



# 针对患有儿童期脑肿瘤或白血病的儿童的沟通和吞咽管理的临床实践指南

医学指南



NEUROKIDS  
COMMUNICATION  
RESEARCH  
LABORATORY



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## Publication Approval



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The guideline recommendations in this document were approved by the Chief Executive Officer of the National Health and Medical Research Council (NHMRC) on 23 November, 2020, under Section 14A of the National Health and Medical Research Council Act 1992. In approving the guideline recommendations, NHMRC considers that they meet the NHMRC standard for clinical practice guidelines. This approval is valid for a period of 5 years. NHMRC is satisfied that the guideline recommendations are systematically derived, based on the identification and synthesis of the best available scientific evidence, and developed for health professionals practising in an Australian health care setting. This publication reflects the views of the authors and not necessarily the views of the Australian Government.

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# 简明英语摘要

儿童期脑肿瘤和白血病是儿童中最常见的两种癌症。近年来, 这些癌症的治疗已有显著改善, 因此现在大多数儿童都得以生存。但是, 这些癌症及其治疗方法可能会对儿童的发育产生负面影响, 包括沟通和吞咽技巧。

本指南针对患有儿童期脑肿瘤或白血病的儿童的沟通和吞咽困难提出如下所示的两个主要建议。



## 建议1

### 应向患有儿童期脑肿瘤或白血病的儿童提供沟通评估和干预

本指南中提出的沟通建议主张对患有脑肿瘤或白血病的儿童进行沟通评估和干预。需要这些措施的原因是这些儿童经常遇到沟通困难, 例如口齿不清, 或者是有理解和使用语言以及识字能力(例如阅读和写作)方面的问题。沟通困难可能在诊断患有癌症时或癌症治疗期间出现, 但也可能在癌症治疗后数月或数年出现。

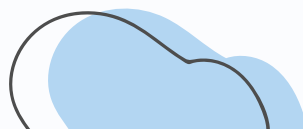




## 建议2

### 应对患有儿童期脑肿瘤或白血病的儿童进行吞咽评估和管理

本指南中提出的吞咽建议主张对患有脑肿瘤或白血病的儿童进行吞咽评估和管理。需要这些措施的原因是这些儿童吞咽食物和液体的能力可能会受到损害。如果食物/液体进入肺部,则会使儿童面临胸部感染的风险,这可能危及生命。据报告,癌症治疗期间经常出现吞咽困难的情况。但是有一些证据表明,在癌症治疗结束之后,吞咽困难也可能会长期存在。



# 执行摘要

## 基于证据的建议1: 沟通

应向患有儿童期脑肿瘤或白血病的儿童提供沟通评估和干预

**强烈建议<sup>a</sup>**

### 主要实践要点

#### 评估和干预

##### 何时评估

应在诊断出患有癌症后尽快进行沟通评估。

沟通评估应在肿瘤治疗阶段和肿瘤随访阶段进行。如果肿瘤护理团队和/或家人存在疑虑,则可能需要在这些阶段进行多次评估。

在儿童的整个生存阶段,直到青春期结束为止,都需要对儿童的沟通能力发展状况进行定期监控。

##### 评估什么

应对言语和语言进行全面评估。评估需要针对儿童的年龄和发育水平进行调整。在适当的情况下,语言评估应包括高级语言、谈话水平技能和读写能力。

评估应包括一系列个性化的评估程序,例如常模参照评估、标准参照工具、护理人员报告以及跨环境的临床观察。

##### 何时干预

对于确诊患有CBTL的儿童,应在肿瘤治疗阶段为已识别出的沟通困难提供早期个体化干预。

针对肿瘤学随访中和生存期直至青春期结束之前发现的沟通困难,应为确诊患有CBTL的儿童及时提供个体化干预。

## 护理团队

从癌症诊断的角度以及在整个肿瘤治疗和随访阶段,言语病理学家应作为肿瘤护理团队中不可或缺的成员来参与其中。

肿瘤护理团队的所有成员都应被告知病人存在沟通困难,并在整个肿瘤治疗和随访阶段参与管理。

言语病理学家应与肿瘤科医生、家庭成员和专业教导人员合作,在整个生存期直至青春期结束之前监测沟通能力的发展。

## 教导

应在诊断出患有癌症时或尽早为家庭提供有关沟通能力发展和CBTL病人所经历的困难等方面的教导。

在整个肿瘤治疗和随访阶段,应继续向家庭提供有关沟通能力发展和CBTL病人所经历的困难方面的教导。

在整个肿瘤随访和生存阶段,应向家庭和专业教导人员提供有关CBTL病人中潜在的长期沟通困难方面的教导。

<sup>a</sup>基于GRADE EtD框架



## 基于证据的建议2: 吞咽

应向患有儿童期脑肿瘤或白血病的儿童提供吞咽评估和管理

**强烈建议<sup>a</sup>**

### 主要实践要点

#### 评估和干预

##### 何时评估

应在诊断出CBTL时或之后尽快进行吞咽评估。

应在肿瘤治疗阶段进行吞咽评估。如果肿瘤护理团队和/或家人表示有疑虑, 则可能需要进行多次评估。

在整个肿瘤随访和生存期, 应继续定期监控儿童的吞咽情况, 直到青春期结束。

##### 评估什么

应进行全面的吞咽评估。评估需要针对儿童的年龄和发育水平进行调整。吞咽的所有阶段(口部吞咽前、口部吞咽准备阶段、口部阶段和咽部阶段)都需要进行评估。

应视情况考虑进行视频透视吞咽研究(VFSS), 作为检查误吸的评估方案的一部分。

##### 何时干预

诊断患有CBTL的儿童应在肿瘤治疗阶段针对吞咽困难得到早期个体化管理。

对于诊断出患有CBTL的儿童, 应在肿瘤随访和生存阶段为肿瘤护理团队和/或家人发现的吞咽困难提供个性化管理。

#### 护理团队

从癌症诊断的角度以及在整个肿瘤治疗阶段, 言语病理学家应作为肿瘤护理团队中不可或缺的成员来参与其中, 以便管理吞咽问题。

肿瘤护理团队的所有成员都应被告知病人存在吞咽困难的情况, 并在整个肿瘤阶段根据需要参与吞咽管理。



言语病理学家应与肿瘤科医生及其家人合作, 在病人整个生存期直至青春期结束之前监测其吞咽情况。

### 教导

应在诊断出患有癌症时或尽早为家庭提供有关CBTL病人所经历的吞咽困难方面的教导。

在整个肿瘤治疗和随访阶段, 应继续向家庭提供有关CBTL病人存在的吞咽困难方面的教导。

<sup>a</sup>基于GRADE EtD框架





