



# PAEDIATRIC PALLIATIVE CARE IN NEW ZEALAND: CLINICAL GUIDELINES FOR END-OF-LIFE CARE

## DEVELOPMENT METHODOLOGY

### 1. Introduction

The Paediatric Society of New Zealand in 2019 commissioned a suite of clinical guidelines for paediatric end of life care in New Zealand. The guidelines addressed 19 stand-alone topics in symptom management, care planning, and psychosocial, spiritual and cultural care. Published on the website of Starship Child Health in 2015, the Guidelines recommended a review and update five years after publication. A literature review and report conducted in 2018 (Chang, 2018) found some of the source guidelines that informed the 2015 Guidelines had been updated and that others had subsequently been published; and recommended that the 2015 Guidelines be updated.

In 2019, the Paediatric Society of New Zealand in 2019 commissioned a review and update of existing Guidelines. This section explains the way that the review and update was conducted.

### 2. Methodology

#### 2.1. Project Aim

The project had two aims:

1. Update existing *Paediatric Palliative Care in New Zealand: Clinical Guidelines of End-of-Life Care* (2015)
2. Create new guidelines for end-of-life care

#### 2.2. Project approach

The project was conducted over 15 months in three consecutive phases. Phase 1 comprised: (1) development of the project plan; (2) completion of a literature review to identify high quality source guidelines; and (3) review of existing project development methodology and tools. Phase 2 consisted of selection of guidelines for inclusion. Phase 3 comprised extraction of relevant material from source guidelines to updating existing guidelines and develop new guidelines.

#### 2.3. Project Personnel

The project was conducted by Dr Elizabeth Bennett and Dr Emily Chang. Reviews and edits completed by the Paediatric Palliative Care Clinical Reference Group, led by Karyn Bycroft (Chair).

## 2.4. Development Process

### 2.4.1. Source guideline assessment

Because of resource constraints that precluded development of guidelines de novo, the 2015 guidelines were adapted from source guidelines. This project used the same internationally-developed instruments that were employed to guide development of the 2015 guidelines: ADAPTE and AGREE II. The ADAPTE instrument guided the overall development process, while the AGREE II instrument was used to: (1) assess the quality of source guidelines; and (2) the quality of new guidelines.

### 2.4.2. Source guideline selection

The following methods were used to locate potential source guidelines:

- Internet searches using search terms *paediatric palliative care* and *end of life care*
- Searches of professional organisation websites
- Emails to: authors of existing source guidelines; Paedpalcare network; New Zealand Paediatric Palliative Care network

Using the AGREE II instrument, we sourced and assessed 32 publicly-available, English-language policy and guidance documents for quality, currency, content and consistency. Twenty guidelines were selected for inclusion. Of these, 10 were source guidelines which informed the 2015 guidelines, seven of which had subsequently been updated. Of these, seven had been updated since 2015. Ten new source guidelines were included. As reference, we also included the Starship Advance Care Plan document.

#### Retained source guidelines (unchanged)

- Children's Health Queensland Hospital and Health Service. 2014. *A Practical Guide to Palliative Care in Paediatrics*. Brisbane: Queensland Government
- Mancini A, Uthaya S, Beardsley C, Wood D and Modi N. 2014. *Practical Guidance for the Management of Palliative Care on Neonatal Units*. Unpublished document of the Royal College of Paediatrics and Child Health and the Chelsea and Westminster Hospital NHS Foundation Trust, Together for Short Lives Website resources search page. <https://www.togetherforshortlives.org.uk/changing-lives/supporting-care-professionals/resources-and-research/>. Accessed 27/11/22
- Texas Pediatric Society. 2014. *Palliative Care Toolkit*. Available at: [Palliative Care Toolkit | Texas Pediatric Society \(txpeds.org\)](https://www.txpeds.org/palliative-care-toolkit) accessed 27/11/22

#### Retained source guidelines (updated)

- Dickson G. 2017. *A Perinatal Pathway for Babies with Palliative Care Needs*. 2<sup>nd</sup> ed. Bristol: Together for Short Lives. Available at: <http://www.togetherforshortlives.org.uk/resource/perinatal-pathway-babies-palliative-care-needs>. Accessed 27/11/22

