). Research co-designed with consumer partners that specifically focus on communication outcomes of children from culturally, linguistically, socially, and geographically diverse communities will also ensure continued progress towards equitable and accessible services across all populations of children diagnosed with CBTL. Greater accuracy in identifying prevalence of communication difficulties in children diagnosed with CBTL is also needed, as are larger-scale studies focusing on effectiveness of communication rehabilitation programs.[47]

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What are the swallowing outcomes associated with childhood brain tumour or leukaemia?

Contents

Evidence-based recommendation

GRADE Recommendation?	Grade	Approval
Evidence-based Recommendation 1: Swallowing Swallowing assessment and management should be offered to children diagnosed with childhood brain tumour or leukaemia.	**Strong**	23-Nov-2020 – 22-Nov-2025

Key practice points

Practice point?

Assessment & Intervention

When to assess

- Swallowing assessment should occur at or as soon as possible after diagnosis of CBTL.
- Swallowing assessment should occur during the oncology treatment phase.
- Multiple assessments may be required where concerns are indicated by the oncology care team and /or family. Regular monitoring of the child's swallowing should continue throughout the oncology follow-up and survivorship phases until end of adolescence.

What to assess

- A comprehensive swallowing assessment should be conducted. Assessment needs to be tailored to the age and developmental level of the child. All phases of the swallow (pre-oral anticipatory, oral-preparatory, oral and pharyngeal) need to be assessed.
- Videofluoroscopy Swallowing Study (VFSS) should be considered on a case-by-case basis as part of the assessment protocol to examine aspiration if required.

When to intervene

- Children diagnosed with CBTL should be provided with early individualised management for swallowing difficulties during the oncology treatment phase.
- Children diagnosed with CBTL should be provided with individualised management for swallowing difficulties identified by the oncology care team and/or family in the oncology follow-up and survivorship phases.

Practice point?

Care Team

- Speech Pathologists should be involved as integral members of the oncology care team from the point of cancer diagnosis and throughout the oncology treatment phase to manage swallowing.
- All members of the oncology care team should be informed about swallowing difficulties and involved in their management as needed throughout oncology phases.
- Speech Pathologists should work in partnership with oncologists and family members to monitor swallowing throughout the survivorship phase until the end of adolescence.

Practice point?

Education

- Education about swallowing difficulties in CBTL should be provided to families at cancer diagnosis or as early as possible.
- Education about swallowing difficulties in CBTL should continue to be provided to families throughout the oncology treatment and follow-up phases.

Strength of recommendation

The strength of this recommendation was determined through the use of the GRADE EtD Framework. The EtD framework provided a structured approach to determine the strength of recommendation, integrating the systematic review findings with pre-specified criteria. The Steering Committee provided input throughout the process. Further detailed information about the EtD process and the complete EtD framework for swallowing can be found in the accompanying Administrative & Technical Report (Table 10).

Based on the results of the GRADE EtD Framework, this recommendation was rated as strong. This means that the Steering Committee was confident that the desirable effects of adherence to the recommendation outweighed the undesirable effects. The implications of a strong recommendation for patients, clinicians and policy makers as identified by GRADE[1] are:

- for patients — most people in your situation would want the recommended course of action and only a small proportion would not; request discussion if the intervention is not offered;
- for clinicians — most patients should receive the recommended course of action; and
- for policy makers — the recommendation can be adopted as a policy in most situations

Evidence for swallowing recommendation

The swallowing recommendation made in this guideline calls for swallowing assessment and management to be offered to children diagnosed with childhood brain tumour or leukaemia (CBTL). This is vital because swallowing difficulties are frequently reported in children with CBTL (see Summary of Findings – Swallowing; Administrative & Technical Report, Table 8). Difficulties are most likely to be experienced during oncology treatment (e.g. Goncalves et al[2]; Newman et al[3]). For some children diagnosed with CBTL, particularly those children diagnosed with brain tumour, swallowing difficulties may continue into the longer-term (e.g. Brannon Morris et al;[4] Mei & Morgan[5]).

Acute swallowing difficulties in children with CBTL are typically characterised by difficulties across the oral preparatory and oral phase (e.g. reduced lip seal, food/ liquid residue post-swallow, food spillage/drooling, impaired transfer of food in mouth) and the pharyngeal phase (e.g. initiation of swallow delayed, food/liquid residue in pharynx, coughing/gurgly voice, aspiration) of the swallow.[6][5][7] General clinical factors or pre-oral anticipatory factors that can impact swallowing ability such as fatigue and alertness/awareness may also be affected[5][7] and therefore need to be assessed. During the time when children are receiving cancer treatment, swallowing difficulties can be severe, with aspiration of food or liquids possible.[8][3] As a result, supplemental tube feeding may be required.[6][5][7][9][4]

It was clear from the literature evidence that swallowing difficulties exist in children with CBTL and are frequently seen immediately or soon after cancer treatment. However, there are limitations in the body of evidence that need to be considered. To date, studies have relied on descriptive designs and relatively small samples. Heterogeneity across studies in relation to participant factors, outcome measures and timing of assessments limit the ability to draw conclusions about the prevalence of swallowing difficulties in this population. Furthermore, there is a paucity of evidence related specifically to the swallowing outcomes of children with leukaemia.

The need for swallowing assessment and management for children diagnosed with CBTL was reflected in evidence systematically gathered from experts, health professionals and consumers. The possibility for swallowing difficulties to result in aspiration and to be life-threatening was emphasised. Ensuring adequate nutrition in the acute period was also highlighted. Longer-term swallowing difficulties and their potential to influence quality-of-life were also recognised such as the impact on independence, family mealtimes and social eating/fitting in with peers at school.

This source of evidence also emphasised the need to consider diversity in the CBTL population when providing swallowing management. In the Health Professional and Consumer survey, consideration of risk factors was seen to be particularly important. Identified risk factors included child factors (e.g. age, socio-economic background, hospital stay), swallowing-related factors (e.g. prolonged tube feeding, poor physical positioning), tumour properties (e.g. cancer location, brain tumour size) and cancer treatment (e.g. treatment type/ combination, frequency) (see Administrative & Technical Report, Box C). Given the inherent diversity in this population, swallowing assessment and management should be offered to all children diagnosed with CBTL in the context of an individualised approach.

The desirable effects of providing swallowing assessment and management were rated by the Steering Committee (panel of experts) as large. The desirable effects focused on the safe swallowing of fluids and food and the prevention of aspiration and subsequent health complications such as chest infections and pneumonia. The undesirable effects were rated as small and related to the potential for stress/anxiety related to assessment for children and family. The desirable effects were rated as outweighing the undesirable effects.

Evidence for key practice points

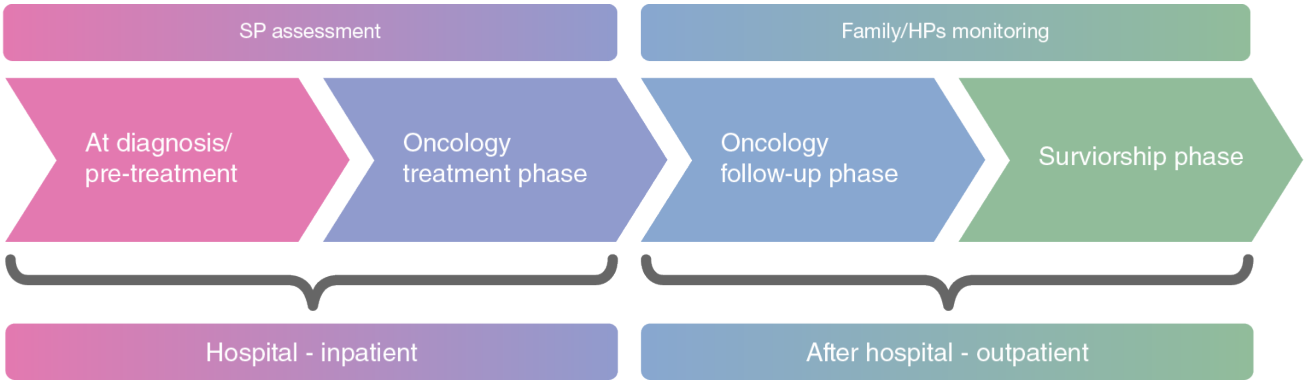
Assessment & intervention

When to assess

Swallowing assessment is vital at cancer diagnosis and during the oncology treatment phase. Research has identified that swallowing difficulties are frequent during these phases.[6][5][7][8][3][9][10][2][11][12][13] During oncology follow- up and survivorship, continued close monitoring of swallowing by family and involving health professionals with referral as needed is warranted given some evidence of longer-term swallowing impacts.[5][7][9][10][11]

The evidence from experts, health professionals and consumers also supported the need for swallowing assessment to occur in the acute phases. One member of the Steering Committee (panel of experts) reported that the assessment of swallowing should be as commonplace as measuring temperature during the post-operative period. The importance of safe swallowing and the need to minimise the risk of aspiration and subsequent chest infections/pneumonia during oncology treatment were key themes in the committee’s discussion. Regular swallowing assessment and/or monitoring was viewed as necessary by the majority of health professionals and consumers in the survey results and was thought to contribute to improved swallowing outcomes (see Administrative & Technical Report, p. 69). In Figure 7, key practice points regarding timing of swallowing assessment are embedded in the ‘timing and setting framework’.

