COVID-19 and Paediatric Palliative, End of Life and Bereavement Care (Northern Ireland)

Version date: 28th April 2020

Context and Disclaimer

The current worldwide COVID-19 pandemic is unprecedented and requires everyone to work together to contribute to the health and well-being of populations, as well as ensure that appropriate guidance and sharing of good practice occurs. This is essential in order to support the care of patients at the end of their lives, or who are significantly unwell as the result of both COVID-19 and their underlying life-limiting illness.

This guidance is based on guidance produced by the Association for Palliative Medicine of Great Britain and Ireland (APM) https://apmonline.org/ and Northern Care Alliance NHS Group, and is adapted for use in children and young people in collaboration with the Association of Paediatric Palliative Medicine (APPM) https://www.appm.org.uk and Paediatric End of Life Care Managed Clinical Network (PELiCaN). While is it not nationally endorsed by the National Health Service, it is hoped useful for colleagues across the country to support the provision of end-of-life care in challenging circumstances. The RCPCH has published guidance on the management of COVID 19 in the healthcare setting, and have regular updates via their website, https://www.rcpch.ac.uk/key-topics/covid-19

Staff should be aware that this guidance is subject to change as developments occur. Every effort will be made to keep this guidance up to date. Additional information can be found at https://www.gov.uk/coronavirus and https://www.publichealth.hscni.net/news/covid-19-coronavirus

The utmost consideration and care must be given to the safety of other patients, visitors and staff by maintaining infection control procedures at all times.

Given the rapidly evolving scenario, the information contained within this document has been reviewed by experts across the paediatric palliative care profession. However none of the aforementioned organisations; Northern Care Alliance NHS Group, APM, APPM or PELiCaN can accept any responsibility for errors or omissions in this document.

This guidance was originally written to support care provision in Scotland and has been adapted through the APPM for use in England, Wales and Northern Ireland.

Dr Jonathan Downie
Consultant in Paediatric Palliative Medicine
Paediatric Supportive and Palliative Care Team
Royal Hospital for Children
Glasgow

Adapted for use in Northern Ireland by:
Dr Marian Williams
Consultant Paediatrician, Southern Health and Social Care Trust, Northern Ireland and Executive committee member of the APPM

Endorsements

- Dr Anna Karenia Anderson, Chair of the Association of Paediatric Palliative Medicine (APPM) and Consultant in Paediatric Palliative Medicine, The Royal Marsden NHS Foundation Trust, London and Shooting Star Children's Hospice, Surrey

- Dr Chris Kidson, Clinical Lead 'Paediatric end-of-life Care network (PELiCaN) National Managed Clinica Network' and Consultant Paediatric Intensivist, Royal Hospital for Children, Glasgow

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- Dr Ella Aidoo, Consultant in Paediatric Palliative Medicine, Evelina Children's Hospital, London

- Dr Lizzie Bendle, Consultant in Paediatric Palliative Medicine, Evelina Children's Hospital, London

- Stephen Bowhay, Lead Pharmacist, Royal Hospital for Children, Glasgow

- Gillian Bowskill, Lead Nurse Infection Prevention and Control Paediatrics, Royal Hospital for Children, Glasgow

- Dr Morag Campbell, Clinical Director, Critical Care and Neonatology and Consultant Neonatologist, Royal Hospital for Children, Glasgow

- Dr Pat Carragher, Medical Director, Children's Hospices Across Scotland (CHAS)

- Dr Finella Craig, Consultant in Paediatric Palliative Medicine, Great Ormond Street Hospital for Children NHS Foundation Trust, London

- Dr Phil Davies, Consultant in Paediatric Respiratory Medicine, Royal Hospital for Children, Glasgow

- CNS Michelle Deans, Clinical Nurse Specialist, Paediatric Supportive and Palliative Care Team, Royal Hospital for Children, Glasgow

- Eileen Docherty, Mortuary Manager, Queen Elizabeth University Hospital and Royal Hospital for Children, Glasgow

- Dr Jo Griffiths, Consultant in Paediatric Palliative Medicine and Community Child Health. All Wales Managed Clinical Network and Swansea Bay University Health Board

- Dr Emily Harrop, Consultant in Paediatric Palliative Care and Medical Director of Helen and Douglas House, Oxford

- CNS Elizabeth-Anne Kelly, Clinical Nurse Specialist, Paediatric Supportive and Palliative Care Team, Royal Hospital for Children, Glasgow

- Dr Louise Leven, Consultant Neonatologist, Royal Hospital for Children, Glasgow

- Dr Lesley Jackson, Consultant Neonatologist, Royal Hospital for Children, Glasgow

- CNS Katrina Marshall, Clinical Nurse Specialist Children and Young People's Palliative Care, Royal Hospital for Children and Young People, NHS Lothian

- Dr Lorna McKerracher, StR Neonatal Medicine, Royal Hospital for Children, Glasgow

- Kate McCusker, Lead Pharmacist, Children's Hospices Across Scotland (CHAS)

- Mr Bhumik Patel, Senior Specialist Pharmacist in Paediatric Palliative Care, Great Ormond Street for Children NHS Foundation Trust

- Caroline Pretty, Bereavement Coordinator, NHS Lothian

- CAMHS Team, Southern Health and Social Care Trust, NI
- Grace Stewart, Head Of Childrens Hospice Services, NICH
- Debbie Burns, Director of Care and Quality Governance, NI Hospice
- Dawn McKimm, Team Manager, Northern Ireland Organ Donation Team
- Dr Sharon McCloskey, Trust Bereavement Co-ordinator, Southern HSC Trust
- Medical leads, Paediatric Palliative Care, NI

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Background: COVID-19

Coronaviruses are mainly transmitted by large respiratory droplets and direct or indirect contact with infected secretions. They have also been detected in blood, faeces and urine and, under certain circumstances, airborne transmission is thought to have occurred from aerosolised respiratory secretions and faecal material.

