Leicester, Leicestershire & Rutland COVID-19 and Palliative, End of Life and Bereavement Care

Guidance to aid care

Collated for the Leicester. Leicestershire & Rutland Health and Care Economy
Adapted from the Association for Palliative Medicine of Great Britain and Ireland

Version 1.1 06.04.2020

Please note

The COVID-19 outbreak currently being experienced around the world 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 or other possibly life-limiting illnesses.

This guidance, which has been prepared for secondary care initially and is not intended to be comprehensive, has been prepared and adapted from a document collated by the Northern Care Alliance NHS Group and the Association for Palliative Medicine of Great Britain and Ireland.

This will be a 'live' document that will be updated, expanded and adapted as further contributions are received and in line with changing national guidance. The most current version of the guidance document will be available on the Insite pages of the UHL website. It is advised that you always check that you are referring to the most current version. **Please do not share the guidance on social media, as it contains some information that may be distressing to the public if not presented in a sensitive way with appropriate opportunity for discussion and explanation.**

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.

As far as is possible in such a short period of time, the information contained within this document has been checked by experts from across the palliative care profession.

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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).

COVID-19 is classified as an airborne, high consequence infectious disease (HCID) in the UK.

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.

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

Palliative, end of life and bereavement care (PEoLB), whose basis is one of 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.

The sectors of the population most at risk at this time are those who are elderly, frail, have serious illness or co-morbidities and this is the population supported and managed by PEoLB professionals every day. In the context of COVID-19, its presence may exacerbate co-existing illness or lack of reserve and create a situation where the patient becomes sick enough that they might die and 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 some under so much pressure that difficult decision-making is required, the management of those patients not expected to survive then such decision-making can be complex both to undertake, but also to communicate to patients and those close to them. Again, this is where PEoLB professionals can help support their colleagues in the processes of triage and planning, difficult conversations and coordinating care.

Because travel or hospital visiting restrictions have been put in place, conversations regarding decision-making, sharing clinical and prognostic information and supporting families may have to be carried out remotely. Again, this is an area where PEoLB professionals are already highly skilled and can be utilised effectively during the COVID-19 outbreak.

As one author has recently stated, "**In this time, palliative care is just as critically needed as fluids, fever reducers, and respirators.** We know the strength and extraordinary human kindness and caring that palliative care professionals live every day, in every interaction with patients, with families, with colleagues, and communities. Their role in the time of COVID-19 is to keep the "care" in healthcare, even as systems, patients, and providers are under siege." (Ballentine, 2020)

The guidance

As health care professionals, we all have general responsibilities in relation to COVID-19 and for these, we should seek and act on national and local guidelines. All professionals 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. We also have a specific responsibility to ensure that essential palliative and end of life care is delivered, both for those who are likely to be in their last year of life because of a pre-existing health condition as well as those who may die as a consequence of infection with COVID-19.

This guidance is aimed at all professionals, carers supporting patients with COVID-19, and their families, in General Practice, or any type of hospital setting – whether this is in the community, critical care or elsewhere in an acute or community hospital bedded environment.

All hospitals have access to specialist palliative care teams, whether as in-house Hospital Palliative Care Teams or as in-reach teams from the local palliative care services. These teams will be able to provide additional advice and guidance but it will not be possible for them to provide direct care to everybody who needs it, especially as the pandemic progresses.

LEICESTER, LEICESTERSHIRE & RUTLAND

THINK AHEAD: GUIDELINES FOR END OF LIFE AND PALLIATIVE CARE FOR PRIMARY CARE

Prepared by Mayur Lakhani on behalf of End of Life Care Taskforce

Guidance for Primary Care

We appreciate you are working very hard at these tough times, and we thank you for this. We are sending this note to urge practices to support vulnerable patients who are at high risk of dying by leading discussions on advance care planning. This guidance provides details of the necessary actions required.

Aims of Guidance

- To continue to support non-COVID-19 patients at the end of their life in the community
- To anticipate the discharge of dying patients with COVID-19 to their preferred place of care
- To support EOLC patients with COVID in the community
- To support families and communities who may need enhanced support including bereavement
- To play a part in supporting the LLR system and specialist colleagues where difficult decisions will need to be made about access to critical care
- To promote a coordinated response in LLR at a time when number of deaths may increase.

Key Message: Think Ahead – Be Proactive: Create, Update and Share More Advance Care Plans for Vulnerable Patients

Actions for Primary Care:

- Ensure every patient on the end of life register (GSF) feels cared for and knows how to access support. Please make sure they have an up-to-date ReSPECT or (predecessor plans) – particularly all amber and red patients, noting that the content of the ReSPECT form will be individualised.
- Ensure that all patients with severe frailty have had an up to date review (desktop +/- remote) with an updated frailty* status (or score) added to the ReSPECT form.
- Ensure that every vulnerable patient has a consent status for eSCR (enhanced summary care records* (protocol provided to run searches on Page 4)
- Ensure every care home resident has an up to date advance care plan and ReSPECT (where applicable).
- Any admission from a care home or a severely frail patient will need to be discussed individually with a geriatrician prior to conveyancing (except for fracture, or other similar emergencies) using consultant connect. More information is available here for care home management: https://www.bgs.org.uk/resources/covid-19-managing-the-covid-19-pandemic-in-care-homes
- Ensure the practice register is as complete as possible by identification of vulnerable groups*

The people most likely to benefit from having an advance care plan are:

- Those likely to be in the last year of life (www.spict.org.uk/)
- Many care home residents already have advance care plans; record treatment escalation and resuscitation status
- Have long term conditions such as severe heart failure, severe COPD, dementia.
- People may choose to set an advance care directive (living well)

    - Have key discussions about preferences including: resuscitation, merits/demerits of hospital admission, treatment ceilings e.g. ventilation. Update plans and issue anticipatory medication (prioritise amber and red patients). Add contact information of professionals who can be called by urgent care services for advice and support.

    - Be prepared to support discussions about advance directives. You may get more requests to discuss Advanced Decision to Refuse Treatment (ADRT); sometimes called a living will. Helpful guidance is given here to which patients can be referred to:

        - https://www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment/

    - Service delivery, ways of working and revised authorisation forms: More guidance will be issued shortly on the community services issues and an easier to use authorisation form. An authorisation for medications on an ICE letter should be accepted in all community settings.