Figure 7 When to assess and when to monitor swallowing skills in CBTL



What to assess

Given that swallowing difficulties may be across multiple phases of swallowing,[6][5][7] comprehensive assessment that examines pre-oral anticipatory factors such as alertness and awareness, oral-preparatory, oral and pharyngeal phases of the swallow is needed. The systematic review of the evidence revealed most swallowing assessments were conducted via clinical observation with or without a specific checklist (see Administrative & Technical Report, p. 20). Five studies included a Videofluoroscopy Swallowing Study (VFSS) in the assessment of children with CBTL to identify aspiration[5][8][3][9][11] indicating that it may be a useful tool to consider as part of assessment for this population. The rationale for performing VFSS was not definitive in the literature. Thus, Speech Pathologists should be guided by the findings from bedside assessment and their clinical judgement and expertise to make decisions about the need for VFSS on a case-by-case basis. The provision of comprehensive swallowing assessment for children diagnosed with CBTL was seen as important by the majority of the health professionals and consumers and related to improved swallowing outcomes for this population (see Administrative & Technical Report, p. 69).

When to intervene

Given that children with CBTL are likely to show evidence of swallowing difficulties at diagnosis and/or during oncology treatment (see Summary of Findings – Swallowing; Administrative & Technical Report, Table 8), immediate management is needed at these early oncology phases for those with identified difficulties following assessment. This was reflected in comments from the experts, health professionals and consumers who overwhelmingly recognised the need for swallowing management during the acute phases of diagnosis and cancer treatment. They identified that appropriate management would result in improved swallowing outcomes and reduce longer-term adverse effects related to medical health and quality of life.

In the oncology follow-up and survivorship phases, some children diagnosed with CBTL may require direct swallowing management as research evidence shows persistent difficulties can be possible, although limited in the length of follow-up.[5][7][9][4][11] In such cases, monitoring and identification of swallowing difficulties by the oncology care team and/or family is crucial. It is important that those responsible for monitoring can refer to Speech Pathology services for swallowing assessment and decisions regarding management can subsequently be made on a case-by-case basis.

Care team

Speech Pathologists have expertise in the assessment and management of swallowing and therefore should be integral to the oncology care team. Health professional and consumer survey evidence supported this, with Speech Pathologists the most frequently identified member required as part of the team in the management of swallowing (see Administrative & Technical Report, p. 69 and Table 12).

The importance of multidisciplinary care teams in joint management of swallowing was also identified by the Health Professional and Consumer Group (see Administrative & Technical Report, p. 69). In particular, they acknowledged the essential roles of dietitians and doctors in assessing nutritional status/needs and recommending/providing supplemental feeding options. The role of doctors, nurses, oncologists, psychologists, paediatricians as well as family in the monitoring of overall clinical state and day-to-day swallowing functioning was highlighted.

Education

Considering the potentially life-threatening consequences of swallowing difficulties and possible long-term quality of life impacts, it is crucial that families of children with CBTL receive appropriate education about the nature and course of such difficulties. Education about aspiration and its medical consequences, safe swallowing practices, food/fluid consistencies, supplemental feeding and the importance of monitoring swallowing into the long-term is needed. As swallowing difficulties are most likely evident during the acute oncology phases (see Administrative & Technical Report, p. 20–21), education needs to be provided at or soon after cancer diagnosis, with continued education throughout oncology treatment. Upon hospital discharge, education about the potential for long-term swallowing difficulties and management and the role of the family in monitoring and referral is needed. One member of the Steering Committee (panel of experts) recognised that the value placed on swallowing assessment and management may be influenced by how well-informed they have been, thus, emphasising the key role of education about swallowing in this population.

Implications for clinical practice

There are important considerations in planning for the adoption of this guideline. In addition to guiding the process from research to recommendation, the GRADE EtD provided valuable context about the likely impact of this recommendation on clinical practice. As part of the GRADE EtD framework, the Steering Committee (panel of experts) considered five factors that weigh the risk versus benefit of recommendations. Specifically, these considerations included: resources required, cost effectiveness, equity, acceptability and feasibility. The implications on clinical practice described in Table 3 are based upon the detailed information provided in the GRADE EtD framework (see Administrative & Technical Report, Table 10).

Table 3 Implications of swallowing recommendation for clinical practice

Implications for clinical practice	Summary of judgements and comments from GRADE EtD Framework
Resources Required	**Negligible costs** The Steering Committee determined that there were negligible costs related to offering swallowing assessment/management to children diagnosed with CBTL. They recognised that the resources to provide assessment and management in the acute phases were already available, however, longer-term follow-up could require additional resources in relation to staff, education and assessment tools. Health professionals time was the main resource identified.

Implications for clinical practice	Summary of judgements and comments from GRADE EtD Framework
Cost Effectiveness	**Favours providing assessment/management** The Steering Committee determined that swallowing assessment/management would be more cost effective compared to no swallowing assessment/management. Providing management was seen as outweighing the potential negative impacts of swallowing difficulties related to aspiration, chest infection and hospital stay length.
Equity	**Increased** The Steering Committee determined that equity would be likely to be increased if swallowing assessment/management was offered to children diagnosed with CBTL. In particular, equity may be increased for children from non-English speaking backgrounds or lower socio-economic backgrounds where families may be less able to identify swallowing difficulties or advocate for needs. One member of the Steering Committee noted that more targeted approaches to identifying which children need swallowing assessment/management would be preferable to the current “status-quo”.
Acceptability	**Yes** The Steering Committee determined that offering swallowing assessment/management would be acceptable to the majority of stakeholders, including families and health professionals.
Feasibility	**Yes** The Steering Committee determined that offering swallowing assessment/management would be feasible to incorporate into current services. However, they did recognise that this would depend on funding and staffing resources. It was recognised that it is not onerous and mostly requires time from the Speech Pathologist. Note: Feasibility was considered by the Steering Committee prior to COVID-19. It is acknowledged that the financial impacts of this pandemic may last several years. However, it has since been considered that implementing this recommendation from a cost perspective within the current climate remains feasible.