As coronaviruses have a lipid envelope, a wide range of disinfectants are effective. PPE and good infection prevention and control precautions are effective at minimising risk but can never eliminate it.

As COVID-19 has only been recently identified, there is currently limited information about the precise routes of transmission. This guidance is based on knowledge gained from experience in responding to coronaviruses with significant epidemic potential such as Middle East Respiratory Syndrome Coronavirus (MERS-CoV) and Severe Acute Respiratory Syndrome Coronavirus (SARS-CoV).

Emerging information from these experiences has highlighted factors that could increase the risk of nosocomial transmission, such as delayed implementation of appropriate infection prevention and control measures combined persistence of coronavirus in the clinical setting.

How long any respiratory virus survives in the environment will depend on a number of factors, for example:

- the surface the virus is on
- whether it is exposed to sunlight
- environmental conditions such as temperature and humidity
- exposure to cleaning products

Under most circumstances, the amount of infectious virus on any contaminated surfaces is likely to have decreased significantly by 72 hours.

In the absence of effective drugs or a vaccine, control of this disease relies on the prompt identification, appropriate risk assessment, management and isolation of possible cases, and the investigation and follow up of close contacts to minimise potential onward transmission.

Effective infection prevention and control measures, including transmission-based precautions (airborne, droplet and contact precautions) with the recommended PPE are essential to minimise these risks. Appropriate cleaning and decontamination of the environment is also essential in preventing the spread of this virus.

Paediatric Context: COVID 19

The great majority of children who test positive for COVID 19 appear to have a mild or moderate form of the disease. The hypotheses around why children appear to have a milder form of COVID 19 include variations in the composition and functionality of the developing immune system. One reason maybe that the virus appears to directly infect cells via ACE2 receptors. In children's lungs the cells appear to express this receptor less but the answer is as yet unclear.
While children are less likely to become unwell with COVID 19, there are subpopulations of children with an increased risk for more significant illness, including those of pre-school age and those with underlying health vulnerabilities i.e. lung disease/immune deficiencies. Consensus for these populations has been to follow government guidance on shielding and isolation. This will help children to remain well and avoid exposure to COVID 19.

Fortunately, even the very small number of children who develop moderate to severe disease appear to recover well, and as such we would not anticipate an increase in mortality over this period. This is important as our goals of care for children with COVID 19 should, unless agreed as part of clear anticipatory care planning, include consideration of full supportive care, identification and treatment of reversible factors with an aim of restoring health and promoting recovery.

However, this is a worrying time for children, young people and their families. Open, honest and regular communication is important. In addition, the Paediatric Clinical Psychology Service at the Royal Hospital for Children have compiled a list of useful resources to support children, young people and their families through this uncertain time.
The CAMHS team from the Southern Health and Social Care Trust, Northern Ireland, have forwarded further resources, some of which are NI specific.
See Appendix A.

How Palliative, End of Life & Bereavement Care Services can contribute

Palliative, end of life and bereavement care (PEoLB), which is based on effective symptom control, promotion of quality of life, complex decision-making and holistic care of physical, psychological, social and spiritual health is ideally placed to provide care and support to patients, those close to them and colleagues during the COVID-19 outbreak.

Even in the presence of a mild or moderate viral illness, including COVID 19, deterioration in an underlying or co-existing illness may occur. This can lead to reduced reserve and increased vulnerability, and create a situation where a child or young person becomes sick enough that they may die. PEoLB skills of discussing and reviewing advance care plans, ensuring a comfortable and dignified death and supporting families and colleagues will be imperative.

Where healthcare resources and facilities come under considerable pressure and there are concerns that the medical intervention for an individual patient may offer no or limited benefit, the management of patients not expected to survive requires complex and collaborative decision-making and communication to patients and those close to them. In this scenario, PEoLB professionals can support their colleagues in the processes of triage and planning, collaborative decision-making, guiding difficult conversations and coordinating care.

Given the current restrictions on travel and hospital visiting, there may be times where conversations with families regarding decision making, sharing clinical and prognostic information and offering support may be required to be carried out remotely. This is an area where PEoLB professionals are already highly skilled and can be utilised effectively during the COVID-19 outbreak.

Purpose of Paediatric-Specific guidance

All professionals have a responsibility to provide palliative and end of life care symptom control in irreversible situations and also to support honest conversations about goals of care. Treatment escalation planning should be initiated as early as is practicable so that a personalised care and support plan can be developed and documented.

This guidance is specifically for children and young people with symptomatic COVID 19 disease who have an underlying serious illness and are either irreversibly deteriorating despite full active management or have prior limitations of treatment escalation in place (i.e. through an advance or anticipatory care plan).

This guidance is aimed at all professionals and carers in Northern Ireland who are supporting children and young people with COVID-19, and their families, in the hospital setting – whether this is in intensive care or elsewhere in the hospital.

Contacting Paediatric Palliative Care Lead

Each Health and Social Care Trust in Northern Ireland has a medical lead for Paediatric Palliative Care.