    - Consider plans and pathways to deal with three groups:
    - Non COVID 19 and EOLC – maintain a good standard of care – usual care but with more remote working
    - Discharge of COVID -19 patients to die in PPD
    - Procedures for COVID 19 and EOLC in the community

- Be aware of and be prepared to support families whose loved ones are very ill in hospital and where clinicians have to make very difficult decisions for admissions to critical care (ITU). Please be aware of the NICE guidance that will be followed here in deciding admissions to ITU:
  https://www.nice.org.uk/guidance/ng159

- Develop skills and try out technology to consult remotely with patients and/or to speak to community staff. If you have a method that works, this is fine. If not, an approved standalone method is suitable for use by any clinicians and is approved by the NHS (see ref from NHS England re: remote working)

Ideally use video where possible, by health care professionals known to the patient and handle sensitivity. Prior notification is helpful. Tailor each discussion and plan to individual patients. Age alone is NOT a criterion – functional status is a key determination as indicated by the frailty status, or the clinical frailty score (CFS which is used in hospital) or the Karnofsky Performance Status:

https://www.mdcalc.com/karnofsky-performance-status-scale

- Shielding Advice

  Note this important caveat from HM Government advice on shielding and Group One patients

  'We also suggest that anybody with a terminal diagnosis who is thought to be in their last 6 months of life should be excluded from (shielding) this group (unless they wish to be included), to allow them to maintain contact with their loved ones during the last phase of their illness'.

- Support for upskilling in difficult conversations and management of clinical issues specific to COVID 19:

COVID 19 specific training:
https://elearning.rcgp.org.uk/mod/page/view.php?id=10389
General Training:
https://www.e-lfh.org.uk/programmes/end-of-life-care/
LOROS Webpage for GPs:
https://www.loros.co.uk/healthcare-professionals/

- Death Certification

  The recent Covid Act
  - means a coroner is only to be notified where a doctor believes there is no medical practitioner who may sign the death certificate, or that they are not available within a reasonable time of the death
  - enables electronic transmission of documents that currently have to be physically presented in order to certify the registration of a death
  - remove the need for a second confirmatory medical certificate in order for a cremation to take place

- **LLR needs you**! Do you have palliative care experience and training? Would to be willing to help in LLR to help support the increased demand for palliative care? Support and upskilling training will be given. Please send your indication to the Workforce Cell: Louise.Young@westleicestershireccg.nhs.uk

- Implantable Cardioverter defibrillators (ICDs/CRT-D): These should be recorded on ReSPECT. If somebody is in last weeks of life consider discussing deactivation of shock function of ICD to avoid painful and distressing shocks which are not going to improve clinical picture. There are many GPs who already do this well. It's not specific to COVID-19. The BHF has good patient leaflet deactivating shock function of ICD
  https://www.bhf.org.uk/informationsupport/publications/living-with-a-heart-condition/deactivating-the-shock-function-of-an-implantable-cardioverter-defibrillator-towards-the-end-of-life

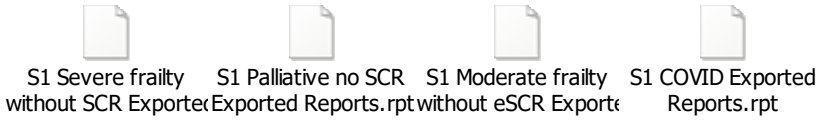
If you identify a patient where deactivating the shock function of the implantable cardioverter defibrillators is required, please contact use these contact details to arrange: Between Mon-Fri 8am-6pm to contact the Pacing Clinic (Tel: 0116 258 3837)

•Out of hours to contact the On call Cardiac Physiology Service – this is done via the On call Cardiology Registrar or Consultant

Enhanced Summary Care Record Consent Status

Urgent: please run these searches (import into your S1 in clinical reporting)

Please ensure consent status is updated either by telephone discussion or using text messaging using Accurx to enable a one off response or whatever system suits your practice the best.



County:

County pts on S1:	616128
With Escr:	179275
EOL/Palliative Care:	1693/6161 do not yet have eSCR consent
Severe frailty:	1612/6499 do not yet have eSCR consent
Moderate frailty:	4567/12775 do not yet have eSCR consent
COVID high risk:	4412/8857 do not yet have eSCR consent

City:

EOL/Palliative Care:	616/2470 do not yet have eSCR consent
Severe frailty:	641/2915 do not yet have eSCR consent
Moderate frailty:	2155/6502 do not yet have eSCR consent
COVID high risk:	2492/5249 do not yet have eSCR consent

Steps for effective End of Life Care

Steps	Actions	Comments
1. Public and Patient Awareness of Think ahead	Put Information on Practice websites, signposting to resources to prompt patients to think ahead	
2. Identification, care planning	Use Surprise Question SPICT Guidance Review EOLC, Registers, Frailty and LTC registers Ensure consent set for Enhanced Summary Care Records Care Homes	
3. Coordination of Care	Virtual MDT RESPECT plans shared Anticipatory Drugs issued Before transfers of care discuss with senior decision makers	Pathway for screening this cohort of patients prior to conveyance (inc. care homes)
4. Palliative Care Services Delivery	More remote working Rules for home visits PPE	Community offer for COVID+ EOL Community offer for non-COVID+ EOL
5. Care in the last few days of life	Close liaison with Integrated Palliative Care services – More LPT guidance to follow working with LPT	Discharge of COVID+/COVID- patients to die in place of choice
6. Care after death	Don't forget bereavement support, the number of deaths is likely to increase, people will need support especially if death is in difficult circumstances	Personal Video or phone call Letter CRUSE Spiritual support

Key contacts for LLR primary care:

Professor Mayur Lakhani: Mayur.Lakhani@westleicestershireccg.nhs.uk

Dr Raj Than: Tun.Than@gp-c82033.nhs.uk

For Specialist Palliative Care advice for people in the community:

The Integrated Community Specialist palliative Care Team can be rung on 03005555255 (times) or advice via LOROS on 01162313771

Symptom Management flowcharts
COVID-19 Outbreak

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:

- Dyspnoea
- Cough
- Fever
- Restlessness/anxiety
- Delirium
- Nausea & vomiting
- Seizures
- Pain
- Terminal respiratory tract secretions

Local palliative care guidelines already exist for other symptoms commonly experienced by people with advanced disease, and should continue to be adhered to – this is not an attempt to replace normal symptom control guidelines or the local formulary.