Future research directions

There is a clear need for larger-scale studies with prospective-longitudinal research designs examining swallowing outcomes and intervention in children diagnosed with CBTL.[14] In particular, additional research focusing on swallowing outcomes in children diagnosed with leukaemia is warranted. This includes further examination of swallowing difficulties longitudinally across all timepoints and settings (e.g. diagnosis, during oncology treatment, oncology-follow-up and survivorship). Research co-designed with consumer partners that specifically focus on swallowing outcomes of children from culturally, linguistically, socially, and geographically diverse communities will also ensure continued progress towards equitable and accessible services across all populations of children diagnosed with CBTL. Greater accuracy in identifying prevalence of swallowing difficulties in children diagnosed with CBTL is also needed, as are larger-scale studies focusing on effectiveness of swallowing rehabilitation programs.[14]

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About this guideline

Organisations Responsible

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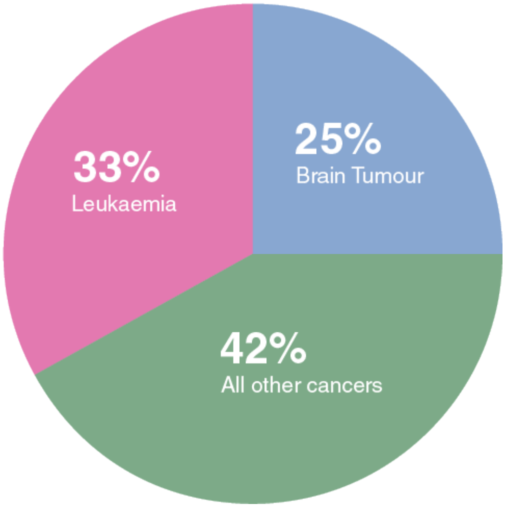
Background

Contents

Incidence of childhood brain tumour/leukaemia

Childhood brain tumour and leukaemia are the leading forms of cancer in children in Australia and developed countries worldwide.[1][2][3][4][5] Leukaemia is frequently reported as the most common cancer in children, representing approximately one-third of all diagnosed cancers[4][6] (see Figure 3). This is closely followed by brain tumours, the most common of all solid tumours in children. Brain tumours are commonly reported to represent one- quarter of all cancers in children in Australia.[1][2][7][4][6] In Australia, approximately 240 children are diagnosed with leukaemia every year, and 192 with brain tumour.[4] Forty-five percent of new cases of childhood brain tumour are in young children aged 0–4 years.[8] In the United States (US), brain and other central nervous system (CNS) cancers are more common than leukaemia in children in the 0–14 year age group.[3] Presentation, histology, and diagnosis of a brain tumour or leukaemia in childhood provides important insight into the progression, incidence, location, accompanying symptoms and complications, malignancy, and the treatments required to halt, remove, or cure it. The most common brain tumour type in children is widely reported to be the astrocytoma with an incidence rate of 30–50%.[9] The five-year survival rate for astrocytomas is reported to be 84%.[6] Most prevalent is the juvenile pilocytic astrocytoma, which is a solid tumour currently with a ten-year survival rate of 96%.[10][11][12][13][14][15][16][17] This brain tumour type commonly arises in the posterior fossa region in the brain, which includes the cerebellum, brain stem, and fourth ventricle. Sixty percent of all childhood brain tumours are located in the posterior fossa.[10][13][14][15][16] Males are more likely to develop an astrocytoma compared to females.[15] The next most frequently occurring brain tumour types in children are the medulloblastoma and the ependymoma; both malignant tumours with an incidence of 15–20% and 5–15% respectively.[15] [16][18][19] Five-year survival rates for medulloblastomas have been reported at 69%,[20] and 72% for ependymomas.[6] A slight male predominance is reported for both malignant types.[21][6] Other common brain tumour types include craniopharyngiomas (4–7%), followed by supratentorial primitive neuroectodermal tumours (PNETs), visual pathway gliomas, choroid plexus tumours, pineal area tumours, and brainstem tumours.[22][15][16]

Figure 3 Incidence of childhood cancers[1][7][4][6]



The most common leukaemia type in children is acute lymphoblastic leukaemia (ALL), accounting for more than 78% of diagnoses, followed by acute myeloid leukaemia (AML) at 16%.[9][23][24][25] Children diagnosed with ALL have a higher five-year survival rate of 93%, with 76% for AML.[6] Survival rates are similar across both genders.[6]

The occurrence of childhood brain tumour or leukaemia (CBTL) in children shows wide diversity. For example, tissue origin for brain tumours, location within the central nervous system (CNS), and natural history in terms of growth rate and tumour dissemination.[26] Resulting effects of CBTL are also greatly influenced by the age of the child at presentation. In particular, children aged less than 3 years of age at the time of CNS cancer treatment are considered to be at greatest risk for late effects due to the immature stage of their brain development.[21] Inherently, a great challenge exists in the management of CBTL in regard to the developing brain, in addition to a need to respect the long-term function of the CNS.[21][27][28]

Time to diagnosis rates are also one of the difficulties associated with paediatric diagnoses. This includes issues with early detection and accurate acknowledgement of early generalised, non-specific symptoms and insidious onset.[29][30][31] Increased detection rates and more widely adopted and routinely administered diagnostic imaging practices have contributed to increases in incidence rates,[14] particularly those seen in Australia and other developed countries worldwide.

However, continual improvements in imaging, neurosurgical techniques, radiobiographical knowledge of CNS radiation tolerance, and advances in chemotherapy and implementation of CNS prophylaxis, have resulted in improved treatment strategies and survival rates for brain tumours and ALL.[21][32] [24][25][26][27][28][33][34]

Additionally, late sequelae that can occur as a result of treatment for CBTL is now routinely recognised, with effects on cognitive, neuroendocrine, and neuropsychological systems being evaluated critically and minimised where possible.[21]

Impact of childhood brain tumour/leukaemia on communication and swallowing

While cancer treatment is essential for survival, the developing brain is extremely fragile and susceptible to the effects of treatment required to treat brain cancer and leukaemia.[35][36] In fact, many effects resulting from CNS-targeted treatment are not realised until many years later,[12][37][38][39][40] with persistent impact on subsequent development and communication skills in particular, due to late-occurring structural and functional changes in the brain.[24][41][42] These changes are progressive and often irreversible and can appear any time up to 10–20 years post-treatment, interrupting normal development in children who face the largest proportion of their lives post-survival.[43][36] Even though modern treatment protocols have changed over the decades to reduce negative effects from CNS targeted treatments, such as phasing out the use of cranial radiotherapy for ALL and adopting CNS-targeted chemotherapy, not all negative treatment effects have been avoided.[44][24]

Children diagnosed with CBTL are at risk of a range of communication difficulties, from difficulties with producing clear speech, to understanding instructions, using vocabulary, producing sentences and grammar, and reading and writing.[12][24][37] [45][46][47][48][49][50][51] Children who are treated surgically for a brain tumour in the cerebellum are also at-risk of developing post-operative cerebellar mutism syndrome (pCMS), which involves a phase of mutism, or a total loss of speech, followed by speech and language difficulties.[52][53] [54][55][56][57]

The impact of these communication difficulties on a child/adolescent's ability to participate in everyday life can be vast. They may find it harder to learn to talk as toddlers, tell stories, solve problems, make friends, understand jokes, succeed at school, get their first job or date. Survivors remain highly at-risk for developing communication difficulties well after cancer treatment is completed. Skills that are yet to develop are most vulnerable, with these children failing to develop skills at the expected rate over time after CNS cancer treatment.[43][42] However, early intervention can minimise or prevent communication and swallowing difficulties if identified early.[12] [50][57][58][59][60][61]

Children diagnosed with CBTL also commonly experience swallowing difficulties.[62] These difficulties may look like: trouble with chewing and biting, difficulty clearing food from the mouth effectively, difficulty with different food and fluid consistencies, fatiguing during eating, uncoordinated swallowing, or not coughing to bring up food. Swallowing difficulties frequently occur during oncology treatment, however, they may also exist into the longer-term.[50][58] Swallowing difficulties can have life-threatening impacts related to choking and chest infections.[58] Poor management of swallowing can lead to malnutrition and compromise development.[62] Swallowing difficulties also have significant participation impacts for these children/adolescents such as the ability to engage in family mealtimes and eat out with friends.