- Jassal S, Anderson A, Griffiths J, Mellor C, Hain R, Lidstone V. 2016. Paediatric Palliative Care Guidelines 4<sup>th</sup> Ed. Available at: <http://paed.pallcare.info>. Accessed 27/11/22
- Jassal, Satbir Singh (ed). 2016. Basic Symptom Control in Paediatric Palliative Care: The Rainbows Children's Hospice Guidelines. Ed 9.5. Unpublished document of The Rainbows Children's Hospice Guidelines. Available at: <http://www.togetherforshortlives.org.uk/resource/basic-symptom-control-paediatic-palliative-care/>. Accessed 27/11/22
- The Sydney Children's Hospital Network. Pain Management CHW- Practice Guideline 2019. Available at: <http://www.schn.health.nsw.gov.au/policies/pdf/2006-8215.pdf>. Accessed 27/11/22
- The Sydney Children's Hospital Network. Palliative Care for Inpatients Practice Guideline 2016. Available at: <http://www.schn.health.nsw.gov.au/policies/pdf/2013-9075.pdf>. Accessed 27/11/22
- Starship Child Health. 2018. Allow Natural Death (Te Wa Aroha). Available at: <https://www.starship.org.nz/guidelines/allow-natural-death-te-wa-aroha>. Accessed 29/11/22
- West Midlands Paediatric Palliative Care Network. 2018. Toolkit Available at: <http://www.togetherforshortlives.org.uk/resource/west-midlands-toolkit/>. Accessed 29/11/22

### **New source guidelines**

- Child and young person's advance care plan collaborative. Child and young person's advance care plan policy v1.6. Unpublished document of the Child and young person's advance care plan collaborative. Available at: <http://cypacp.uk/document-downloads/policy/>. Accessed 29/11/22
- Jassal S ed. 2020. The Association of Paediatric Palliative Medicine Master Formulary 5th edition 2020. The Association of Paediatric Palliative Medicine. <https://www.appm.org.uk/guidelines-resources/appm-master-formulary/>. Accessed 29/11/22
- Knops Rutger R, Kremer Leontien C, Verhagen A Eduard, on behalf of Dutch Paediatric Palliative Care Guideline Group for Symptoms. Paediatric palliative care. 2015. Recommendations for treatment of symptoms in the Netherlands. BMC Palliative Care 14:57. Doi:10.1186/s12904-015-0054-7. Available at: <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-015-0054-7>. Accessed 29/11/22
- National Institute for Health and Care Excellence. 2016. End of life care for infants, children and young people. Unpublished document of the National Institute for Health and Care Excellence. Available at: <https://www.nice.org.uk/guidance/ng61/chapter/Recommendations>. Accessed 29/11/22

- Palliative Care Australia. 2018. *Paediatric Addendum: Palliative Care Service Development Guidelines*. Canberra: Australian Government Department of Health. Available at: [https://palliativecare.org.au/wp-content/uploads/dlm\\_uploads/2018/12/PalliativeCare-Paediatricaddendum-2018\\_web.pdf](https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/PalliativeCare-Paediatricaddendum-2018_web.pdf). Accessed 29/11/22
- Royal Australasian College of Physicians. 2016. Improving care at the end of life: Our roles and responsibilities. Unpublished document of the Royal Australasian College of Physicians. Available at: <https://www.racp.edu.au/docs/default-source/advocacy-library/pa-pos-end-of-life-position-statement.pdf>. Accessed 29/11/22
- Starship Child Health 2019. Acute pain relief in children with renal impairment. Unpublished document of Starship Child Health. Available at: <https://www.starship.org.nz/guidelines/acute-pain-relief-in-children-with-renal-impairment>. Accessed 29/11/22
- Starship Child Health. 2014. Intranasal Fentanyl. Unpublished document of Starship Child Health. Available at: <https://www.starship.org.nz/guidelines/intranasal-fentanyl/>. Accessed 29/11/22
- Starship Child Health. 2019. Pain - Paediatric pain assessment. Unpublished document of Starship Child Health. Available at: <https://www.starship.org.nz/guidelines/paediatric-pain-assessment/>. Accessed 29/11/22
- Starship Child Health. 2019. Regional infusions for pain. Unpublished document of Starship Child Health. Available at: <https://www.starship.org.nz/guidelines/regional-infusions-for-pain>. Accessed 29/11/22

### Reference document

- Starship Child Health. No date. *Advance Care Plan*. Unpublished document of Starship Child Health.