Consider contacting when:

- Patient already known to 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

Contact details for Trust medical leads for Paediatric Palliative Care

Belfast Health and Social Care Trust
Dr Mairead McGinn
Tel No. 07810838085
Email: Mairead.McGinn@belfasttrust.hscni.net

Northern Health and Social Care Trust
Dr Ruth Sutherland
Tel No. (028) 27660330
Email:
Ruth.Sutherland@northerntrust.hscni.net

South Eastern Health and Social Care Trust
Dr Karen Courtenay
Tel No. (028) 90484511 or 07711391122
Email: Karen.Courtenay@setrust.hscni.net

Western Health and Social Care Trust
Dr Joe Clarke
Community Paediatrics
Bridgeview House
Gransha Park
Derry
Tel No. (028) 7186 5298
Email: joe.clarke@westerntrust.hscni.net

Southern Health and Social Care Trust
Dr David Graham (Craigavon)
Tel No. (028) 38334444
Email: David.Graham@southerntrust.hscni.net
Dr Marian Williams (Newry)
Tel No. (028) 30835000
Email: Marian.Williams@southerntrust.hscni.net

NI Childrens Hospice (Horizon House)

Northern Ireland Children's Hospice
Horizon House
18 O'Neill Road
Newtownabbey
BT36 6WB

Phone: 028 9077 7635

https://www.nihospice.org/referrals

Decision-making around treatment escalation plans

In the context of the COVID-19 pandemic, decisions about treatment escalation or reorienting the focus to supportive palliative care may need to be made rapidly. Ideally professionals should be identifying high risk patients early and ensuring advance care planning discussions are taking place. Conversations around specific pandemic concerns should be addressed including recognising the potential impact on preferred place of death (e.g. workforce limitations) and the presence of family (e.g. needing to self-isolate or access is restricted by institution's infection policies) during end of life.

Where escalation of medical intervention on to a paediatric intensive care unit is not considered appropriate, the switch in focus to high quality, compassionate palliative care is equally important.

Specific ethical guidance for use in the COVID-19 pandemic has been developed by the Royal College of Paediatrics and Child Health (RCPCH), available at https://www.rcpch.ac.uk/resources/ethics-framework-use-acute-paediatric-settings-during-covid-19-pandemic

How to use the symptom management flowcharts

These flowcharts relate to the relief of the common symptoms that may arise because of an infection with COVID-19, including how they should be managed if the patient is dying:

- breathlessness
- cough
- delirium
- fever
- pain
- secretions

This guidance is not intended as a substitute for specialist palliative care advice, nor is it intended to replace local paediatric palliative care symptom control guidelines of the local formulary.

They are described in terms of the severity of the disease and adopt the general approach of:

- correct the correctable
- non-drug approaches
- drug approaches

These guidelines assume that the patient is receiving all appropriate supportive treatments and that correctable causes of the symptoms have been considered and managed appropriately. Examples include:

- antibiotic treatment for a superadded bacterial infection may improve fever, cough, breathlessness and delirium
- optimising treatment of co morbidities may improve cough and breathlessness.

Generally, non-drug approaches are preferred, particularly in mild to moderate disease. Drug approaches may become necessary for severe distressing symptoms, particularly in severe disease.

Typical starting doses of drugs are given. However, these may need to be adapted to specific patient circumstances e.g. organ failure. Seek appropriate advice from the relevant specialists including specialist palliative care teams.

It is anticipated that critically ill patients with Acute Respiratory Distress Syndrome (ARDS) will be mechanically ventilated and be receiving some level of sedation ± strong opioids. Death may still ensue from overwhelming sepsis or organ failure. If endotracheal extubation is planned in a dying patient, teams should follow their own guidelines on withdrawal of ventilation.

Management of breathlessness in children and young people COVID-19 Outbreak

Note: This guidance is specifically for children and young people with symptomatic COVID 19 disease who have an underlying serious illness and are either irreversibly deteriorating despite full active management or have prior limitations of treatment escalation in place (i.e. through an advance or anticipatory care plan).

Breathlessness is the subjective sensation of discomfort with breathing and is a common cause of major suffering in children and young people with acute, advanced and terminal disease. Treatment of underlying causes of dyspnoea should be considered and optimised where possible. Both COVID-19 and non-COVID-19 conditions ***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 'abdominal breathing' in infants
- consider oxygen saturation check

Non-pharmacological measures

- positioning
- relaxation techniques
- reduce room temperature
- cooling the face by using a cool flannel or cloth
- Portable or hand held fans must NOT be used
- Relaxation techniques, CD or DVD

Pharmacological measures

Oxygen therapy:
No benefit in the absence of hypoxia

Nebulisers:
Not AGP (aerosol generated procedure) and can be used in if evidence of bronchospasm i.e. salbutamol and ipratropium bromide (BNFc for doses)

Steroids:
Not recommended for symptom control in COVID 19

Step One – Opioids:
Use morphine sulfate oral solution (e.g. Oramorph 10mg/5ml) as first line opioid. (See Table 1 for dosing)

Step Two – Anxiolytics:
<10 years:
1st line: midazolam (Buccal)
>10 years – either:
midazolam (Buccal)
(See Table 1 for dosing)
OR
lorazepam (Sublingual) 0.5mg PRN 4-6 hourly
(Genus, PVL or TEVA brands can all be used sublingually)

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Table 1: Opioid and Anxiolytic dosing guidance for breathlessness

Morphine sulphate oral Solution (Route: PO or NGT/PEG)			
1-5 months	25 micrograms/kg/dose	As required 1-2 hourly	Maximum dose 2.5mg
6-11 months	50 micrograms/kg/dose		
1 year to 11 years	100 micrograms/kg/dose		
12 years +	2.5mg/dose		
Midazolam (Route: Buccal)			
6 months – 9 years	50–100 micrograms/kg/dose	This dose can be repeated after 10-15 minutes if required	Maximum dose 2.5mg
> 10 years	1.5mg – 3mg/dose		Maximum dose 3mg

Management of cough in children and young people COVID-19 Outbreak

Note: This guidance is specifically for children and young people with symptomatic COVID 19 disease who have an underlying serious illness and are either irreversibly deteriorating despite full active management or have prior limitations of treatment escalation in place (i.e. through an advance or anticipatory care plan).