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

- Reversible causes to consider and treat where possible
- Non pharmacological approaches for all symptomatic patients
- Symptom management
- Medications in the last days or hours of life

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 comorbidities (e.g. chronic obstructive airways disease, heart failure) 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 does of drugs are given. However, these may need to be adapted to specific patient circumstances, e.g. frail elderly (use even lower doses of morphine), or renal failure (use an alternative to morphine). Seek appropriate advice from the relevant specialists including specialist palliative care teams.

It is anticipated that critically ill patients with 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 Dyspnoea
COVID-19 Outbreak

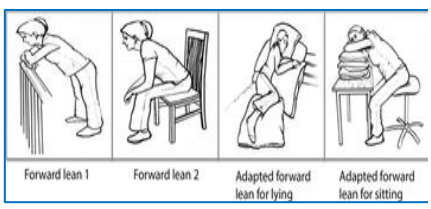
Sudden shortness of breath, or breathing difficulty **(dyspnoea)** is the most common reason for visiting a hospital accident and emergency department

Reversible causes to consider and treat where possible

- bacterial infection
- heart failure
- Asthma, COPD
- Pleural effusion
- PE
- Anaemia
- Check blood oxygen levels

Non-pharmacological approaches for all symptomatic patients

- Positioning (See figure)
- Calm and reassure the patient
- Relaxation techniques – music, relaxation CD
- Reduce room temperature
- Cool flannel applied to the face
- Open the window
- Guided breathing techniques (not all patients will be familiar with these)
- NB: Portable fans **are not advised in Covid-19**



Pharmacological Measures

Trial of oxygen if SaO_2 <92%

Opioids may reduce the perception of breathlessness:

- Morphine sulphate modified release 5mg bd PO (titrate up to maximum 30mg daily for breathlessness)
- Oral morphine solution 2.5mg - 5mg PO PRN up to hourly (1mg - 2mg morphine sulphate via a subcutaneous injection up to hourly if unable to swallow)
- If a patient is taking regular opiates, the PRN opiate dose for breathlessness is ½ of the PRN dose for pain (e.g. morphine sulphate MR 30mg BD breakthrough dose for pain is 1/6 of total 24 hour dose, or 10mg oral morphine solution. Breakthrough dose for dyspnoea is 5mg oral morphine solution)
- Prescribe a PRN antiemetic in opioid naïve patients (e.g. levomepromazine 2.5mg - 5mg via a subcutaneous injection PRN or levomepromazine 6.25mg oral once to twice daily) as well as a laxative

Anxiolytics may be needed for anxiety associated with dyspnoea if non-pharmacological approaches do not work:

- Lorazepam 500microgram-1mg oral or sublingual prn, max 4mg in 24h
- Midazolam 2.5mg - 5mg via subcutaneous injection PRN for associated agitation or distress up to hourly

Medications in the last days or hours of life

'As needed' (PRN) medication:

- Morphine sulphate 2.5mg-5mg via a subcutaneous injection prn up to hourly
- Midazolam 2.5mg-5mg via a subcutaneous injection prn up to hourly for anxiety or distress

Regular medication for background symptom control:

- Consider a subcutaneous infusion of morphine sulphate 10mg and / or midazolam 10mg via a syringe driver over 24hours, starting at the lowest dose and titrating

Alternative routes and medications when syringe driver or injectable medications are unavailable or if non clinicians need to provide medication in the last days

'As needed' (PRN) medication:

- Immediate release Concentrated oral morphine solution (20mg/ml) at a dose of 5mg (0.25 ml) given buccally. Please ensure that the prescribed dose can be measured easily. Put in the mouth between the cheek and lower gums. Slowly administer half the liquid in the syringe then repeat on the other side. Rub cheek to aid buccal absorption.

When a syringe driver is not available AND regular medication is required:

- Methadone 0.5mg via a subcutaneous injection once daily

Management of Cough
COVID-19 Outbreak

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.

Reversible causes to consider and treat where possible

- Bacterial infection
- Heart failure
- Asthma, COPD
- Pleural effusion
- PE
- Reflux
- Post nasal drip

Non-pharmacological approaches for all symptomatic patients

- Humidify room air if possible
- Oral fluids
- Honey & lemon in warm water
- Suck cough drops / hard sweets
- Elevate the head when sleeping with pillows
- Avoid smoking

Pharmacological Measures

- Codeine linctus 30mg - 60mg PO QDS

Or

- Oral morphine solution 2.5mg PO 4 hourly

Or

- Methadone 1mg liquid at night

Or

Limited evidence: derived from use for cough from primary lung cancers, lung metastases or malignant pleural effusion - keep under review

- Consider adding Pregabalin 50mg nocte PO
- Unlikely suitable for COVID only cough

Medications in the last days or hours of life

'As needed' (PRN) medication:
Morphine 2.5mg – 5mg via subcutaneous injection PRN up to hourly
Regular medication for background symptom control:
Consider a subcutaneous infusion of morphine sulphate 10mg via a syringe driver over 24 hours

Alternative routes and medications when syringe driver or injectable medications are unavailable or if non clinicians need to provide medication in the last days

- Immediate release concentrated oral morphine solution (20mg/ml) at a dose of 5mg (0.25ml) given buccally. Please ensure that the prescribed dose can be measured easily. Put in the mouth between the cheek and lower gums. Slowly administer half the liquid in the syringe then repeat on the other side. Rub cheek to aid buccal absorption.

