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

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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). This guidance is aimed to support colleagues across the country who may have to deliver 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

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 both England, Wales and Northern Ireland.

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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, Glasgow, have kindly compiled a list of useful resources to support children, young people and their families through this uncertain time, 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 Pandemic.

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.

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 Pandemic.

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, and 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, receiving care from paediatric services 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, throughout England, 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 Specialist Paediatric Palliative Care

Some regions have access to specialist paediatric palliative care teams. These teams can provide tailored advice and support. 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

Contact details for Specialist Paediatric Palliative Care teams in England (alphabetical order):

Alder Hey Hospital, Liverpool, Specialist Palliative Care team
Tel: 01512525408

Birmingham Children Hospital Palliative Care Team
0121 333 9999 ext 6780

Evelina London Children's Hospital Paediatric Palliative Care Team
Tel: 07747 267799 (mon-fri 9am-5pm), 02071887188 (out of hours)
Team email: paediatricpalliativecare@gstt.nhs.uk

Great Ormond Street Hospital, London, Paediatric Palliative Care Team
Tel: 02078298678 (mon-fri 8am-6pm), 02074059200 (out of hours)

Leeds Teaching Hospitals NHS Trust Paediatric Palliative Care
Provided by Martin House Children's Hospice 01937 845045

Oxford University Hospitals' Paediatric Palliative Care Support
Provided by Helen & Douglas House, 01865794749

Royal Marsden Hospital, Sutton, Paediatric Palliative Care Team
Tel: 02086613625 (oncology) or 01483230960 (non-oncology, ask for symptom team).
Out of hours 020286426011 (ask for the PATCH service)
Email: patchteam@nhs.net and symptomcare@shootingstar.org.uk

Sheffield Children's Hospital Paediatric Palliative Care
Provided by Bluebell Wood Children's Hospice 01909 517360

Southampton General Hospital Paediatric Palliative Care Team
Tel: 023 8120 4101 or email michelle.koh@uhs.nhs.uk or kate.renton@uhs.nhs.uk

University Hospital of Bristol Paediatric Palliative Care & Bereavement Support Team
Tel: 0117 3427293, email: childrenspalliativecare@uhbw.nhs.uk

Local Children's Hospices may also be able to offer support and provide contact details for local symptom control teams. Please see www.hospiceuk.org to find your nearest children's hospice.

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. The symptoms covered here include:

- 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 or 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 Pandemic

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)

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 Pandemic

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 Pandemic

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
(Genus, PVL or TEVA brands can all be used sublingually)

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 Pandemic

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

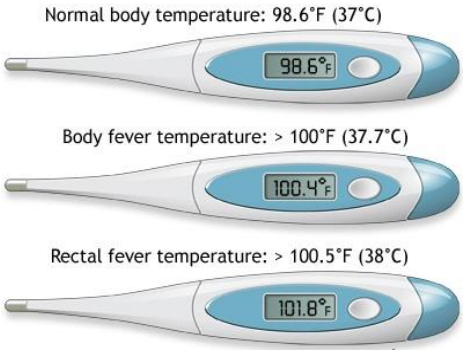
Pharmacological measures

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

Option Two – Ibuprofen:
(Route PO/NG/PEG)
See BNFc for age/weight related dosing

See RCPCH guidance at:
https://www.rcpch.ac.uk/resources/anti-inflammatory-medicines-covid-19-advice-parents-carers

Use paracetamol as first line, and then if required consider a NSAID as second line



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

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
Option 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

Option two – ibuprofen
(Route PO/NG/PEG)

Dosing:
See BNFc for age/weight related dosing
Frequency:
As required 6-8 hourly, maximum 3 doses/24 hours

See RCPCH guidance on the use of NSAIDS at https://www.rcpch.ac.uk/resources/anti-inflammatory-medicines-covid-19-advice-parents-carers

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 table 2 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

Table 2: 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 Pandemic

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 considered an Aerosol Generating Procedure, AGP (see local guidelines on the use of PPE for AGPs)**
- 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, Specialist Bereavement Nurses, Equality and Inclusion Leads 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 – Pandemic

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.

Children's hospices have had to review and change their working practices during this pandemic, so it is best to speak with them directly to explore what they can offer. In normal circumstances Children's Hospices can offer:

- end of life care
- bereavement care
- family support

See www.hospiceuk.org to find the details of your local children's hospice.

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

There are important considerations to make with regards 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 their local SNOD (Specialist Nurse in Organ Donation) or the organ donor referral line: 03000 20 30 40 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 and Tissue Donation Referral Line (24 hours a day): 03000 20 30 40

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

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.

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 confirmation of Death process wearing appropriate PPE and maintaining infection control measures

Process for completion of the medical certificate of cause of death (MCCD):

- Adhere to NHS Guidance for medical practitioners available at: https://improvement.nhs.uk/documents/6590/COVID-19-act-excess-death-provisions-info-and-guidance-31-march.pdf
- Please see full guidance, but in summary:
  - Any GMC registered medical practitioner can sign the MCCD if the medical practitioner who attend the deceased is unable to sign the MCCD, if a cause of death can be stated, and if a medical practitioner has attended the deceased within 28 days before death (extended from 14), or after death. The name and GMC numbers of both medical practitioners should be on the MCCD
  - If no medical practitioner has attended the deceased in the 28 days before, or after, death, then a MCCD can be signed if the GMC registered medical practitioner is able to state the cause of death, and if the coroner agrees to the MCCD completion.
  - COVID-19 is an acceptable direct/underlying cause of death (please note it is a notifiable disease)
  - MCCD's can be scanned or photographed to be sent electronically

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.

The UK government has specific guidance on the care of the deceased, see www.gov.uk/government/publications/covid-19-guidance-for-care-of-the-deceased

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 funeral directors 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

1. www.gov.uk/government/publications/covid-19-guidance-for-care-of-the-deceased
2. https://improvement.nhs.uk/documents/6590/COVID-19-act-excess-death-provisions-info-and-guidance-31-march.pdf

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

Registering the death of a child or young person
COVID-19 Pandemic

Clear and complete documentation

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

Most local authority Registrars have now stopped face-to-face appointments. See www.gov.uk/when-someone-dies to find the local registrar

Following completion of the MCCD, it is the responsibility of the completing doctor to **email a scanned copy or photograph of the MCCD to the designated Registrar**. This should be done over secure email accounts (it is the responsibility of the registrar to determine the appropriate email address). The paper copy of the MCCD should be posted to the Registrar in addition to the electronic copy.

Where electronic transfer is not possible, and the next of kin/informant is self-isolating, arrange for an alternative informant who is not self-isolating to collect the MCCD and deliver it to the registrar. An informant can be someone who was present at the death, a hospital official, or a funeral director

Where no medical practitioner has seen the deceased in the preceding 28 days of, or after, death, but the cause of death is clear, the coroner must be informed. The coroner, medical practitioner and registrar should work together to enable rapid completion of registration of death

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 can not be buried/cremated until registration process is complete.

Full guidance on cremation form completion at https://improvement.nhs.uk/documents/6590/COVID-19-act-excess-death-provisions-info-and-guidance-31-march.pdf

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.

Bereavement support services:

- Local and specialist hospital bereavement services
- Local children's hospice bereavement services

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

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

Promoting wellbeing and support for staff
COVID 19 Pandemic

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-

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

References

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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. 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 Pandemic:

- 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/