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

- oral fluids
- honey & lemon in warm water
- suck cough drops / hard sweets
- elevate the head when sleeping

Pharmacological measures

If there is a history or features of reactive airway disease, consider:

Nebulisers:
Not AGP and can be used in if evidence of bronchospasm i.e. salbutamol and ipratropiumromide (BNFc for doses)

Step One – Simple Lintus:
Paediatric Simple Linctus (see BNFc for dosing)

Step Two - Opioids:
Opioids may reduce cough:

Use morphine sulfate oral solution (e.g. Oramorph 10mg/5ml) as first line opioid. (Dose as for breathlessness, see Table 1)

Please note we would recommend 4 hourly dosing of opioids if indication is cough.

Management of delirium in children and young people COVID-19 Outbreak

Note: This guidance is specifically for children and young people with symptomatic COVID 19 disease who have an underlying serious illness and are either irreversibly deteriorating despite full active management or have prior limitations of treatment escalation in place (i.e. through an advance or anticipatory care plan).

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. Children and young people may be confused at some times 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
- 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
- consider involving family, friends and carers to help with this
- ensure that people at risk of delirium are cared for by a team of healthcare professionals who are familiar to the person at risk
- avoid moving people within and between wards or rooms unless absolutely necessary
- ensure adequate lighting

Pharmacological measures: First line measures

Option One – Anxiolytics:
<10 years:
1st line: midazolam (buccal)

>10 years – either:
midazolam (buccal)

Midazolam dosing guidelines (as per guidance for breathlessness, see Table 1 on Page 10)

OR

Lorazepam (Sublingual) 0.5mg PRN 4-6 hourly

Pharmacological measures: Second Line measures

Option Two - haloperidol:
(Route: PO/NGT/PEG)
1year to 17 years:
Dose:
10-20 micrograms/kg/dose
(Maximum 10mg/day)
Frequency:
Every 8 hours as required

Option Three – levomepromazine:
(Route: PO/NGT/PEG)
2 years to 11 years:
Dose:
50-100 micrograms/kg/dose
(Maximum: 1mg/kg/dose; 25mg/dose)
Frequency:
Every 12 hours as required

11 years +:
Dose:
3mg
(Maximum dose: 25mg/dose)
Frequency:
Every 12 hours as required

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, treatment of urinary tract infections, management of hypoxia, etc.).

Management of fever in children and young people
COVID-19 Outbreak

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:
  - 37.5ºC or greater (oral)
  - 37.2ºC or greater (axillary)
  - 37.8ºC or greater (tympanic)
  - 38ºC or greater (rectal)

- associated signs & symptoms:
  - shivering
  - shaking
  - chills
  - aching muscles and joints
  - other body aches

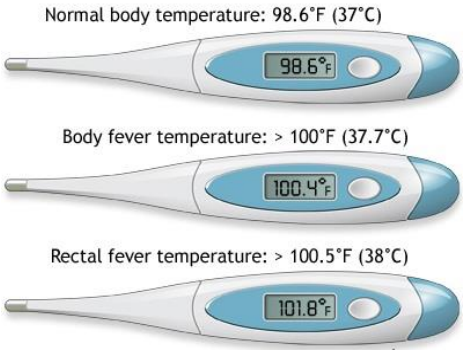
Non-pharmacological measures

- reduce room temperature
- wear loose clothing
- cooling the face by using a cool flannel or cloth
- oral fluids
- Portable or hand held fans must NOT be used in the context of Covid-19 infections as they increase aerosol spread of the virus

Pharmacological measures

Step One - paracetamol:
(Route: PO/NGT/PEG/IV/PR)
See BNFc for age/weight related dosing

When to consider NSAIDs:
If a patient is close to the end of life, it may be appropriate to consider use of NSAID i.e. Ibuprofen as per BNFc



Management of pain in children and young people
COVID-19 Outbreak

Pain is not a predominant feature of COVID 19 disease. However, patients may experience pain due to existing co-morbidities, but may also develop pain as a result of excessive coughing or immobility. Such symptoms should be addressed using existing approaches to pain management.

Patient on no analgesics – Mild pain

Step One – Paracetamol:
(Route: PO/NGT/PEG/IV)

Dosing:
See BNFc for age/weight related dosing

Frequency:
Prescribe regularly 6 hourly; maximum 4 doses/24 hours

When to consider NSAIDs:
If a patient is close to the end of life, it may be appropriate to consider use of NSAID i.e. Ibuprofen as per BNFc

Patient on no analgesics – Moderate to severe pain

Step Two – Opioids:
(Route: PO/NGT/PEG)

If no response to simple analgesia please consider opioid. Use morphine sulfate oral solution (e.g. Oramorph) as first line opioid.

