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Clinical guidelines for children and young people with palliative care needs in all care settings during the COVID-19 pandemic

17 April 2020

This clinical guidance, produced by the Association of Paediatric Palliative Medicine (APPM), is aimed at all professionals looking after children and young people with palliative care needs who are infected with COVID-19, potentially entering their end of life phase and the decision is not for medical escalation into paediatric intensive care.

Children and young people

It is important to remember that most people with COVID-19 will survive and recover. Children and young people (CYP), on the whole, experience mild or moderate symptoms. Notwithstanding this, CYP with palliative care needs may become more vulnerable when exposed to COVID-19, impacting on a CYP's already vulnerable health status.

Decision-making around treatment escalation plans

In the context of the COVID-19 pandemic, decisions about treatment escalation or shifting the focus to palliative care may need to be made rapidly. Ideally health and care professionals should be identifying high-risk patients early and ensuring advance care planning discussions take place. Conversations around specific pandemic concerns should be addressed and may include:

- Delivery of end of life care in the family's preferred place not being possible (eg due to workforce limitations and restrictions on transfer of patients between care settings).
- Awareness that the presence of family members may be limited, including the end of life phase (because family members are needing to self-isolate and/or access is restricted by an institution's infection control policies).

Where escalation of medical intervention onto a paediatric intensive care unit is not considered appropriate, care will continue with a change in its focus to high quality, compassionate, palliative care.

Contacting specialist paediatric palliative care

Some regions have access to specialist paediatric palliative care teams. These teams can provide tailored advice and support. **It is important to know how to contact your local paediatric palliative care service for advice and support.** Consider contacting when:

- patient already known to specialist palliative care
- needing support and guidance on symptom management or not responding to clinical guidelines
- complex symptoms that require specialist advice
- decision not to escalate treatment in the face of deterioration or uncertain prognosis.

Principles of palliative care

Despite the challenging circumstances of the COVID-19 pandemic, the importance of holistic child and family centred care is recognised and should be offered, albeit, in potentially new, unique and innovative ways.

Clinical approach

- Consider and treat reversible causes, eg secondary bacterial infections.
- Many patients will survive. Managing their symptoms during this period remains important.
- Use non-pharmacological approaches, especially in mild to moderate infections.
- If the patient is severely distressed by shortness of breath and/or agitated, then stat doses of medication delivered by SC/IV/buccal offers rapid relief compared to infusions and oral routes.

Symptoms of COVID-19

The end of life phase can be distressing and rapid, lasting just a few hours. The most common end of life symptoms have been addressed (see Appendix 1):

- pyrexia and rigors
- severe dyspnoea
- cough
- delirium and agitation.

Challenges in secretion management in some patients who have an underlying neurological disorder have also been reported and may be pertinent to the paediatric population, requiring a fine balance between removing and/or 'drying-up' copious loose secretions and loosening thick tenacious secretions.

Appendix 1

1.1 Management of fever in children and young people at end of life with recognised coronavirus infection COVID-19 outbreak

It is generally understood that children and young people experience milder coronavirus symptoms compared with adults. However, these guidelines have been written to support symptom management, in the potentially rare event, of a children or young people with a life limiting condition whose advance care plan is not for escalation into a paediatric intensive care unit.

Fever is when a human's body temperature goes above the normal range of 36–37° Centigrade (98–100° Fahrenheit). It is a common medical sign. Other terms for a fever include pyrexia and controlled hyperthermia. As the body temperature goes up, the person may feel cold until it levels off and stops rising.

Is it fever?

- significant fever is defined as a body temperature of:
 - 37.5°C or greater (oral)
 - 37.2°C or greater (axillary)
 - 37.8°C or greater (tympenic)
 - 38°C or greater (rectal)
 - A few children may have an altered central thermostat related to their neuro-disability. In these cases, smaller temperature rises may require earlier intervention
- associated signs & symptoms:
 - shivering
 - shaking
 - chills
 - Flushed face or cheeks
 - aching muscles and joints
 - other body aches

Non-pharmacological measures

- reduce room temperature
- wear loose clothing
- cooling the face by using a cool flannel or cloth
- keep well hydrated
- cooling the face by using a cool flannel or cloth
- portable fans used in clinical areas have been linked to cross infection in health and social care facilities, although there is no strong evidence yet
- portable fans are not recommended for use during outbreaks of infection or when a patient is known or suspected to have an infectious agent

Pharmacological measures*

Paracetamol PO/IV/PR

Dose is dependent on age and route (cBNF)

NSAIDS is contraindicated in COVID-19 infections. At end of life, clinicians need to consider its benefit on a case by case, in reducing the fever.