When a syringe driver is not available AND regular medication is required:

- Methadone 0.5mg via a subcutaneous injection once daily

Management of Delirium COVID-19 Outbreak

Delirium is a sudden change in mental state, which may be confusion, agitation, personality change, and difficulties with understanding and memory

Prevention is better than treatment

Consider and manage possible causes including:

- Sepsis
- Hypoxia
- Electrolyte imbalance,
- Urinary retention
- Faecal impaction
- Dyspnoea
- Pain

Non pharmacological approaches for all symptomatic patients

- Spiritual support
- Music
- Calm atmosphere
- Avoid multiple moves
- Complete a profile with family help e.g. what usually helps the person. Do they have a profile such as 'all about me' which might help staff understand their usual responses
- Ensure glasses and hearing aids are being used
- Avoid constraints, or interventions that cause distress
- Encourage mobilisation,
- DoLS assessment
- Use calendars/ clocks, photos
- Aim for continuity with ward staff
- Promote nutrition

Pharmacological Measures

- Aim to <u>use verbal and non-verbal de-escalation measures</u> prior to prescribing any medications.
- Consider 1-1 supervision.
- Regularly update carers/family members with progress/treatment plan.

<u>Sedatives may also cause delirium – use carefully</u>

- **ONLY to be used to manage dangerous or distressing symptoms; or to allow tests or treatment to be given:**
- **Haloperidol** is the preferred option: Dosage: 500microgram PO – up to 2 hrly. Max dose: 5mg / 24hrs.

AVOID HALOPERIDOL IN LEWY BODY DEMENTIA AND PARKINSON'S DISEASE - Lorazepam 500microgram -1mg orally stat may be given as an alternative.

If agitation continues, consider adding Olanzapine tablet orally 2.5mg-5mg daily

Pharmacological Measures in the last days and hours of life

'As needed' (PRN) medication:

- Midazolam 2.5mg-5mg via a subcutaneous injection prn 1-2 hourly
- Levomepromazine 6.25mg-12.5mg via a subcutaneous injection 2-4 hourly prn, up to maximum daily dose of 50mg
- Haloperidol 1.0-2.5mg via subcutaneous injection prn, maximum of 5mg in 24hours

Regular medication for background symptom control:

- Consider a subcutaneous infusion of midazolam 10-30mg/24hours via a syringe driver, starting at the lowest dose and titrated to effect

or

- Consider a subcutaneous infusion of Levomepromazine 12.5mg-50mg via a syringe driver 24 hours, starting at the lowest dose and titrated to effect

or

- If Haloperidol PRN is effective, convert total 24 hour PRN doses to a syringe driver.

Alternative routes and medications when syringe driver or injectable medications are unavailable or if non clinicians need to provide medication in the last days

'As needed' (PRN) medication**:**

- Pre-filled midazolam buccal oromucosal solution 2.5mg/0.5ml 0.5ml (2.5mg) prn 2 hourly. Put in the mouth between the cheek and lower gums. Slowly administer half the liquid in the syringe then repeat on the other side. Rub cheek to aid buccal absorption.

Or

- Olanzepine SF or odispersible melts or tablet 2.5mg-5mg orally once to twice daily

When a syringe driver is not available AND regular medication is required:

- Olanzepine 2.5-10mg as a subcutaneous injection once daily.

Management of Fever
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.

Reversible causes to consider and treat where possible

Only treat if fever is causing patient discomfort

Non-pharmacological measures

- Reduce room temperature
- Loose clothing
- Cooling face with a tepid flannel
- Oral fluids
- Avoid alcohol
- **Avoid portable fans in COVID-19**

Pharmacological measures

- Paracetamol 500mg - 1000mg PO QDS, using the lower dose where patients have a weight <50kg. In hospital, this can be given IV up to QDS
- **Renal impairment has been reported in COVID-19, leading to concerns about using NSAIDs in these patients. Avoid where possible, although patients already established on these for pain may express a wish to continue to take them.**

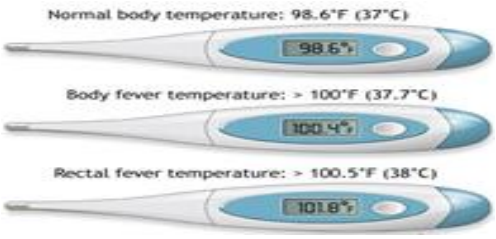
Medications in the last days or hours of life

If a patient is close to death, it may be appropriate to consider the use of NSAIDs (e.g. parecoxib 40mg SC OD-BD; maximum 80mg in 24 hours)

Alternative routes and medications when syringe driver or injectable medications are unavailable or if non clinicians need to provide medication in the last days

'As needed' (PRN) medication**:**

- Paracetamol and Ibuprofen 'melts' may be suitable



Management of restlessness/anxiety COVID-19 Outbreak

Terminal **restlessness** also known as terminal agitation is a syndrome that may occur near the end of life. People experiencing terminal restlessness show signs of physical, emotional and/or spiritual restlessness as well as **anxiety**, agitation and cognitive decline in the days leading to death. Often maintaining as calm an environment as possible and staying with the person when able and safe to do so is at least as effective as medication.

Reversible causes to consider and treat where possible

- Fear of dying
- Spiritual distress
- Dyspnoea
- Urinary retention
- Positioning in bed e.g. pillows, are sheets ruckled?
- Are treatments e.g. NIV/ CPAP contributing? –if so, review appropriateness

Non Pharmacological measures

- Human presence/ virtual presence –can family video call?
- Even in severe agitation, maintaining as calm a presence and environment as possible
- Think about number of people around the distressed person – sometimes less people and more space is helpful.
- Consider relaxation CDs, breathing exercises, headspace app or similar
- Spiritual support
- Music

Pharmacological measures

- Lorazepam 500 micrograms – 1mg PO or sublingual PRN 1-2 hourly, maximum 4mg in 24 hours

Or

- midazolam 2.5mg-5mg via a subcutaneous injection prn 1-2 hourly

Or

- Consider a subcutaneous infusion midazolam 10mg-30mg via a syringe driver over 24hours, starting at the lowest dose and titrated to effect

Medications in the last days or hours of life

'As needed' (PRN) medication:

- Midazolam 2.5mg-5mg via a subcutaneous injection prn 1-2 hourly
- Or
- Levomepromazine 6.25mg-12.5mg via subcutaneous injection.

Regular medication for background symptom control:

- Consider a subcutaneous infusion of midazolam 10mg - 30mg via a syringe driver over 24hours, starting at the lowest dose and titrate to effect

Alternative routes and medications when syringe driver or injectable medications

'As needed' (PRN) medication**:**

- Lorazepam 500micrograms – 1mg PO/SL prn 1-2 hourly, maximum 4mg in 24 hours

Or

- Pre-filled midazolam buccal oromucosal solution 2.5mg/0.5ml 0.5ml (2.5mg) prn 2 hourly. Put in the mouth between the cheek and lower gums. Slowly administer half the liquid in the syringe then repeat on the other side. Rub cheek to aid buccal absorption.