Dosing:
(See dosing guidance below)

General advice when commencing opioids

- start an immediate-release (IR) opioid i.e. oral morphine sulphate solution i.e. Oramorph
- monitor the patient closely for effectiveness and side effects
- always prescribe laxatives alongside strong opioids
- always prescribe an antiemetic regularly or prn
- If regular IR opioid is required consider converting to a long acting opioid preparation

Opioid dosing guidance for pain:

Morphine sulphate oral solution (Route: PO or NGT/PEG)			
1-5 months	50 micrograms/kg/dose	As required 4 hourly	
6-11 months	100 micrograms/kg/dose		
1 year to 11 years	200 micrograms/kg/dose		Maximum dose 5-10 mg
12 years +	5mg/dose		

When the oral route is not available – consult Specialist Palliative Care or Pain Service

- if analgesic requirements are stable - consider transdermal patch or rectal route
- if analgesic requirements are unstable consider initiating subcutaneous or intravenous opioids seek specialist advice from specialist palliative care or pain service
- Morphine is recommended as the first line strong opioid for subcutaneous/intravenous use for patients, except for children and young people who have been taking oral oxycodone or those with severe renal impairment

Management of secretions in children and young people COVID-19 Outbreak

Secretions can be more challenging in the context of a respiratory tract illness, particularly (but not exclusively) in children or young people with conditions which effect their muscle tone or bulbar control. Secretions can also cause concerns at the end of life, being associated with noisy breathing.

General principles:

- Secretions vary throughout the day and can reflect hydration status
- Secretion management at end-of-life is aimed at reducing distress associated with a loss of secretion control
- Children and young people at the end-of-life are often unaware of loss of secretion control, but the noises associated with this can be very distressing for parents

Non-pharmacological measures

- **Suctioning should only be undertaken with appropriate PPE.**
- **Open suctioning i.e from an ET tube or tracheostomy tube is an AGP** https://www.gov.uk/government/publications/wuhan-novel-coronavirus-infection-prevention-and-control/covid-19-personal-protective-equipment-ppe#section-10:
- Utilise position to encourage postural drainage of secretions
- Regular mouth and perioral skin care

Pharmacological measures

Thick secretions:

- Consider use of 0.9% or hypertonic saline nebulisers

Copious thin secretions:

Option One – glycopyrronium bromide:
(Route: PO/NGT/PEG)
1month to 17 years:
Dose:
10-40 micrograms/kg/dose
(Maximum 2mg four times/day)
Frequency:
Every 6 hours as required

Option Two – hyoscine hydrobromide (1mg patch):
(Route: Transdermal patch)
Neonate> 32 Cor GA – 2 yrs
Dose and Frequency:
1/8 to ¼ patch every 72 hours

3yrs – 9yrs
Dose and Frequency:
¼ to ½ patch every 72 hours

10-17 years
Dose and Frequency:
½ to 1 patch every 72 hours

Management of rapidly escalating symptoms or refractory symptoms in children and young people

Note: This guidance is specifically for children and young people with symptomatic COVID 19 disease who have an underlying serious illness and are either irreversibly deteriorating despite full active management or have prior limitations of treatment escalation in place (i.e. through an advance or anticipatory care plan).

In the context of rapidly escalating symptoms, AND/OR symptoms which are refractory despite the above enteral symptom management strategies, use of the intravenous or subcutaneous route should be considered.

Use of intravenous/subcutaneous boluses or continuous infusions in the context of end-of-life in a paediatric setting is uncommon and as such healthcare professionals should seek advice and guidance from an appropriate clinician with experience in paediatric palliative care.

Chaplaincy and Spiritual Care

Spiritual care in simple terms addresses the fundamental human need to have a sense of peace, security and hope particularly in the context of injury, illness or loss.

Chaplains will routinely provide emotional and spiritual support to patients and those close to them. They will regularly be involved in the support of patients' families and will often play a significant role in end of life and bereavement care.

The Chaplain can offer and facilitate religious, spiritual care, comfort and practical support to patients and families of any faith (or none), tradition or background. As members of the multi-disciplinary team chaplains will often be responsible for supporting staff, especially in difficult circumstances.

The chaplain is someone you can share your fears, concerns and hopes with, someone (outside the medical team) who can support and encourage you as you explore difficult questions and issues.

The individual needs of the patients, relatives, carers and members of staff should be fully assessed as part of a Spiritual Needs Assessment to take into consideration their religious, spiritual and cultural requirements. This will ensure that the safety of staff and patients is maintained and will enable a full risk assessment to be undertaken before each visit.
Chaplaincy teams should continue to work alongside relevant clinical staff, and to liaise with community partners to provide faith-related advice and resources around end of life issues, death and bereavement.

Considering preferred place of death for children and young people COVID 19 – Outbreak

In normal circumstances, when there is professional consensus that a child or young person is at the end of their life, where possible we would advocate offering families an informed choice of where they would want to be i.e. hospital, hospice or home. **It is important to note that choices around end of life care wishes may be temporarily suspended during the current pandemic.**

In children or young people with suspected or confirmed COVID 19, transfer prior to death will not be possible. This information should be sensitively shared with families, particularly those who have made prior decisions as part of an Anticipatory Care plan.

Northern Ireland Childrens Hospice (NICH)

- NICH continues to actively support children and families through virtual contact with a team member once a week or more frequently as required by the family
- Family and sibling support via our social work team continues through visits where required and by virtual means where appropriate. All current caseloads are being addressed through these 2 mechanisms
- NICH continues to support children and families with end of life care and step down from Hospital in either the Hospice or in their own home with deployment of staff from our virtual bed to assist.
- NICH has suspended supported short break services but will open In House services for End of life and emergency care as and when required
- NICH continue to accept referrals and provide bereavement support at this time.

Organ and Tissue donation guidance for children and young people COVID-19 Outbreak

There are important considerations to make with regarding to organ and tissue donation during this period. It is important to note that there have been no changes to the referral criteria for paediatric or neonatal organ donation, and the organ/tissue donation service would encourage staff to contact the organ donor referral line to discuss individual cases prior to conversations with a family.