Normal body temperature: 98.6°F (37°C)



Body fever temperature: > 100°F (37.7°C)



Rectal fever temperature: > 100.5°F (38°C)



*For SC/IV and neonate/infant dosing: consult the APPM formulary 2020 (<https://www.appm.org.uk/guidelines-resources/appm-master-formulary/>)

1.2 Management of delirium for children and young people at end of life with recognised coronavirus infection COVID-19 outbreak

It is generally understood that children and young people experience milder coronavirus symptoms compared with adults. However, these guidelines have been written to support symptom management, in the potentially rare event, of a children or young people with a life limiting condition whose advance care plan is not for escalation into a paediatric intensive care unit.

Delirium is an acute confusional state that can happen when someone is ill. It is a **sudden** change over a few hours or days and tends to vary at different times of day. People may be confused at sometimes and then seem their normal selves at other times. People who become delirious may start behaving in ways that are unusual for them- they may become more agitated than normal or feel more sleepy and withdrawn.

Non-pharmaceutical measures

- identify and manage the possible underlying cause or combination of causes, eg fever
- ensure effective communication and reorientation (for example explaining where the person is, who they are, and what your role is) and provide reassurance for people diagnosed with delirium
- parents, carers, family and familiar health professionals may offer more reassurance
- familiar surrounding

Pharmacological measures*: first line

- Midazolam buccal
 - For 1-9 years:
Midazolam buccal 50-100micrograms/kg (max 2.5mg)
 - For 10-17years:
Midazolam buccal 1.5-3mg

Pharmacological measures*: second line

Option 1

1-17years:
Haloperidol
10-20 micrograms/kg every 8-12 hours PRN PO
(max: 5mg twice a day)

Option 2

2-11 years:
Levomepromazine
50-100 micrograms/kg twice/day PRN PO
(max 1mg/kg/dose; 25mg/dose)

12-17 years:
Levomepromazine
3mg twice/day PRN PO
(max dose 25mg/dose)

Option 3

For 10-17 years:
Lorazepam S/L 0.5-1mg TDS PRN

Management of this symptom, which is distressing for parents, carers and staff (patients are usually unaware of what they are doing at this time), can be troublesome. Through use of the medications above, titrated appropriately, this can usually be managed effectively. Delirium may be reduced with important delirium prevention strategies (orientation, management of fever and hypoxia, treatment of urinary tract infections, etc).

*For SC/IV and neonatal/infant dosing: consult the APPM formulary 2020 (<https://www.appm.org.uk/guidelines-resources/appm-master-formulary/>).

1.3 Management of cough for children and young people at end of life with recognised coronavirus infection COVID-19 outbreak

It is generally understood that children and young people experience milder coronavirus symptoms compared with adults. However, these guidelines have been written to support symptom management, in the potentially rare event, of a children or young people with a life limiting condition whose advance care plan is not for escalation into a paediatric intensive care unit.

Cough is a protective reflex response to airway irritation and is triggered by stimulation of airway cough receptors by either irritants or by conditions that cause airway distortion.

Cough hygiene

To minimise the risk of cross-transmission:

- cover the nose and mouth with a disposable tissue when sneezing, coughing, wiping & blowing the nose
- dispose of used tissues promptly into clinical waste bin used for infectious or contaminated waste
- clean hands with soap and water, alcohol hand rub or hand wipes after coughing, sneezing, using tissues, or after contact with respiratory secretions or objects contaminated by these secretions

Non-pharmacological measures

- humidify room air
- oral fluids
- honey & lemon in warm water
- elevate the head when sleeping

Pharmacological measures*

- If history of reactive airways consider Salbutamol or Atrovent inhaler/ nebuliser
- Suppress cough, eg Simple Linctus 5ml to 10ml TDS to QDS

If these measures fail, seek specialist advice, to discuss:

- For persistent irritant cough, morphine sulphate immediate release solution 30-50% of pain dose.
 - If no cough after 72hrs reduce and stop
- Further option:
- Sodium Cromoglycate aerosol inhalation



*For SC/IV and neonatal/infant dosing: consult the APPM formulary 2020 (<https://www.appm.org.uk/guidelines-resources/appm-master-formulary/>).