Or

- Levomepromazine 6.25mg (1/4 25mg tablet) placed under tongue as needed up to 1 hourly

Management of nausea & vomiting COVID-19 Outbreak

Nausea is an unpleasant sensation of the need to **vomit**, which is often accompanied by autonomic symptoms for example pallor, cold sweat and salivation.

Reversible causes to consider and treat where possible

- Medications (e.g. antibiotics, anticholinergic drugs)
- Low sodium, elevated calcium
- Raised intracranial pressure

Non pharmacological approaches for all symptomatic patients

- Consider drug causes and electrolyte disturbances such as hyponatraemia or hypercalcaemia
- Reduce cooking or other odours
- Small meals, snacks
- Ice chips or sips of cold water
- Accupressure bands

Pharmacological management

Metabolic/drug induced:

- Haloperidol 500microgram - 1mg oral or via subcutaneous injection once to twice daily

Raised intracranial pressure:

- Cyclizine 50mg oral three times per day

Gastric stasis

- Metoclopramide 10mg oral three times per day

Second line when haloperidol / cyclizine / metoclopramide have not worked, or where the cause of nausea and vomiting is unclear:

- Levomepromazine 6.25mg oral or via subcutaneous injection once to twice daily

Medications in the last days or hours of life

If already established on an antiemetic, and this is controlled symptoms, convert to the SC route

If symptoms are not controlled:

'As needed' (PRN) medication:

- Levomepromazine 6.25mg -12.5mg via subcutaneous injection prn, converted to a continuous infusion via a syringe driver if effective 6.25mg-12.5mg over 24hours

Or

- Haloperidol 0.5mg - 1mg sc prn hourly, maximum 5mg/24 hours or as a continuous infusion haloperidol 3mg-5mg via a syringe driver over 24 hours

Alternative routes and medications when syringe driver or injectable medications are unavailable or if non clinicians need to provide medication in the last days

- Prochloperazine buccal tablet 3mg three times per day

Or

- Ondansetron 4-8mg PO 4 hourly prn (orodispersible tablets or orodispersible film) or SC prn, maximum 16mg/24 hours

Or

- Olanzepine orodispersible tablets 5-10mg (dissolve 10mg tablet in 2ml water and use half volume for 5mg dose). Draw up in an oral syringe. Put in the mouth between the cheek and lower gums. Slowly administer half the liquid in the syringe then repeat on the other side. Rub cheek to aid buccal absorption.

Or

When a syringe driver is not available and regular medication is required:

- Levomepromazine 12.5mg SC as a single daily dose

Or

- Hyoscine hydrobromide patches 1mg/72 hours (can use up to 2 patches at once)

Or

- Granisetron 3.1mg/24hrs. Change patch every 5 – 7 days

Or

- Olanzepine 2.5-10mg as a subcutaneous injection once daily

Management of Seizures
COVID-19 Outbreak

Seizures are bursts of electrical activity in the brain that temporarily affect how it works.

Reversible causes to consider and treat where possible

Non-pharmacological Approaches for all symptomatic patients

- Continue regular oral medications

Pharmacological management

- Midazolam 5mg – 10mg via subcutaneous injection prn up to hourly

Note: due to risk of viral transmission in faeces the PR route is not routinely recommended

Medications in the last days or hours of life

- Continuous subcutaneous infusion of Midazolam 20mg – 30mg via a syringe driver over 24 hours

Alternative routes and medications when syringe driver or injectable medications are unavailable or if non clinicians need to provide medication in the last days

- 10mg midazolam buccally administered using pre-filled midazolam oromucosal solution 10mg/2ml prn. Repeat after 10 minutes if seizures persist. Put in the mouth between the cheek and lower gums. Slowly administer half the liquid in the syringe then repeat on the other side. Rub cheek to aid buccal absorption.

Management of pain
COVID-19 Outbreak

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.

Reversible causes to consider & treat where possible

Co-existing pain such as arthritis, pressure sores, cancer pain

Non pharmacological approaches

- Positioning
- Heat pads over affected area
  Massage

Notes:

- Always prescribe laxatives alongside strong opioids
- Always prescribe an antiemetic regularly or prn, e.g. levomepromazine 6.25mg-12.5mg oral or via subcutaneous injection prn or haloperidol 500microgram-1mg oral or via subcutaneous injection prn
- If analgesic requirements are stable - consider transdermal patches (e.g. buprenorphine, fentanyl)
- Seek advice if eGFR<30

Pharmacological measures

- Start **regular** paracetamol (usual dose 1 gram four times a day), reducing dose where weight <50kg
- **Renal impairment has been reported in COVID-19, leading to concerns about using NSAIDs in these patients. Avoid where possible.**

Starting strong opioids, oral route:

- Start immediate release oral morphine solution liquid 2.5 - 5mg PO PRN up to hourly and titrate to response
- If pain control is achieved, consider conversion to morphine sulphate modified-release (MR) twice daily (total MR dose is the same as 24-hour total e.g. oral morphine solution 5mg QDS is the equivalent of morphine sulphate MR 10mg bd)
- PRN dose is 1/6 total daily dose of opiate e.g. morphine sulphate MR 30mg bd, PRN oral morphine solution is 1/6 of 60mg so 10mg up to 1 hourly

Titrating oral opiates:

- Monitor the patient closely for effectiveness and side effects
- Dose increments should not exceed 33-50% every 24 hours
- Titration of the dose of opioid should stop when either the pain is relieved or side effects occur

Medications in the last days or hours of life

- Morphine is the first line strong opioid for subcutaneous use, except for patients who have been taking oral oxycodone or those with severe renal impairment
- Prescribe morphine sulphate 2.5-5mg via subcutaneous injection prn up to hourly
- Subcutaneous infusion of morphine sulphate 10mg via a syringe driver over 24 hours

- To convert from oral to subcutaneous morphine, divide by 2: oral morphine 10mg ≈ subcutaneous morphine 5mg
- prn dose is 1/6 of regular 24-hour opioid dose and should be prescribed up to hourly (e.g. a patient on a continuous subcutaneous infusion of morphine 90mg via a syringe driver over 24h requires 15mg morphine via subcutaneous injection prn up to hourly

See next page for opioid conversion charts

Alternative routes and medications when syringe driver or injectable medications are unavailable or if non clinicians need to provide medication in the last days

- Buprenorphine transdermal patches starting at 5-10microgram/hour every 7 days (equivalent to 10-20mg oral morphine/24 hours)

Or

- Immediate release Concentrated oral morphine solution (20mg/ml) at a dose 5mg (0.25ml buccally. Put in the mouth between the cheek and lower gums. Slowly administer half the liquid in the syringe then repeat on the other side. Rub cheek to aid buccal absorption.