Data was extracted from the source guidelines and draft clinical guidelines were developed according to the protocols of the ADAPTE instrument. Draft guidelines were reviewed by the Project Group, the New Zealand Clinical Reference Group and three Australian reviewers, before development of the final version.

## 2.5. Development of Guidelines

### 2.5.1. Pain and symptom management

It is appropriate to address specific issues in the development of guidelines for pain and symptom management. We point out that no set of guidelines can cover all variations required for specific patient circumstances. We emphasise the responsibility of clinicians who use these guidelines to adapt them for safe use within their institutions and according to the needs of individual patients.

The topics selected by the development group, took into account the following:

- How likely the symptom is to occur in a population of paediatric palliative care patients
- Level of specialist knowledge required to effectively manage a given symptom

Dosing information has largely been taken from *A Practical Guide to Palliative Care in Paediatrics* (Children's Health Queensland Hospital and Health Service, 2014). This reference was chosen because the drugs available, and prescribing practices, are similar in Australia and New Zealand.

Dosing information included in the Pain Management Guideline references the *WHO Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses* (WHO, 2012). This reference was used because of its high AGREE II rating.

Pain and symptom management guidelines are provided for use by specialist paediatric health care professionals in New Zealand. While great care has been taken to see that the information in this section is accurate, users are advised to check drug doses carefully. Where there is uncertainty regarding the guidance provided, users are advised to seek advice. Telephone advice is available from the Palliative Care Service at Starship Children's Health.

Medication doses given in pain and symptom management guidelines are standardised by *body-weight*. To calculate the dose for a given child the weight-standardised dose is multiplied by the child's weight (or, occasionally, by the child's ideal body-weight for height). The calculated dose should not normally exceed the maximum recommended dose for an adult. For example, if the dose is 8 mg/kg (maximum 300 mg), a child of 10 kg body-weight should receive 80 mg, but a child of 40 kg body-weight should receive 300 mg (rather than 320 mg).

Calculation by body-weight in the overweight child may result in much higher doses being administered than necessary; in such cases, the dose should be calculated from an ideal body-weight for height. For WHO mean values, see [Weight, height, and gender \(mean values\)](#).

### **2.5.2. Planning end of life care**

The 2015 guidelines that addressed care planning comprised: Sharing Significant News; and Planning Care. Our source guidelines provided better and more specific information, enabling more specific new guidelines. These include:

- Sharing Significant News about End of Life
- Planning End of Life Care
- Location of End of Life Care
- Allow Natural Death
- Organ and Tissue Donation
- Dispute Resolution

### 2.5.3. Psychosocial, spiritual and cultural support

Three 2015 guidelines related to psychosocial, spiritual and cultural care. These were: Psychosocial Care; Spiritual Care; and Cultural Care. Source guidelines suggest a different structure, and so, new guidelines comprise:

- Emotional and Psychological Support at End of Life
- Supporting Beliefs and Values at End of Life

## 3. ADAPTE Instrument

The ADAPTE Collaboration is an international group of researchers, guideline developers and implementers who have developed a generic process that aims to foster and validate high-quality guidelines. The ADAPTE instrument guides a systematic development process that is flexible and adaptable to specific circumstances. It is supported by a resource toolkit and specific tools. The ADAPTE process comprises three stages, each of which has specific components:

### Setup phase

- Outlines specific tasks to be completed before adaptation process begins

### Adoption phase

- Assists process of topic and question selection
- Guides process of searching for, and retrieving guidelines
- Guides assessment of consistency of evidence and guideline quality, currency, content and adoption
- Assists in preparing drafts of adopted guidelines

### Final phase

- Guides users through stakeholder feedback process
- Guides consultation with developers of original guidelines
- Assists in updating original guidelines
- Guides creation of final document (ADAPTE Collaboration, 2009)

## 4. AGREE II Instrument

The ADAPTE developers recommend the use of the Appraisal of Guideline Research and Evaluation (AGREE II) instrument to appraise the quality of original guidelines, in order to assess their appropriateness for adaptation, as well as adapted guidelines.