In relation to COVID 19 it is important to be aware of the following:

- Confirmed COVID 19 infection is an absolute contraindication for organ and/or tissue donation
- Presumed COVID 19 infection would be considered while awaiting test results
- All potential donors will be tested for COVID 19
- Donation can only proceed if there is staff/ICU capacity

Organ Donation Referral Line (Organ and Tissue): 03000203040

Please note that this is the 24/7 national referral number.
This will connect to a pager service and the on call specialist nurse will return your call within a maximum of 20 minutes.

Care immediately before and after death in children and young people - COVID-19 Outbreak

This advice is for cases where a COVID-19 is suspected or confirmed.
The utmost consideration and care must be given to the safety of other patients, visitors and staff by maintaining infection control procedures at all times. Additional information and guidance can be obtained from the mortuary department. Also see **COVID-19 - Guidance surrounding death | Department of Health**

Clear and complete documentation

Open, honest and clear communication with colleagues and the deceased's family / significant others

Before death

If death is imminent and parent or carer wish to stay with their child staff must advise them that they should wear appropriate PPE according to local protocol.

At the time of death

Support the child/ young person's family.

Appropriately trained professional completes Verification of Death process wearing appropriate PPE and maintaining infection control measures

Appropriate doctor completes MCCD as soon as possible

Check COVID-19 – Guidance surrounding death Department of Health for up to date information (NI) -

- https://www.health-ni.gov.uk/publications/covid-19-guidance-surrounding-death

Please see full guidance, but in summary:

- If the original treating doctor cannot certify the death, then a colleague from the same hospital or GP Practice can certify the death;
- If the deceased has not been treated within 28 days and dies of a natural illness, any medical practitioner who can state, to the best of their knowledge and belief, the cause of death, is permitted to sign the MCCD.
- COVID-19 is an acceptable direct/underlying cause of death (please note it is a notifiable disease)
- MCCD to be sent electronically.

Also see https://www.health-ni.gov.uk/topics/professional-medical-and-environmental-health-advice/guidance-surrounding-death for further information.

Memory making should be offered to all families and can be done both before and after death. In relation to patients with COVID 19, memory making cannot be offered following transfer to the mortuary.

Standard infection control precautions and transmission-based precautions should be continued after death. A body bag **is required** for transfer and for identification purposes within the mortuary.

Consideration of emotional/spiritual/religious needs of the deceased & their family/significant others

Consideration of referral to appropriate bereavement service i.e. CBUK

Mortuary transfer and care of children and young people COVID-19 Pandemic

Clear and complete documentation

Open, honest and clear communication with colleagues and the deceased's family / significant others

In hospital, local protocol should be followed. Usually porters wearing appropriate PPE collect patient from ward and transfer to Mortuary by way of the process in place for safe removal

If a pacemaker, defibrillator or other implantable device (e.g. intrathecal pump is in situ) please make mortuary staff aware. At present the majority of medical devices can be removed by mortuary staff from deceased patients with COVID 19 with use of appropriate PPE. Please discuss individual cases. If a device is unable to be removed, then cremation would not be offered

Visits to the mortuary for viewing will be significantly restricted, but may remain possible. Please contact local mortuary staff for guidance if parents or carers wish to view their child's body. Use of virtual platforms may also be supported, e.g. FaceTime, video calls

Families that do wish to visit their loved one should be advised that this **may** be arranged via their chosen funeral director, depending on current protocol

Families will not be permitted to take their child's body home if the cause of death is presumed or confirmed COVID 19 disease. The chosen funeral director should be informed and collection of child's body arranged with mortuary staff

Please refer to the national guidance available at www.gov.uk/government/publications/covid-19-guidance-for-care-of-the-deceased

Consideration of emotional / spiritual / religious needs of the deceased and their family / significant others

Registering a death of a child or young person COVID-19 Outbreak

In Northern Ireland, a death should be registered within five days to allow funeral arrangements to be made. This is with the exception of deaths which have been referred to the coroner. A death may be registered in any district registration office in Northern Ireland. https://www.nidirect.gov.uk/articles/registering-death
Changes to death registration, enabling modifications to registration processes, have now come into force in Northern Ireland
https://nafd.org.uk/2020/03/27/coronavirus-act-changes-to-death-registration-in-northern-ireland/

Clear and complete documentation

Open, honest and clear communication with colleagues and the deceased's family / significant others

Registrars have now stopped face-to-face appointments for death registration, this will now be done remotely.

Following completion of the MCCD, it is the responsibility of the completing doctor to **email the MCCD.**
Using NIECR, All Medical Certificates of Cause of Death (MCCDs) should be sent via email to: GRO-pandemic@finance-ni.gov.uk The paper copy of the MCCD should be posted to the Registrar in addition. **Please check up to date guidance at** https://nafd.org.uk/2020/03/27/coronavirus-act-changes-to-death-registration-in-northern-ireland/ and **COVID-19 - Guidance surrounding death | Department of Health**

Along with the MCCD, please include the following for the Registrar:

- Name, relationship and contact details of the family member registering the child or young person's death
- Any requests for rapid registration e.g. cultural/religious grounds

This will facilitate ease of communication between the Registrar and family, in the event that contact details are not available it is the family's responsibility to contact the Registrar.

The body can be released out of hours once MCCD completed (if local protocol allows) for later registration, but the body cannot be buried/cremated until registration process is complete.

There are likely to be limits set on the number of family and friends able to attend funerals. More information can be obtained from the families chosen funeral director. It may be possible to support electronic/virtual attendance.