When a syringe driver is not available AND regular medication is required:

- Buprenorphine transdermal patches starting at 5-10microgram/hour every 7 days (equivalent to 10-20mg oral morphine/24 hours)

Or

- Fentanyl patch 12microgram/hour every 72 hours (equivalent to approx 40mg oral morphine over 24 hours)

Or

- Methadone 2.5mg via subcutaneous injection once daily

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Opioid conversions

Buprenorphine patch (microgram/hr)	Approximate 24 hour oral morphine dose (mg)	Breakthrough oral morphine solution dose (mg)	Fentanyl patch (microgram/hr)
5	10	1.5	-
10	20	3	-
20	40	5	12
35	90	15	25
52.5	130	20	37
70	180	30	50
	270	40	75
	360	60	100

If you need further advice about a drug conversion, contact the palliative care team, LOROS or medicines management services

Opioid dose	Conversion factor from other opioid to oral morphine	Equivalent oral morphine dose
Oral codeine or oral dihydrocodeine 240mg/24hrs	Divide by 10	≈ 24mg Oral morphine/24hrs
Tramadol 400mg/24hrs	Divide by 10	≈ 40mg Oral morphine/24hrs
Morphine 5mg subcutaneous injection	Multiply by 2	10mg Oral Morphine
Diamorphine 3mg subcutaneous injection	Multiply by 3	10mg Oral Morphine
Oral oxycodone 5mg	Multiply by 2	10mg Oral Morphine
≈ SC oxycodone 2mg to 3mg	Multiply by 4	10mg Oral Morphine
≈ SC alfentanil 1mg	Multiply by 30	30mg Oral Morphine

Management of Terminal respiratory tract secretions COVID-19 Outbreak

Terminal respiratory secretions are sounds often produced by someone who is near death as a result of fluids such as saliva and bronchial secretions accumulating in the throat and upper chest.

Reversible causes to consider & treat where possible

Noisy respiratory tract secretions can be a normal part of dying but is distressing to hear for those observing. Patients are often unaware and not distressed by this symptom. It is often a difficult symptom to treat. Consider whether they are troublesome or need treating at all.

Non pharmacological approaches for all symptomatic patients

- Positioning of the patient to allow gravity to move secretions
- Stop or reduce volume of IV or PEG feeds
- Stop or reduce volume of IV or SC fluids

Symptom Management

To date (March 2020) palliative care experience of treatment of respiratory secretions has mostly been in unconscious patients, where the patient is usually unaware of the secretions, but the family or those observing the dying process can find it distressing.

Early local and UK experience in COVID-19 deaths suggests that some patients who die with COVID-19 have large volumes of secretions and can be conscious. It is recommended therefore that secretions are treated in the COVID-19 setting, although the efficacy of these usual drugs is not yet know and guidance may therefore change.

Medications in the last days or hours of life

- Give glycopyrronium 200 micrograms by subcutaneous injection as required, up to every four hours (maximum dose 1.2mg in 24 hours)
- consider starting a subcutaneous infusion of 600 -1200micrograms glycopyrronium via syringe driver over 24 hours

Alternative routes and medications when syringe driver or injectable medications are unavailable or if non clinicians need to provide medication in the last days

- Hyoscine butylbromide 20mg sc prn or a continuous subcutaneous infusion 60-180mg over 24 hours

Or

- *Hyoscine hydrobromide transdermal patch 1mg/72 hours, maximum 2mg/72 hours

Or

- *Hyoscine hydrobromide 400micrograms prn or a continuous subcutaneous infusion 1200-2400micrograms over 24 hours

Or

- *Atropine 1% PF single use ophthalmic drops 1-2 drops sublingually every 2-4 hours

*can all increase confusion or delirium

Talking about uncertain recovery and goals of care for patients who are at risk of dying during COVID-19 Outbreak