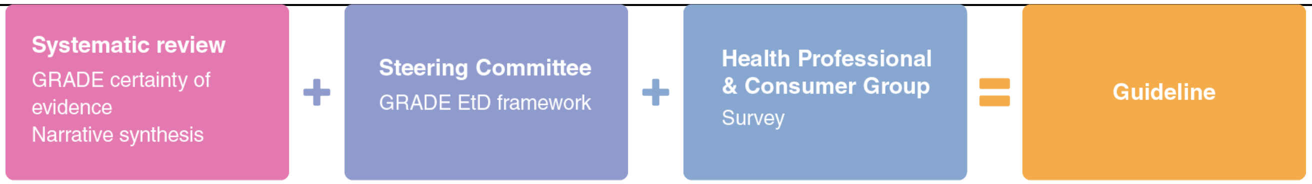
While this guideline focuses on management in children, the impact of communication and swallowing difficulties on quality of life beyond childhood, adolescence, and into adulthood is also acknowledged for this population if they are not managed. Adult survivors of cancer may experience barriers to educational achievement as well as an impact to mental health, vocational independence and earning potential.[63][64][65] The long-term burden of CBTL can weigh on families, communities, and the health system, including costs that are associated with primary and ongoing healthcare services.[63][64]

Evidence that informed the guideline

The two main recommendations presented in this guideline are evidence-based. They have been informed by three sources of evidence as depicted in Figure 4:

1. Systematic review of the literature: GRADE Certainty of Evidence ratings and narrative synthesis methods were employed
2. Input from a Steering Committee comprised of research/ clinical experts and a consumer via the GRADE Evidence to Decision (EtD) Framework
3. Input of a Health Professional and Consumer Group via a survey

Figure 4 Sources of evidence that were used to inform recommendations in this guideline



GRADE = Grading of Recommendations, Assessment, Development and Evaluation; EtD = Evidence to Decision

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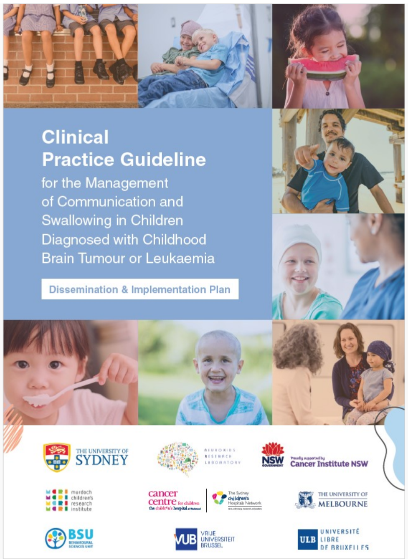
C. Dissemination & Implementation Plan



Clinical Practice Guideline for the Management of Communication and Swallowing in Children Diagnosed with Childhood Brain Tumour or Leukaemia

Dissemination & Implementation Plan

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Journal articles published

Communication and swallowing outcomes of children diagnosed with childhood brain tumor or leukemia: A systematic review

Rosemary Hodges, Lani Campbell, Sara Chami, Stefani Ribeiro Knijnik, Kimberley Docking

Executive summary

1\. Communication

What are the communication outcomes associated with childhood brain tumour or leukaemia?

GRADE Recommendation?	Grade	Approval
Evidence-based Recommendation 1: Communication	**Strong**	23-Nov-2020 –

GRADE Recommendation?	Grade	Approval
Communication assessment and intervention should be offered to children diagnosed with childhood brain tumour or leukaemia.		22-Nov-2025

Practice point?

Assessment & Intervention

When to assess

- Communication assessment should occur at or as soon as possible after cancer diagnosis.
- Communication assessment should occur during the oncology treatment phase and oncology follow-up phase. Multiple assessments during these phases may be required if concerns are indicated by the oncology care team and/or family.
- Regular monitoring of the child’s communication development should continue throughout the survivorship phase until end of adolescence.

What to assess

- A comprehensive assessment of speech and language should be conducted. Assessment needs to be tailored to the age and developmental level of the child. Where appropriate, language assessment should include high-level language, discourse-level skills and literacy.
- Assessment should include a range of individualised assessment procedures such as norm-referenced assessments, criterion-referenced tools, care-giver report and clinical observations across environments.

When to intervene

- Children diagnosed with CBTL should be provided with early individualised intervention during the oncology treatment phase for identified communication difficulties.
- Children diagnosed with CBTL should be provided with timely individualised intervention for communication difficulties identified during the oncology follow-up and survivorship phases through until the end of adolescence.

Practice point?

Education

- Education about communication development and difficulties in CBTL should be provided to families at cancer diagnosis or as early as possible.
- Education about communication development and difficulties in CBTL should continue to be provided to families throughout the oncology treatment and follow-up phases.
- Education about potential long-term communication difficulties in CBTL should be provided to families and education professionals throughout the oncology follow-up and survivorship phases.

Practice point?

Care Team

- Speech Pathologists should be involved as integral members of the oncology care team from the point of cancer diagnosis and throughout the oncology treatment and follow-up phases.
- All members of the oncology care team should be informed about communication difficulties and involved in management throughout the oncology treatment and follow-up phases.
- Speech Pathologists should work in partnership with oncologists, family members and education professionals to monitor communication development throughout the survivorship phase until the end of adolescence.

2\. Swallowing

What are the swallowing outcomes associated with childhood brain tumour or leukaemia?

GRADE Recommendation?	Grade	Approval
Evidence-based Recommendation 1: Swallowing Swallowing assessment and management should be offered to children diagnosed with childhood brain tumour or leukaemia.	**Strong**	23-Nov-2020 – 22-Nov-2025

Practice point?

Assessment & Intervention

When to assess

- Swallowing assessment should occur at or as soon as possible after diagnosis of CBTL.
- Swallowing assessment should occur during the oncology treatment phase.
- Multiple assessments may be required where concerns are indicated by the oncology care team and/or family. Regular monitoring of the child's swallowing should continue throughout the oncology follow-up and survivorship phases until end of adolescence.

What to assess

- A comprehensive swallowing assessment should be conducted. Assessment needs to be tailored to the age and developmental level of the child. All phases of the swallow (pre-oral anticipatory, oral-preparatory, oral and pharyngeal) need to be assessed.
- Videofluoroscopy Swallowing Study (VFSS) should be considered on a case-by-case basis as part of the assessment protocol to examine aspiration if required.

When to intervene

- Children diagnosed with CBTL should be provided with early individualised management for swallowing difficulties during the oncology treatment phase.
- Children diagnosed with CBTL should be provided with individualised management for swallowing difficulties identified by the oncology care team and/or family in the oncology follow-up and survivorship phases.

Practice point?

Care Team

- Speech Pathologists should be involved as integral members of the oncology care team from the point of cancer diagnosis and throughout the oncology treatment phase to manage swallowing.
- All members of the oncology care team should be informed about swallowing difficulties and involved in their management as needed throughout oncology phases.
- Speech Pathologists should work in partnership with oncologists and family members to monitor swallowing throughout the survivorship phase until the end of adolescence.

Practice point?

Education

- Education about swallowing difficulties in CBTL should be provided to families at cancer diagnosis or as early as possible.
- Education about swallowing difficulties in CBTL should continue to be provided to families throughout the oncology treatment and follow-up phases.

Australian Government
National Health and Medical Research Council
NHMRC

The guideline recommendations were approved by the Chief Executive Officer of the National Health and Medical Research Council on **23 November, 2020** under section 14A of the *National Health and Medical Research Council Act 1992*.

D. Glossary and Abbreviations

Contents

Glossary

Term	Definition

Childhood brain tumour	A brain tumour in childhood is an abnormal mass of cells growing in the brain. It can start to grow before birth in the foetal period, or anytime during childhood. Tumours can grow slowly over time, causing a slow onset of symptoms, or quickly with a faster onset of more obvious symptoms. Brain tumours can be treated with a combination of surgery, radiotherapy and/or chemotherapy, depending on the type. There are no clear known causes.
Communication	Communication includes speech, language, voice, and fluency skills.
Dysphagia	A swallowing disorder that occurs when there is a breakdown of the oral, pharyngeal, and/or oesophageal phases, which can also result in significant weight loss, inadequate growth, or negatively impact on development.
Evidence to Decision Framework	The GRADE Evidence to Decision (EtD) Framework provides a structured way to combine research findings with other key factors to develop guidelines and make clinical recommendations. It helps to guide decision makers through a set of criteria, ensuring that each criterion is considered equally, and decisions are transparently reported.
Fluency	Fluency is the rhythm and flow of speech.
GRADE	GRADE (Grading of Recommendations, Assessment, Development and Evaluation) is used to rate the certainty or quality of a body of evidence. Each outcome area is given a rating from high to very low.
Language	Language is the comprehension and production of words, sentences, and texts for communication. This includes vocabulary (e.g. the store of words that an individual understands and uses), grammar/syntax (e.g. the way words are combined into phrases and sentences to form meaning), discourse (e.g. written language and text-level), social communication (e.g. skills needed to manage a conversation successfully, such as turn-taking, staying on topic, inferencing, ambiguity, jokes and metaphors) and literacy (e.g. reading, spelling and writing). Language can occur in many modalities, such as spoken, written and alternative augmentative domains (e.g. sign language, communication devices).
Leukaemia	Leukaemia is a cancer of the white blood cells, where more leukocytes (or immature white blood cells) are produced and suppress normal blood cells. If leukaemia is diagnosed as acute, the disease progresses more quickly and requires more aggressive treatment. Treatments can include monitoring, chemotherapy, radiotherapy, and/or stem-cell transplant.
Quality of life	Quality of life refers to an individual’s ability to participate based on functional outcomes. Quality of life is often considered alongside quantity (or duration) of life.
Speech	Speech is the production of speech sounds in words. It involves both articulation/ motor speech production and linguistic skills (e.g. sounds, intonation, stress, prosody).
Swallowing	Swallowing includes feeding behaviours that occur when eating or drinking (e.g. sensory responses to food, opening the mouth, chewing, and moving food or liquid around the mouth).
Voice	Voice is the coordination of respiration, phonation and resonance.