See below for further and up to date advice -
https://www.nidirect.gov.uk/articles/coronavirus-covid-19-guidance-bereaved-about-funeral-arrangements

Consideration of emotional/spiritual/religious needs of the deceased & their family/significant others

Consideration of referral to appropriate bereavement service i.e. CBUK

Bereavement support services

NI Bereavement Network and PHA:

Grief And Bereavement During The COVID-19 Pandemic Supporting Yourself And Others

https://www.publichealth.hscni.net/publications/covid-19-bereavement-resources

Northern Ireland Bereavement Service:

https://www.communities-ni.gov.uk/sites/default/files/publications/communities/dfc-ni-bereavement-service.pdf

The Bereavement Service is a telephone based service that will allow you to:

• Report a death – The service will record the date of death and tell each office that paid benefit to the deceased.

• Check for help with Funeral Costs – If eligible the service can take claim details for a Funeral Expenses Payment over the phone or arrange a suitable call back.

• Check for help from a Bereavement Support Payment – If eligible the service can take claim details for a Bereavement Support Payment over the phone or arrange a suitable call back.

• Offer advice on potential benefits or other support that may be available.

Further information and contact details are available from www.nidirect.gov.uk/bereavement

Palliative Care in Partnership:

https://pcip.hscni.net/covid-19/information-for-hsc-professionals/bereavement-and-grief/

Northern Ireland Social Care Council:

'Hope, Hints and How To; Helping you respond to living and dying issues during Covid-19' which includes a section on 'Grieving & Support during Covid-19'

https://learningzone.niscc.info/storage/adapt/5e87625d5ee73/index.html

Support Organisations:

Anam Cara (supporting Bereaved Parents): https://anamcara.ie/resources/resource-downloads/

Cruse Bereavement Care: https://www.cruse.org.uk/get-help/coronavirus-dealing-bereavement-and-grief

NI Children's Hospice - Telephone: 028 9077 7635

Locally
Further advice available from Trust Bereavement Co-Ordinator and/or Bereavement Midwife.

Promoting wellbeing and support for staff during COVID-19 Outbreak

It is essential that staff continue to look after themselves and their colleagues during this challenging period. Most NHS Trusts have local guidelines for staff wellbeing, so please look for local resources and advice.

Some nationally available mental health and wellbeing resources include:

National guidance for the public on mental health and wellbeing during COVID-19:
https://www.gov.uk/government/publications/covid-19-guidance-for-the-public-on-mental-health-and-wellbeing

Coronavirus and your well-being
https://www.mind.org.uk/information-support/coronavirus-and-your-wellbeing/

Taking care of your mental well-being during the coronavirus pandemic
https://www.mindwell-leeds.org.uk/home/information-on-coronavirus

How to look after your mental health during the coronavirus outbreak
https://mentalhealth.org.uk/coronavirus
https://www.mentalhealth.org.uk/publications/looking-after-your-mental-health-duringcoronavirus-

RCPCH Your wellbeing during the COVID-19 pandemic
https://www.rcpch.ac.uk/key-topics/your-wellbeing-during-covid-19-pandemic

Please look for the local provisions available in your NHS trust as you should have access to wellbeing support and advice.

References

Sinha, I.P., Harwood, R., Semple, M.G., Hawcutt, D.B., Thursfield, R., Narayan, O., Kenny, S.E., Viner, R., Hewer, S.L. and Southern, K.W., 2020. COVID-19 infection in children. *The Lancet Respiratory Medicine*.

Qiu, H., Wu, J., Hong, L., Luo, Y., Song, Q. and Chen, D., 2020. Clinical and epidemiological features of 36 children with coronavirus disease 2019 (COVID-19) in Zhejiang, China: an observational cohort study. *The Lancet Infectious Diseases*.

Ballentine SM. The Role of Palliative Care in a COVID-19 Pandemic. Shiley Institute for Palliative Care. 2020. https://csupalliativecare.org/palliative-care-and-covid-19/ [Accessed 15 March 2020]

Brighton LJ, Bristowe K. Communication in palliative care: talking about the end of life, before the end of life. *Postgrad Med J* 2016;92:466–70. https://doi.org/10.1136/postgradmedj-2015-133368

Downar, J., Seccareccia, D. and Associated Medical Services Inc. Educational Fellows in Care at the End of Life, 2010. Palliating a pandemic:"all patients must be cared for". *Journal of pain and symptom management*, *39*(2), pp.291-295.

Jassal S, Brook L, Aindow A et al. Association of Paediatric Palliative Medicine Formulary, Fifth Edition, 2020. https://www.appm.org.uk/_webedit/uploaded-files/All%20Files/Event%20Resources/2020%20APPM%20Master%20Formulary%202020%20protected.pdf [Accessed 30 March 2020]

Royal College of Paediatrics and Child Health, COVID-19 – clinical management of children admitted to hospital with suspected COVID-19, Antipyretics, Health Policy Team, 17th April 2020 https://www.rcpch.ac.uk/resources/covid-19-clinical-management-children-admitted-hospital-suspected-covid-19#nhs-clinical-management-guidance [Accessed 17 April 2020]

Royal College of Paediatrics and Child Health. Ethics framework for use in acute paediatric settings during COVID-19 pandemic. 16th April 2020. https://www.rcpch.ac.uk/sites/default/files/generated-pdf/document/Ethics-framework-for-use-in-acute-paediatric-settings-during-COVID-19-pandemic.pdf [Accessed 22 April 2020]

Coronavirus Act – excess death provisions: information and guidance for medical practitioners, NHS. 31 March 2020. https://improvement.nhs.uk/documents/6590/COVID-19-act-excess-death-provisions-info-and-guidance-31-march.pdf [Accessed 22 April 2020]

Public Health England – Guidance for care of the deceased with suspected or confirmed coronavirus (COVID-19). 20th April 2020. www.gov.uk/government/publications/covid-19-guidance-for-care-of-the-deceased [Accessed 22 April 2020]

COVID-19 - Guidance surrounding death | Department of Health. https://www.health-ni.gov.uk/publications/covid-19-guidance-surrounding-death [Accessed 24 April 2020]

Appendix A: Resources to support openness, wellbeing and resilience in children, young people and their families

Resources compiled by Paediatric Clinical Psychology, Royal Hospital for Children, Glasgow
Additional resources (as forwarded by CAMHS Team, Southern Health and Social Care Trust) added p28 – 31
Please also contact your local hospital or hospice who may be able to direct you to further resources.