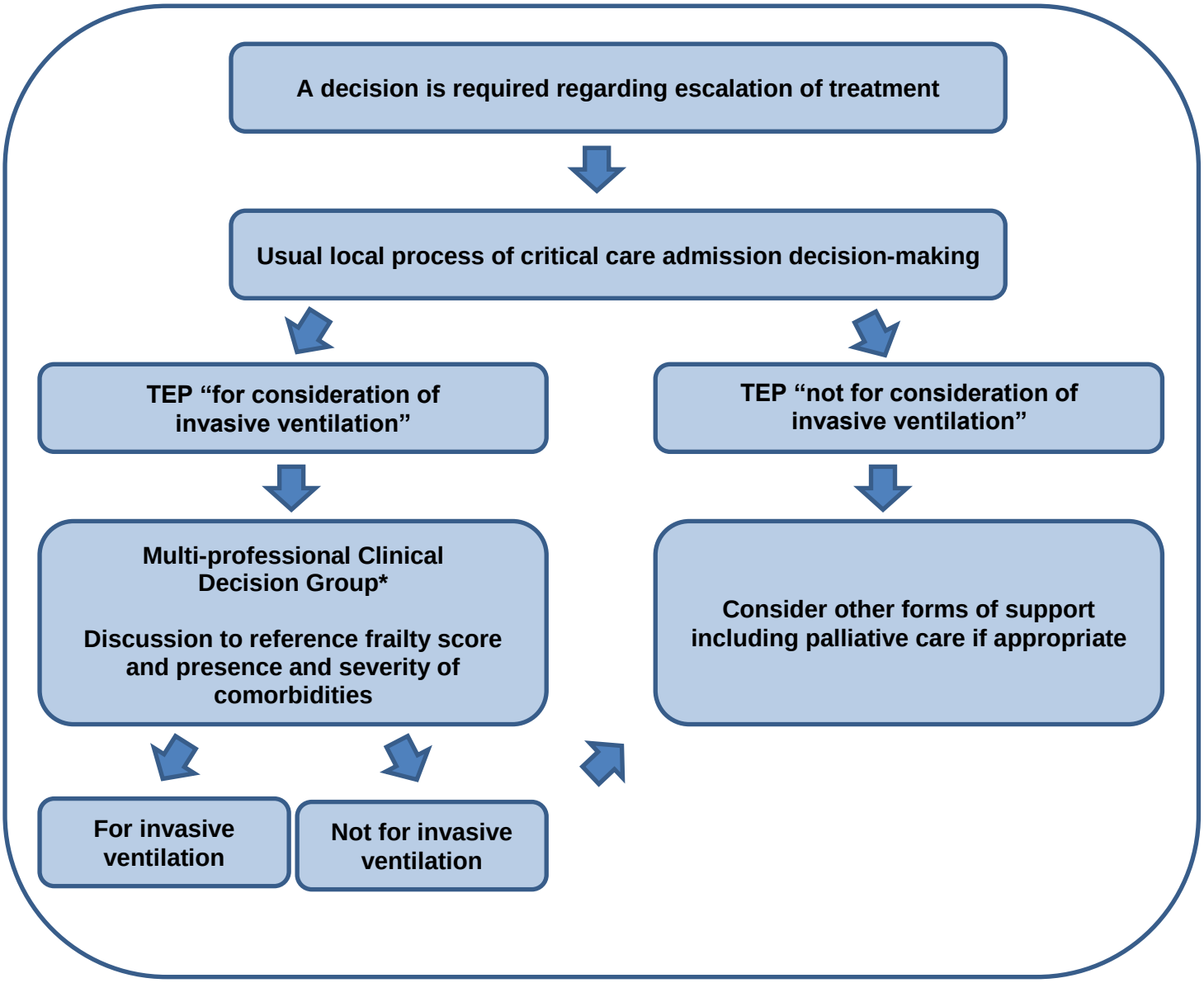
S	**Setting/ situation**	Read clinical records, ensure privacy, no interruptions. Take time if you can and use a measured pace and tone. Use silences to allow processing. Be honest and clear, avoid jargon. Consider raising the bed or being at their level
P	**Perception**	"What do you understand about what is happening at the moment?"
I	**Invitation**	"How much information do you want from me?... Are you someone who likes all the details or just the basics of what's going on…?"
K	**Knowledge**	Explain what the illness is and which organs are not working properly. I'd like to share my understanding of what is happening and to talk about what we need to do next….." "I am worried about how unwell you are and that you might not respond to treatment… This is really serious… I wish we were not in this situation… I hope that starting (oxygen, medicines to help with symptoms) will help **but I am worried that you might die from this**. I am so sorry".
E	**Empathy**	"This seems to have come as a shock/something you were expecting to hear/really upsetting". "I am so sorry this is happening to you"
	Explore Priorities	"What matters most to you at this moment?... What are your biggest fears or worries?... What do you think might help with these feelings?... How much do your family know about what is important to you?.... What help do they need at the moment?"
	Escalation planning	**A dying patient or unstable patient where CPR would not work and ventilator support is not appropriate:** "we have talked about (supporting you with..) but there are some other things we need to discuss too. We need to make the right plan for you if things do get worse. I am worried that you are **sick enough to die** (because of…) and we need to talk about how we look after you. Is that ok? This is really hard to talk about but it is so important. If your heart stops or you stop breathing, resuscitation would not work. This is because of how ill you are". "We know that if your heart and/or breathing stopped, we would not be able to restart them with resuscitation or a ventilator and you would not survive. It's important we complete a special form, called a ReSPECT form where we record what is important to you and a plan of how we look after you if things do get worse". "Are there other treatments that you want to discuss with me? Do you have any questions?"
S	**Summary/ Strategy**	Summarise what you've said; explain next steps. Complete a ReSPECT form and document clearly in the notes. Ensure the principles of the Mental Capacity Act, 2005 are applied. Communicate with multidisciplinary team and family (with consent).

For advice/support for palliative and end of life care between 9am – 5pm, call the Specialist Palliative Care Team on Ext: 5414 (LRI); Ext: 3540 (GH); Ext: 4680 (LGH). Referrals should be sent via ICE. Outside these hours, contact the Consultant in Palliative Medicine via switchboard. For further information, see InSite/LPT pages for end of life care.

Clinical decision-making in respiratory failure
COVID-19 Outbreak

All emergency COVID positive and negative medical admissions to have Treatment Escalation Plan (TEP) including decision regarding invasive ventilation discussed and recorded.

Refer to Lasting Power of Attorney, Advance Decision to Refuse treatment, Statement of Wishes or Electronic Palliative Care Coordination system record if available and patient lacks capacity.



The National Institute for Health and Care Excellence (NICE) has produced a more comprehensive rapid guideline for critical care, published on 20 March 2020. It is available on their website at https://www.nice.org.uk/guidance/ng159.

Withdrawal of NIV/CPAP/High Flow Nasal Oxygen (HFNO) When Proven/ Suspected Covid-19

Respiratory support can be continued until death alongside symptom control, if it is felt to be helpful. Consult InSITE for guidance on symptom control measures for breathlessness (morphine) and distress (Midazolam).

When to consider withdrawal of respiratory support:

- A patient deteriorating despite therapy, and burdens of treatment outweigh benefits.
- A patient with capacity who requests withdrawal
- A patient with a valid advance care plan/ ADRT declining respiratory support.
- When the respiratory support is contributing to terminal agitation

Withdrawal of ineffective or unwanted medical treatment including respiratory support is good clinical practice. It is not assisted dying/suicide or euthanasia.

- Patients and next of kin
- A senior clinical decision maker (registrar or consultant).
- A second senior decision maker (consultant) if requested/any concerns with plan.
- Seek MDT opinion e.g.: ward nurses, ventilation team, Specialist Palliative Care Team.
- A doctor with dedicated time to initiative/run withdrawal.
- A dedicated nurse to be involved with withdrawal.
- A "runner" who can quickly bring medicines/extra equipment.
- Chaplaincy: consider religious/spiritual needs prior to withdrawal.