Abbreviations

Acronym	Expansion
AGREE II	Appraisal of Guidelines for Research and Evaluation II
ALL	Acute Lymphoblastic Leukaemia
AML	Acute Myeloid Leukaemia
CALD	Culturally and Linguistically Diverse
CBTL	Childhood Brain Tumour or Leukaemia
CNS	Central Nervous System
EtD	Evidence to Decision
GRADE	Grading of Recommendations, Assessment, Development and Evaluation
JBI	Joanna Briggs Institute
MDT	Multidisciplinary team
NHMRC	National Health and Medical Research Council
pCMS/CMS	Postoperative Cerebellar Mutism Syndrome/ Cerebellar Mutism Syndrome
PFS	Posterior Fossa Syndrome

Plain English summary

Childhood brain tumour and leukaemia are the two most common types of cancers in children. Treatments for these cancers have improved dramatically in recent years and now a majority of children survive. However, these cancers and their treatments can have negative effects on child development, including communication and swallowing skills. This guideline makes two main recommendations about the management of communication and swallowing difficulties in children diagnosed with childhood brain tumour or leukaemia as shown below.

Recommendation 1

Communication assessment and intervention should be offered to children diagnosed with childhood brain tumour or leukaemia

The communication recommendation made in this guideline calls for communication assessment and intervention to be offered to children diagnosed with brain tumour or leukaemia. This is needed because these children often experience communication difficulties such as problems with producing clear speech, understanding and using language, and literacy skills such as reading and writing. Communication difficulties may be seen at the time of cancer diagnosis or during cancer treatment but can also be seen months or years after cancer treatment.

Recommendation 2

Swallowing assessment and management should be offered to children diagnosed with childhood brain tumour or leukaemia

The swallowing recommendation made in this guideline calls for swallowing assessment and management to be offered to children diagnosed with brain tumour or leukaemia. This is needed because the ability to swallow foods and fluids can be compromised in these children. This can be life-threatening as it puts the child at-risk of chest infections if food/fluid enters the lungs. Swallowing difficulties are frequently reported during cancer treatment. However, there is some evidence that swallowing difficulties may continue into the longer-term, once cancer treatment has finished.

Purpose and scope

Contents

Purpose

This guideline was developed to address the need for a systematic, evidence-based approach to the management of communication and swallowing in children diagnosed with childhood brain tumour or leukaemia (CBTL). It aims to assist health professionals to provide and advocate for evidence-based care and management of communication and swallowing in children diagnosed with CBTL. It also aims to educate patient consumers (parents of children with CBTL, survivors of CBTL) and support them to advocate for best practice management of communication and swallowing difficulties.

The intended outcome of this guideline is to improve quality of life for children surviving brain cancer and leukaemia. This has involved translating evidence from the research and clinical/consumer expertise into recommendations that will guide improvements in cancer services and quality of clinical care for this population across Australia and worldwide.

The implementation of the evidence-based recommendations presented here will support a systematic and equitable approach to clinical management for communication and swallowing in CBTL, including long-term follow-up. This guideline will also form the basis for targeted early intervention program development and survivorship surveillance planning. These recommendations will support children to keep healthy and lead a fulfilled life, not only during cancer diagnosis and treatment, but critically after cancer survival.

Clinical problem

Child survivors of brain cancer and leukaemia - the top two most common childhood cancers in Australia and developed countries worldwide - often face a new challenge during and after their cancer treatment is completed.[1][2][3][4][5][6] While incidence rates continue to rise, so do survival rates and the size of this rapidly growing population of survivors, due to advancements in medical care and treatments.[3][6][7][8] Effects from the cancer and treatments can have significant and often severe impact to quality of life in the areas of communication and swallowing; affecting a child or adolescent's development of new skills, the ability to communicate their needs, succeed at school, make friends, engage in family mealtimes or eat-out socially, use social media, successfully date, or achieve social and financial independence in adulthood.[9]
To date, an equitable and systematic approach to management for communication and swallowing has not been established in Australia or worldwide; despite children diagnosed with CBTL remaining at-risk throughout development and into adulthood if untreated or lost to follow-up.

Clinical questions

To guide the evidence review for this guideline, two clinical questions were developed. The questions were developed by the Chair and Project Co-ordinator with opportunities for feedback from the Steering Committee. The questions are consistent with the PICOTS (population, intervention, comparison, outcome, timing, setting) format.[10] The clinical questions are shown in Box A below.
Box A Clinical questions used to develop this guideline

	What are the communication outcomes associated with childhood brain

Communication Outcomes	tumour or leukaemia?*
Swallowing Outcomes	What are the swallowing outcomes associated with childhood brain tumour or leukaemia?*
*PICOTS format – Population (P): Children with aged 1–16 with brain tumour or leukaemia; Intervention (I) – Any; Comparison (C) – Any; Outcome (O) – Communication/Swallowing; Timing (T) – At diagnosis prior to cancer treatment, during the oncology treatment phase, during the oncology follow-up phase, during the survivorship phase; Setting (S) - Both inpatient and outpatient settings.	

The population

The guideline focuses on children diagnosed with any type of childhood brain tumour or leukaemia aged 0–16 years of age.

Brain tumour or leukaemia

A brain tumour in childhood is an abnormal mass of cells growing in the brain. Tumours can start to grow before birth in the foetal period, or anytime during childhood. They can grow slowly over time, causing a slow onset of symptoms, or quickly with a faster onset of more obvious symptoms. Brain tumours can be treated with a combination of surgery, radiotherapy and/or chemotherapy, depending on the type and malignancy. There are no clear known causes. Leukaemia is a cancer of the white blood cells, where more leukocytes (or immature white blood cells) are produced and suppress normal blood cells. If leukaemia is diagnosed as acute, the disease progresses more quickly and requires more aggressive treatment. Treatments can include monitoring, chemotherapy, radiotherapy, and/or stem-cell transplant.

The population of CBTL is inherently diverse, due to a range of presentation characteristics. Examples of diversity include differences in cancer diagnoses, cancer treatments, cancer treatment effects (during and after), age at diagnosis, as well as progression of disease, periods of admission, medical complications (e.g. increased intracranial pressure, infections), family circumstances and values.

In this guideline, brain tumour and leukaemia have been considered as one population (i.e. childhood brain tumour or leukaemia; CBTL) due to the similarities in central nervous system (CNS) targeted cancer treatments and outcomes for these groups. Both cancer groups often receive CNS applied chemotherapy and/or radiotherapy that are reported to impact the developing brain and CNS.[4] However, a majority of the literature evidence on which the guideline recommendations are based was noted to be more largely represented by reports of children with brain tumour, with a relatively recent increase in the amount of leukaemia studies (see Administrative & Technical report, Table 2 & 3).

Age

The scope of the guideline focuses on children aged 0–16 years. The 16-year age limit represents the upper age limit commonly applied to patients receiving paediatric services in the majority of Australian hospitals/cancer centres. The current available evidence base does not support further sub-grouping of recommendations into separate age groups. However, the key practice points presented in this guideline about assessment consider age of the child to ensure that age-appropriate assessment procedures are applied. It is, however, anticipated that survivorship experiences will extend beyond this age group into upper adolescence and early adulthood. The guideline discusses the implications for future application and services throughout survivorship and into adulthood for child survivors.