General Wellbeing Support Resources:

- www.ayemind.com
- www.youngminds.org.uk
- www.kidshealth.org
- http://hospichill.net

Supporting Children and Families during the COVID 19 Pandemic:

- www.bps.org.uk/news-and-policy/advice-talking-children-about-illness
- www.sheffieldchildrens.nhs.uk/patients-and-parents/coronavirus-resources-for-children-and-families/
- www.who.int/emergencies/diseases/novel-coronavirus-2019/advice-for-public/healthy-parenting

Supporting Parents, Carers and Older Young People During the Covid-19 Outbreak:

- www.baps.org.uk/content/uploads/2020/03/FACE-COVID-by-Russ-Harris-pdf-pdf.pdf
- www.youtube.com/watch?v=BmvNCdpHUYM (animated version)
- www.psychologytools.com/articles/free-guide-to-living-with-worry-and-anxiety-amidst-global-uncertainty/

App	Age Range	Purpose	Cost
Mindshift	Teens and young adults	Anxiety management and relaxation exercises.	Free
Calm	Young adults	Sleep and meditation	1 week free followed by subscription.
Headspace	First steps (ages 3-5), Curious minds (ages 6-8), and Growing up (ages 9-12) Young adults	Meditation and anxiety management	Some stuff free then monthly subscription
Happy Not Perfect	Young adults	Meditation Situation guides	In app purchases
Sam App	Young adults	To help you understand and manage anxiety.	Free
Blue Ice	Young people attending mental health services who are self-harming	Mood diary and a toolbox of evidence-based techniques to reduce distress and automatic routing to emergency numbers if urges to harm continue. Music library, photo library, physical activities, relaxation and mindfulness exercises, and spotting and challenging negative thoughts.	Free
Smiling Mind	Children and young adults	Mindfulness and meditation	Free
Catch it	All ages	Learn how to manage feelings like anxiety, anger and depression. The app will teach you how to look at problems in a different way, turn negative thoughts into positive ones and improve your mental wellbeing.	Free
Calm Harm	Young people attending mental health services who are self-harming	Calm Harm is an app designed to help people resist or manage the urge to self-harm.	Free

		It's private and password protected. Based on DBT The app provides tasks that encourage users to distract themselves from urges to self-harm and help manage their "emotional mind" in a more positive way.	
Chill Panda	Children and Young People	Breathing techniques and light exercise	Free
Cove	All ages	Cove is like a mood journal, except instead of using words to express how you feel, you use music. To create music, choose from six different moods – calm, struggling, longing, playful, clouded and gentle. Once you've selected your mood, you can easily add and remove different musical effects. Store your music in a private journal to revisit at any time. Add some personal thoughts and tags or send it to someone to express yourself	Free
distrACT	Under 17s thinking of self-harming	The distrACT app aims to help you better understand urges to self-harm, and encourages you to monitor and manage your symptoms. It can also help reduce the risk of suicide. There's advice and support information, including emergency contact numbers, how best to work with healthcare professionals, and safer alternatives to	Free

		self-harming. In the app's Chill Zone, you can find resources that may help you feel better, including art, books, films, music, poems, quotes, stories and online videos	
Thrive	All ages	Helps you prevent and manage stress, anxiety and related conditions. The game based app can be used to relax before a stressful situation or on a more regular basis to help you live a happier, more stress-free life.	Free
Breathe, Think, Do with Sesame	2-5	improving emotional self-regulation and problem-solving skills. Uses short games, e.g. help the monster to calm down or solve everyday challenges. Available in English and Spanish.	
The Big Moving Adventure (Sesame Street)	2-5	Games to help them deal with the practical and emotional tasks involved in moving home and making new friends.	
Sesame Street: Divorce	2-8	This app provides parents and caregivers with tools to help children ages 2-8 cope with the many transitions related to divorce or separation, with interactive tools using age appropriate language	

Here are some useful websites for young people who are experiencing some difficulties with their mental health.

www.youngminds.org.uk

www.mycamhschoices.org

www.moodjuice.scot.nhs.uk

www.kidscape.org.uk

www.rethink.org.uk

www.talktofrank.com

www.anxietycanana.com

www.cci.health.wa.gov.auhttp://www.theministryofparenting.com/wp-content/uploads/2018/05/Anxiety-help-book-for-Teens.pdf

Here are some useful websites for parents.

www.youngminds.org.uk

www.minded.org.uk

www.rcpsych.ac.uk

www.nhs.uk

www.mycamhschoices.org

parentingni.org

https://www.rcpch.ac.uk/resources/covid-19-resources-parents-carers

In addition, further support and advice available as appropriate from -

GP Out of Hours – Tel number available from GP surgery.

Social Work Out of Hours – 02895049999

Lifeline – 08088088000

Childline – 0800 1111