AGREE II is an internationally used tool which is both valid and reliable. It is used to assess methodological rigour and transparency of development process. The tool comprises 23 items which are organised in six domains. These are:

- *Scope and purpose*, which assesses: the overall aim of guideline; specific questions or topics; and the target population
- *Stakeholder involvement*, which assesses the extent of development by appropriate stakeholders
- *Rigour of development*, which assesses: the process used to gather and synthesise evidence; and methods used to formulate recommendations

- *Clarity of purpose*, which assesses the language, structure and format
- *Applicability*, which assesses: barriers and facilitators to implementation; strategies to improve uptake; and resource implications
- *Editorial independence*, which assesses the formulation of recommendations based on competing interests

As well, an overall assessment of quality is facilitated by the tool. AGREE II recommends two to four reviewers, who complete four-point scale answers.

AGREE II comprises a comprehensive users' manual and specific tools, which include training tools. An online appraisal platform is provided on the AGREE website ([www.agreetrust.org](http://www.agreetrust.org)) (Brouwers et al, 2010).

The table below sets out: (1) the key processes and components of the international tools and the relationships between each; (2) the components which were adopted, adapted or omitted; and (3) the involvement of project teams in the development process.

ADAPTE/AGREE II PROCESS	NZ PROCESS	TOOLS AND GUIDELINES	RESOURCES
<b>Phase 1: Setup</b>			
Check whether adaptation feasible	No change	ADAPTE	Development team
Establish organising committee	Establish review group	ADAPTE	Development team
Select topic	No change	ADAPTE	Development team Project team
Identify skills and resources needed	No change	ADAPTE	Development team Project team
Complete setup tasks	No change	ADAPTE	Development team
Write protocol	No change	ADAPTE	Development team
<b>Phase 2: Adaptation</b>			
Determine topic and question	No change	PIPOH instrument	Development team Project team
Search for guidelines and other relevant documentation	No change	ADAPTE	Development team
Screen retrieved guidelines	No change	AGREE II	Development team
Reduce number of required	No change	AGREE II	Development team

Assess guideline quality, currency, content, consistency	Modified assessment (reflects quality of source guidelines)	AGREE II	Development team Project Team
Assess acceptability and applicability of recommendation	Modified assessment (reflects quality of source guidelines)	ADAPTE	Development team Project team
Prepare guideline	No change	ADAPTE	Development team
<b>Phase 3: Finalisation</b>			
External review by target users	Review by Clinical Reference Group members and external reviewers	ADAPTE	Clinical Reference Group External reviewers
Consult with relevant endorsement bodies	Omit	-	-
Consult with developers of source guidelines	No change	-	Development team
Acknowledge source document	No change	-	Development team
Plan for aftercare of document	Omit (outside of scope)	-	-
Produce final document	No change	-	Development team Clinical Reference Group



## References: Development Methodology

ADAPTE Collaboration. 2009. *The ADAPTE Process: Resource Toolkit for Guideline Adaptation*. Version 2.0. Available at: <http://www.g-i-n.net> accessed 29/11/22

Chang, E. 2018. *Paediatric Palliative Care in New Zealand: Clinical Guidelines for End-of-Life Care. When Should Clinical Guidelines for End-of-Life Care be Updated?* Unpublished report of the Paediatric Society of New Zealand.

Brouwers M, Kho ME, Browman GP, Burgers JS, Cluzeau F et al, for the AGREE II Consortium. 2010. Advancing guideline development, reporting and evaluation in healthcare. *Canadian Medical Association Journal* 182E:839-42 doi.10.1503/090449