Timing and setting in childhood brain tumour or leukaemia: A framework

Even after cancer diagnosis and treatment, children with CBTL face a long road ahead, with regular monitoring of their medical and cancer status. This is necessary due to risk of cancer recurrence for some cancer types.[11][12] It is also important because of the potential ongoing impact of the cancer and its treatment on health and development.[13][14][15][16][17][18][19]

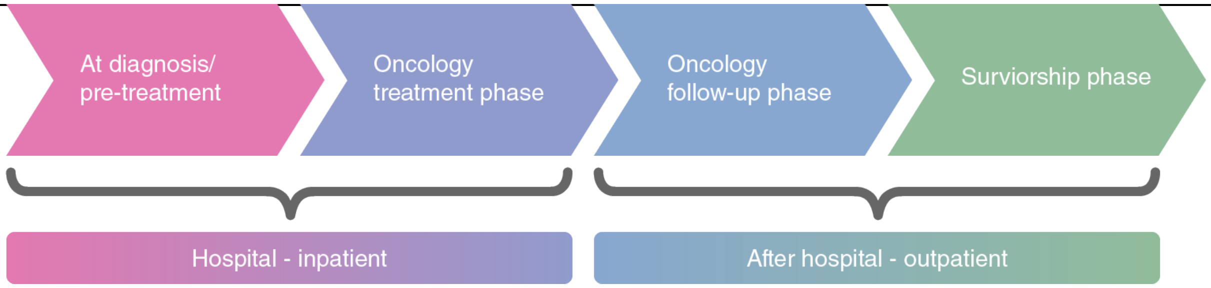
Therefore, the course of CBTL needs to be conceptualised over time, as well as adopting a long-term approach to health and well-being. Literature focusing on communication and swallowing skills in this population have examined outcomes at one or more points in time across a child's cancer journey, from diagnosis through to survivorship. To provide consistency in describing these time points, the authors of this guideline have developed a framework (see Figure 2). This framework identifies four key paediatric oncology phases:

1. At diagnosis/pre-treatment: at cancer diagnosis, prior to the start of cancer treatment
2. Oncology treatment phase: during or, in the weeks after, cancer treatment
3. Oncology follow-up phase: <5 years since cancer treatment has finished
4. Survivorship phase: ≥5 years since cancer treatment has finished

These oncology phases are closely linked with setting. While some studies examine outcomes while children diagnosed with CBTL are still in hospital, others do so in community settings such as clinics, schools and at home. For simplicity, in the framework, setting has been binary classified into: “hospital - inpatient” and “after hospital - outpatient”.

It is important to recognise that due to the possibility of cancer recurrence, secondary cancer/s, or multiple primary cancer/s, a child may return to an earlier phase in this framework. For example, a child who is cancer-free for six years and considered to be in the survivorship phase may experience cancer recurrence and therefore return to oncology treatment phase.

Figure 2 Framework of timing and setting in childhood brain tumour/ leukaemia



Intended end users of the guideline

This guideline has been developed to provide evidence- based recommendations for Speech Pathologists and multidisciplinary health professionals involved in the management of communication and swallowing difficulties for children diagnosed with childhood brain tumour or leukaemia. It is to be used alongside clinician judgement and patient preferences. It is based on the best evidence available at the time of publication. Additional relevant health professionals may include, but are not limited to, Oncologists, Rehabilitation Physicians, Nurses, Occupational Therapists, Physiotherapists, Dietitians, Child Life and Music Therapists. It is also intended that education providers in educational settings will also access the guideline and recommendations in order to support CBTL survivors to transition back into the classroom and school community for educational services.

These recommendations will equip parents and families as lifelong advocates in seeking optimal quality of life outcomes for their children, by providing knowledge about issues their child may likely experience and what these might look like. This will ensure families can be connected with timely management, early intervention services and appropriate referral services. It is important that parents do not feel isolated or lost to follow-up, or do not feel inadequately prepared for their child's future.[20] This cohesive source of information about long-term communication and swallowing management will serve to guide survivors and their families to partner with health professionals where necessary to ensure improved quality of life outcomes for communication and swallowing.

Cultural and socio-economic considerations

Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse (CALD) communities as well as families from socio-economically disadvantaged backgrounds face unique challenges in regard to accessing cancer care services. A rapid review commissioned by the Cancer Institute NSW[17] highlighted the importance of practical, educational and social support in improving cancer outcomes and achieving increased satisfaction for CALD populations. This review specified that the development of culturally appropriate interventions and programs should consider individual and cultural barriers to accessing health services.[17] A lower prevalence has recently been reported for admissions of children with chronic conditions from socio-economically disadvantaged or regional and remote areas, including cancer diagnoses.[9] This has been attributed to reduced access to hospital services due to location, as well as cultural barriers for some population groups.[9] However, presentation of children from these areas were more highly represented in emergency admission rates, suggesting that visits were less likely to be planned.[9]

Australians now come from nearly 200 countries and represent more than 300 ancestries.[21][22][23] Based on the most recent available Australian census data in 2016, 3.3% of the total Australian population is represented by Aboriginal and Torres Strait Islander people (798,400).[24] One in four people in Australia (26%) are born overseas with over 300 separately identified languages spoken at home.[21][22][23] While English is the main language spoken, the most recent population data reports that 21% of Australians speak a language other than English at home.[21] For example, the most commonly spoken language in Sydney is Arabic (4.8% of the total population), closely followed by Mandarin (3.6%), Cantonese (3.5%), Vietnamese (2.3%), Greek (2.1%), and Italian (2.1%). Of the overseas-born people who had arrived in the 25 years prior to 2016, 11% either did not speak English well or at all.[21]

In these guidelines, the cultural diversity of Australians was considered in several ways. In the systematic review of evidence that informed development of the recommendations, the search strategy for the population concept was purposefully broad (i.e., brain cancer or leukaemia AND child) so as to capture studies across all potential population/cultural subgroups (see Administrative & Technical report, p. 15-16). Many studies in the systematic review, however, were found to focus on English-only language speakers and noted to be an eligibility criterion of most reported studies.

Issues relevant to Aboriginal and Torres Strait Islander people and CALD populations were also considered through the evidence from the Health Professional and Consumer Group and Steering Committee members. Several members identified as CALD and/or currently work directly with clinical populations. They incorporated their experience and knowledge of Aboriginal and Torres Strait Islander people and CALD families when providing their input. Important considerations for implementation of the guideline for Aboriginal and Torres Strait Islander people and CALD populations can be found in the Dissemination & Implementation Plan.

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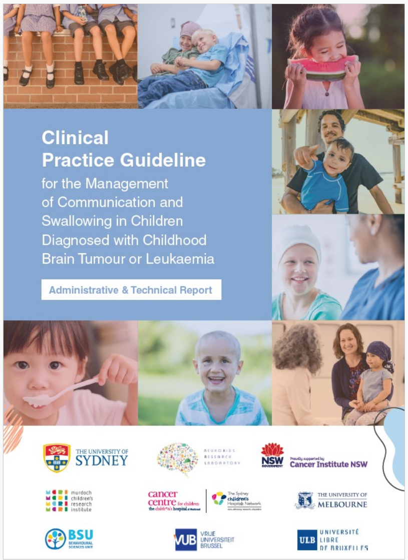

Clinical Practice Guideline
for the Management of Communication and Swallowing in Children Diagnosed with Childhood Brain Tumour or Leukaemia

Administrative & Technical Report

Download: Administrative and Technical reports

A. Guideline development committee

Contents

The Guideline Development Committee comprised a Lead Development Team, a Steering Committee (panel of experts) and a Health Professional and Consumer Group. The Guideline Development Committee are shown in Figure 1 and the specific roles and responsibilities of each member/group are detailed in the following sections. Table 1 includes all members of the Guideline Development Committee detailing name and organisation, discipline, role in the guideline development process and experience with childhood brain tumour and/or leukaemia.