1.4 Management of breathlessness in children and young people at end of life with recognised coronavirus infection COVID-19 outbreak

It is generally understood that children and young people experience milder coronavirus symptoms compared with adults. However, these guidelines have been written to support symptom management, in the potentially rare event, of a children or young people with a life limiting condition whose advance care plan is not for escalation into a paediatric intensive care unit.

Breathlessness is the subjective sensation of discomfort with breathing and is a common cause of major suffering in people with acute, advanced and terminal disease. Treat **reversible** conditions. Both COVID-19 and non-COVID-19 conditions (eg respiratory compromise secondary to their neurodisability, metastatic lung disease) **may** cause severe breathlessness / distress toward end of life.

Reversible causes

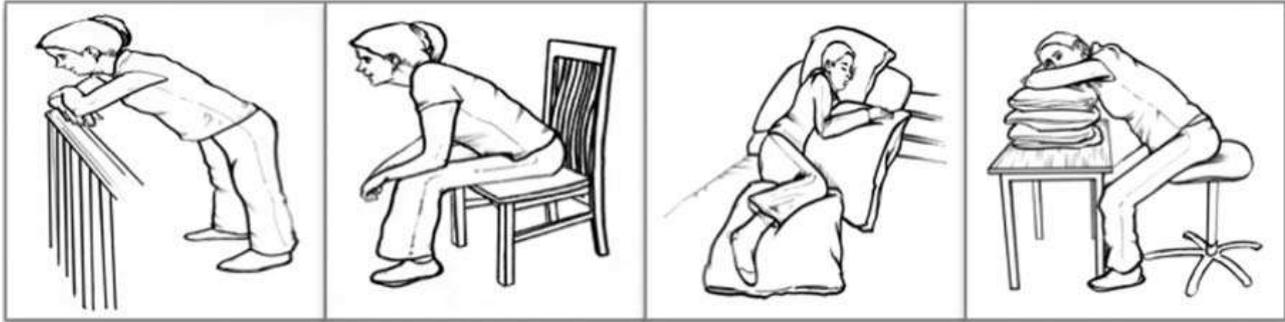
- both COVID-19 and non-COVID-19 conditions **may** cause severe distress / breathlessness toward end of life
- consider reversible or contributing causes eg fever, pain, wheeze
- observe signs/symptoms of breathlessness:
 - Fatigue
 - Peripheral/central cyanosis
 - Reduced peripheral perfusion
 - Increased respiratory rate
 - Increased respiratory effort: tracheal tug, grunting, intercostal/subcostal recession and

Non-pharmacological measures

- positioning (child often finds best position themselves)
- relaxation techniques
- reduce room temperature
- cooling the face by using a cool flannel or cloth
- portable fans used in clinical areas have been linked to cross infection in health and social care facilities, although there is no strong evidence yet
- portable fans are not recommended for use during outbreaks of infection or when a patient is known or suspected to have an infectious agent

Pharmacological measures*

- humidified oxygen (no evidence of benefit in the absence of hypoxaemia)
- opioids may reduce the perception of breathlessness
 - For 1-11 years:
Oramorph (10mg/5ml)
100micrograms/kg
(max 2.5mg) 4hrly PO PRN
 - For 12-17years:
Oramorph (10mg/5ml)
2.5mg every 4hrly PO PRN
- anxiolytics for agitation/distress
 - For 1-9 years:
Midazolam buccal
50-100micrograms/kg PRN
(max 2.5mg)
 - For 10-17years:
Midazolam buccal 1.5-3mg
 - For 10-17 years:
Lorazepam S/L 0.5-1mg
TDS PRN



Forward lean 1

Forward lean 2

Adapted forward lean for lying

Adapted forward lean for sitting

*For SC/IV and neonatal/infant dosing: consult the APPM formulary 2020 (<https://www.appm.org.uk/guidelines-resources/appm-master-formulary/>).