Figure 1 Guideline Development Committee

Lead Development Team

Chair, Project Co-ordinator, Research and Evidence Consultant, Research Assistant Team

Steering Committee (panel of experts)

Six members with research and/or clinical expertise in CBTL and a consumer + Chair, Project Co-ordinator, Research and Evidence Consultant

Health Professional and Consumer Group

Multidisciplinary health professionals with experience in CBTL (22) and consumers (2)

CBTL = Childhood brain tumour or leukaemia

Table 1 Guideline Development Committee Members

Name and Organisation	Role	Discipline	Experience with childhood brain tumour or leukaemia (CBTL)
Dr Kimberley Docking *The University of Sydney*	Chair	Speech Pathology	Leader of research lab focused on communication and swallowing in children diagnosed with CBTL; 20 years clinical and research experience in CBTL as a researcher and Speech Pathologist
Dr Rosemary Hodges *The University of Sydney*	Project Co-ordinator	Speech Pathology	Speech Pathologist with 10 years clinical and research experience in paediatrics and researcher in area of CBTL for over 3 years
Dr Lani Campbell	Research and Evidence	Speech	Speech Pathologist and researcher in

The University of Sydney	Consultant	Pathology	CBTL for 18 months
Ms Sara Chami *The University of Sydney*	Research Assistant	Speech Pathology	Speech Pathologist and researcher in area of CBTL for over 2 years
Ms Stefani Ribeiro Knijnik *The University of Sydney*	Research Affiliate	Speech Pathology	Speech Pathologist experience in infants and children with dysphagia as a result of CBTL; researcher in CBTL for 1 year
Ms Emma Campbell *The University of Sydney; Western Sydney Local Health District*	Research Assistant	Speech Pathology	Researcher in CBTL for 2 years
Professor Angela Morgan *Murdoch Children's Research Institute; University of Melbourne*	Steering Committee	Speech Pathology	20 years of clinical and research work in paediatric Speech Pathology, including CBTL
Professor Claire Wakefield *School of Women's and Children's Health, UNSW Medicine, UNSW Sydney; Behavioural Sciences Unit, Kids Cancer Centre, Sydney Children's Hospital*	Steering Committee	Psychology	Leader of Australasia's largest paediatric psycho-oncology research group; researcher with focus on patient/family needs in childhood cancer, including CBTL
Professor Philippe Paquier *Vrije Universiteit Brussel (VUB) & Université Libre de Bruxelles (ULB)*	Steering Committee	Neurolinguistics	Researcher with focus on paediatric neurocognitive and speech/ language disorders, including special interests in: cerebellar mutism syndrome and the long- term neurocognitive outcomes of childhood brain tumour survivors
Dr Luciano Dalla-Pozza *The Cancer Centre for Children, The Children's Hospital at Westmead, Sydney Children's Hospitals Network*	Steering Committee	Oncology	Director of major metropolitan paediatric cancer centre; provision of primary care and follow-up
Dr Mary-Clare Waugh			Over 20 years experience working with children with congenital and acquired brain and/or spinal cord lesions resulting

The Children’s Hospital at Westmead, Sydney Children’s Hospitals Network; The University of Sydney Medical School	Steering Committee	Rehabilitation	in dysphagia and communication difficulties; Extensive experience working in large multidisciplinary teams with rehabilitation goal directed interventions
Ms Maria Messina *Consumer*	Steering Committee	Consumer & Educator	Mother of child diagnosed with leukaemia
Ms Claire Radford *Queensland Children's Hospital*	Health Professional and Consumer Group	Speech Pathology	5 years experience as senior Speech Pathologist and allied health team leader (oncology and palliative care). Previously, 6 years clinical experience treating children with acquired brain injury including children with CBTL
Ms Brooke Spencer *Queensland Children's Hospital*	Health Professional and Consumer Group	Oncology Nursing	25 years paediatric oncology nursing with the last 4 years in neuro-oncology clinical nurse consultant role
Ms Hayley Coulson *Queensland Children’s Hospital*	Health Professional and Consumer Group	Physiotherapy	5 years experience as senior oncology Physiotherapist in paediatric setting
Dr Cinzia De Luca *The Royal Children's Hospital, Melbourne*	Health Professional and Consumer Group	Neuropsychology	Co-ordinator of the neuropsychology service at major metropolitan children’s hospital
Ms Candice Brady *The Children's Hospital at Westmead, Sydney Children's Hospitals Network*	Health Professional and Consumer Group	Speech Pathology	Speech Pathologist providing services to children post- tumour resection /oncology care
Ms Suzi Drevensek *The Children's Hospital at Westmead, Sydney Children’s Hospitals Network*	Health Professional and Consumer Group	Speech Pathology	Speech Pathologist providing services to children who have acquired brain injury associated with brain tumour
Dr Robyn Stargatt *La Trobe University*	Health Professional and Consumer Group	Neuropsychology	30 years experience in clinical work and research in public and private sector with children diagnosed with CBTL
Ms Amanda Simon	Health		Assessment and management of children

The Children's Hospital at Westmead, Sydney Children's Hospitals Network	Professional and Consumer Group	Speech Pathology	with CBTL who have swallowing difficulties
Ms Kate Osland *The Children’s Hospital at Westmead. Sydney Children’s Hospitals Network*	Health Professional and Consumer Group	Speech Pathology	7 years experience providing inpatient and outpatient assessment and therapy to children with CBTL
Ms Gloria Tzannes *The Children's Hospital at Westmead, Sydney Children's Hospitals Network*	Health Professional and Consumer Group	Speech Pathology	Assessment and management of children with CBTL who present with swallowing difficulties and communication disorders; contributes at governance level model of care within major metropolitan children’s hospital
Ms Melissa Parkin *Sydney Children’s Hospital Randwick, Sydney Children’s Hospitals Network*	Health Professional and Consumer Group	Speech Pathology	Acute and chronic feeding and swallowing disorders in children with CBTL
Dr Jennifer Cohen *Discipline of Paediatrics, School of Women's and Children's Health, University of NSW*	Health Professional and Consumer Group	Dietetics	15 years experience as clinicaldietitian providing nutritional support for families and children being treated for childhood cancer, including CBTL; researcher with focus on nutritional management of childhood cancer patients and survivors
Dr Laura Janzen *The Hospital for Sick Children, Toronto*	Health Professional and Consumer Group	Neuropsychology	12 years experience providing clinical neuropsychology assessment and consultation services to the neuro-oncology and leukemia programs ina major metropolitan children’s hospital; researcher in neuro-oncology
Ms Jane Fong *Women’s and Children’s Hospital, Adelaide*	Health Professional and Consumer Group	Speech Pathology	Speech pathology assessment and therapy for children with brain tumour or spinal cord tumour
Ms Lauren Leeming*Sydney* *Children’s Hospitals Network*	Health Professional and Consumer Group	Speech Pathology	14 years experience working with paediatric feeding/swallowing difficulties within the acute hospital setting including the oncology/ haematology caseload

Dr Amanda Lane- Brown *Sydney Children's Hospitals Network*	Health Professional and Consumer Group	Psychology	Clinical psychologist working in inpatient rehabilitation team with children who are diagnosed with brain tumours
Ms Roxanne McLeod *Sydney Children's Hospitals Network*	Health Professional and Consumer Group	Music Therapy	8.5 years experience providing music therapy to paediatric oncology patients and their families
Miriam Cromie *Child Life and Music Therapy, The Children's Hospital at Westmead, Sydney Children's Hospitals Network*	Health Professional and Consumer Group	Music Therapy	12 years experience in paediatric oncology as both a music therapist and child life therapist
Dr Geoff McCowage *The Children's Hospital at Westmead, Sydney Children's Hospitals Network*	Health Professional and Consumer Group	Oncology	Paediatric oncologist in major metropolitan children's hospital, member of multidisciplinary teams for both neurological cancer (brain and spinal cord) and leukaemia
Eliza-Jane Potter *The Children's Hospital at Westmead, Sydney Children's Hospitals Network*	Health Professional and Consumer Group	Nursing	Paediatric oncology nurse in major metropolitan children's hospital
Dr Sumanth Nagabushan *The Children's Hospital at Westmead, Sydney Children's Hospitals Network; The University of Sydney*	Health Professional and Consumer Group	Oncology	In and outpatient management of children diagnosed CBTL including overseeing routine clinical care, organising chemo-radiotherapy, coordinating multidisciplinary care with tertiary and local healthcare agencies, and engaging in clinically relevant research
Jessica De Bolfo *The Royal Children's Hospital Melbourne*	Health Professional and Consumer Group	Speech Pathology	Provide inpatient and outpatient service to oncology patients
Marion Corbett *Consumer*	Health Professional and Consumer Group	Consumer	Mother of child diagnosed with brain tumour
Tracey Power	Health Professional and	Consumer	Mother of child diagnosed with brain

Consumer	Consumer Group		tumour

Committee Roles

Chair

The Chair, Dr Kimberley Docking, is an experienced Speech Pathologist and researcher with over 20 years of experience in the area of CBTL. The Chair was responsible for:

- Obtaining and managing funding and reporting to the funding body throughout the guideline process;
- Conceptualisation of the guideline;
- Registering the guideline with the National Health and Medical Research Council (NHMRC) and developing NHMRC timeline documentation;
- Employment of paid team members working on the project;
- Inviting and engaging the Steering Committee;
- Liaising with key stakeholders, including major national children's hospitals throughout the guideline process;
- Development of the clinical questions to be addressed in the guideline in consultation with the Project Co-ordinator and Steering Committee;
- Systematic review screening, data extraction and appraisal in conjunction with Project Co-ordinator and Research Assistant team;
- Conducting appropriate methodology for rating the quality of evidence and strength of recommendations in conjunction with Research and Evidence Consultant, Project Co-ordinator, and Research Assistant team;
- Recruitment of a Health Professional and Consumer Group, including consumer members, in conjunction with Project Co-ordinator;
- Development of health professional and consumer survey in conjunction with Project Co-ordinator and Research Assistants, Ms Sara Chami and Ms Emma Campbell;
- Ethics application for health professional and consumer survey in conjunction with Project Co-ordinator and Research Assistant, Ms Sara Chami;
- Data analysis methods for health professional and consumer survey in conjunction with Project Co-ordinator and Research Assistant, Ms Sara Chami;
- Liaising with the Project Co-ordinator and Research and Evidence Consultant to complete the GRADE Evidence to Decision (EtD) Framework processes;
- Providing input as a member of the Steering Committee via completion of the GRADE Evidence- to-Decision Framework;
- Development of evidence-based recommendations in conjunction with Project Co-ordinator and the Steering Committee;
- Development of the Guideline, Administrative & Technical report and other associated documents in conjunction with the Project Co-ordinator and Research and Evidence Consultant;
- Development of the Dissemination & Implementation Plan;
- Organising public consultation; inviting key national and international stakeholder organisations to comment, liaising with organisations;
- Development of Public Consultation Submission Summary and responses to submissions;

- Nominating independent expert reviewers;
- Working with NHMRC to ensure all guideline requirements met in conjunction with the Project Co-ordinator.
- Responded to independent and methodological reviews; completed review response to reviewers documentation as guideline developer;
- Finalised all guideline documentation and submitted to NHMRC for consideration for approval;
- Presented guideline to NHMRC Council Meeting for approval;
- Commissioned and coordinated translations of Guideline Summary;
- Commissioned and coordinated publication of all guideline documents;
- Release of guidelines according to NHMRC requirements.

Project Co-ordinator

The Project Co-ordinator, Dr Rosemary Hodges, is an experienced paediatric Speech Pathologist and researcher. She was responsible for:

- Coordination of the guideline project and team members;
- Development of the clinical questions to be addressed in the guideline in consultation with Chair and Steering Committee;
- Systematic search of the literature evidence;
- Systematic review screening, data extraction and appraisal in conjunction with Chair and Research Assistants;
- Creating summary of individual study evidence tables, GRADE summary of findings tables and GRADE EtD tables with guidance from Research and Evidence Consultant;
- Conducting appropriate methodology for rating the quality of evidence and strength of recommendations in conjunction with Research and Evidence Consultant, Chair, and Research Assistants;
- Recruitment of a Health Professional and Consumer Group in conjunction with Chair;
- Development of health professional and consumer survey in conjunction with Chair and Research Assistants, Ms Sara Chami and Ms Emma Campbell;
- Ethics application for health professional and consumer survey in conjunction with Chair and Research Assistant, Ms Sara Chami;
- Data analysis methods for health professional and consumer survey in conjunction with Chair and Research Assistant, Ms Sara Chami;
- Development of Declarations of Interest form, collecting and collating declarations of interests from all team members;
- Collating the evidence from the systematic review and presenting to the Steering Committee in accessible way to allow completion of the GRADE EtD Framework in conjunction with Research and Evidence Consultant;
- Providing input as a member of the Steering Committee via completion of the GRADE EtD Framework;
- Development of evidence-based recommendations in conjunction with the Steering Committee and Chair;
- Development of the Guideline, Administrative & Technical Report in conjunction with Research and Evidence Consultant and Chair;
- Working with NHMRC to ensure all guideline requirements met in conjunction with Chair.

Research and Evidence Consultant

Dr Lani Campbell is an experienced Speech Pathologist and Research and Evidence Consultant. She provided specific methodological input into the GRADE certainty of evidence ratings and GRADE EtD Frameworks. She was responsible for:

- Providing guidance on the use of the Grading of Recommendations Assessment, Development and Evaluation (GRADE; http://www.gradeworkinggroup.org/) approach to rating the certainty of the evidence;
- Consulting with key GRADE methodologists about the project;
- Developing templates and guidance on completing individual study summary tables, GRADE Summary of Findings tables and GRADE EtD tables;
- Collating the evidence from the systematic review and presenting to the Steering Committee in accessible way to allow completion of the GRADE EtD Framework in conjunction with Project Co-ordinator;
- Providing input as a member of the Steering Committee via completion of the GRADE EtD Framework;
- Contributing to the structure and content of the Administrative & Technical Report in consultation with the Project Co-ordinator;
- Contributing knowledge translation content in guideline document;
- Contributing to Dissemination & Implementation Plan.

Research Assistant team

The Lead Development team also included two Research Assistants (Ms Sara Chami, Ms Emma Campbell) and an honorary Research Affiliate (Ms Stefani Ribeiro Knijnik). All are qualified and experienced Speech Pathologists with research experience and training at either Honours or Research Masters level. Their roles included:

- Contributing to content of the health professional and consumer survey and creation of the survey on Qualtrics platform;
- Preparation of ethics application documents for the health professional and consumer survey, in consultation with Chair and Project Co-ordinator;
- Developing data extraction forms and spreadsheets for systematic review in consultation with Project Co-ordinator;
- Data extraction for systematic review;
- Completing Joanna Briggs Institute (JBI) appraisal checklists for systematic review;
- Data entry and analysis for the health professional and consumer survey;
- Referencing and formatting support for guideline documents;
- Providing input to draft guideline documents.

Steering Committee (panel of experts)

The Steering Committee comprised six members (five clinical researchers and health professionals with expertise in Speech Pathology, Psychology, Neurolinguistics, Rehabilitation, and Oncology; and one consumer who is a parent of a child diagnosed with leukaemia) in addition to the Chair, Project Co-ordinator and Research and Evidence Consultant. Members of the Steering Committee were invited to the role by the Chair or through a call for interest via ANZCHOG (Australian and New Zealand Childrens Haematology/Oncology Group). The rationale for the guideline and roles/responsibilities of Steering Committee members were provided by the Chair and discussed when each individual was invited.

The Steering Committee's role was to provide input and feedback across all phases of guideline development including clinical question development, systematic review, survey development, evidence synthesis and development of the recommendations (please note: the consumer member of the Steering Committee joined prior to the presentation of the evidence synthesis, and contributed to the development of recommendations).

Health Professional and Consumer Group

The Health Professional and Consumer Group included 22 multidisciplinary health professionals with experience in CBTL and two consumers (parents of children diagnosed with CBTL). The role of Health Professional and Consumer Group members was to complete an online survey to gather their perspectives and input into the clinical management of communication and swallowing in children diagnosed with CBTL.

Consumer perspectives and involvement

Consumer involvement was integral to the development of this guideline. A consumer representative was a member of the Steering Committee. She is the mother of a child diagnosed with leukaemia. Her perspectives and input were invaluable in the process of the GRADE EtD frameworks and the development of recommendations. Two consumers provided input as members of the Health Professional and Consumer Group, both mothers of children diagnosed with brain tumour. They provided input via a health professional and consumer survey.

Participation and representation of Aboriginal and Torres Strait Islander people and culturally and linguistically diverse groups

The Guideline Development Committee membership comprised one member who is an Aboriginal and Torres Strait Islander person as well as numerous culturally and linguistically diverse (CALD) members. A total of 38% of the Guideline Development Committee chose to identify as either an Aboriginal and Torres Strait Islander person or CALD group.