Preparation (away from bedside):

- Aim for all withdrawals to be in usual working hours with planned staff available
- Doctor and nurse undertaking the withdrawal should "checklist" the personalised plan.
- Document mental capacity assessment and rationale for withdrawal.

The aim is to provide patients with an adequate level of symptom control before the respiratory support is removed so that they are not distressed once that support is withdrawn. This will require anticipatory medicines "PRN". These medication doses are specifically for the withdrawal process and higher than for management of symptoms in other contexts. Prescribe:

- Morphine 5mg-20mg SC as needed. For pain/breathlessness. Prescribe 10mg/ml ampoules
- Midazolam 5mg – 20mg SC as needed. For sedation/distress. Prescribe 10mg/2ml ampoules or 10mg/5ml midazolam ampoules
- Levomepromazine 12.5mg-50mg SC as needed up to 200mg/24 hr for sedation. Prescribe 25mg/ml levomepromazine ampoules
- Glycopyronnium 200-400mcg SC, as needed up to every 30 minutes, up to 1.2mg/24hr. For secretions. Prescribe 600mcg/3ml ampoules

Preparation (away from bedside) (cont):

For patients established on opiates/benzodiazepines, larger doses may be needed.

For patients know to have severe side effects from morphine, use oxycodone 2.5mg-10mg SC PRN.

- If secure IV access available, opiates and benzodiazepines may be given by this route. Stat doses 2.5mg-10mg morphine and midazolam, with PRN doses 2mg-5mg given every 2 minutes, titrated until patient comfortable.

An alternative to achieving symptom control by repeated stat doses is to commence a continuous SC infusion, and then commence the withdrawal process with stat medicine doses after ~4 hours of infusion. If considering this method, please call the Specialist Palliative Care Team for advice.

Withdrawal process (by bedside):

Discussion points:

- Consider using virtual social contact to allow messages from NOK to be passed on prior to beginning.
- Medic and nurse confirm plan with patient/NOK before proceeding.
- Acknowledge that there is uncertainty about how long the patient will live for after the respiratory support has been stopped.
- Reassure patient and NOK that symptoms will be managed.
- If withdrawal is being done at patient's request, they may request that for NIV/CPAP/HFNO is not reinstated at any point during the withdrawal process.

Afterwards:

- If patient dies within minutes, complete UHL COVID-19 death procedures immediately.
- If patient has not died, ensure regular review. Administer further PRN doses as required.
- Review PRN dose administration after 4 hours and increase syringe driver infusion if required.
- Update next of kin.

Check in with colleagues involved in withdrawal – is everyone OK? Take a break, even if short, before continuing with clinical work wherever possible.

Anything that went well/lessons to be learnt?
Please send any feedback to Specialist Palliative Care Morbidity and Mortality Mailbox: PallCareMortality@uhl-tr.nhs.s.uk

Chaplaincy can support. Check InSiTE for other sources of support

- After patient's death, link NOK to bereavement services promptly
- Ensure bereavement team aware of death (bereavementservices@uhl-tr.nhs.uk)
- After death of patients with COVID-19, offer NOK mementoes (eg: lock of hair) at the time. These cannot be offered or undertaken at a later date. Any mementoes should be placed in a sealed bag which then must not be opened for 7 days.

The evidence base for withdrawal of NIV/ CPAP/ HFNO is lacking, and at the time of writing there is no existing guideline for withdrawal in the context of COVID-19.

Please document experiences clearly in medical records for future coding and potential analysis of care.

With your help, this document will evolve with our experience over time.

Guidelines prepared with reference to: COVID-19 and Palliative, End of Life and Bereavement Care in Secondary Care. Role of the speciality and guidance to aid care V1.0 Association of Palliative Medicine, Northern Care Alliance NHS Group. (https://apmonline.org/ - online version evolving with time)

Withdrawal of Assisted Ventilation at the request of a patient with MND. Association of Palliative Medicine, 2015.

CHECKLIST FOR PERSONALISED PLAN: WITHDRAWAL OF RESPIRATORY SUPPORT

- ✓ Decision for withdrawal from a senior clinical decision maker (registrar or consultant).
- ✓ Documented mental capacity assessment and rationale for withdrawal
- ✓ MDT in agreement
- ✓ Dedicated nurse/medic to run withdrawal
- ✓ "Runner" to be available to quickly bring medicines/extra equipment
- ✓ Anticipatory medicines for withdrawal process prescribed

Morphine 5mg-20mg SC as needed. For pain/breathlessness
Midazolam 5mg-20mg SC as needed. For sedation/distress
Levomepromazine 12.5mg-50mg SC as needed, up to 200mg/24hr. For sedation.
Glycopyronnium 200-400 microgram SC, every 30 minutes, up to 1.2mg/24hr. For secretions.

1. **Give medicines in anticipation of symptoms when respiratory support is stopped.**

Ensure two separate SC lines are in situ: alternate site if giving repeated doses to help drug absorption.
Administer opioid and midazolam with aim for patient sedation.
Start with lower doses, repeat as needed at 10 minute intervals.

2. **Assess the level of sedation before the respiratory support is stopped.**

Observe for several minutes.

3. **Test whether the level of sedation is adequate.**

If patient sedated and peaceful, switch off the respiratory support but keep the mask/HFNC in place.
Observe for any signs of distress.
Administer further medication if required and temporarily restart the respiratory support if needed (at same setting to previous).

4. **Repeat step 3 until the patient is adequately symptom controlled without respiratory support.**

Consider SC levomepromazine in addition to opioid and midazolam.

IF NO EFFECT SEEN FROM REPEATED PRN DOSES, PAUSE PROCESS
Is there another source for symptoms?
Call Specialist Palliative Care Team for advice

5. **Remove respiratory support.**

If patient remains peaceful, remove mask/HFNC. Observe for several minutes.
If patient symptomatic, administer further PRN medication and consider re-starting the respiratory support, repeating steps 3-4.

6. **Ongoing symptom control**

Consider oxygen mask eg: venturi 40% once withdrawal from NIV/CPAP/HFNO completed.
If patient is peaceful post-withdrawal, commence syringe driver to continue to deliver medicines for symptom relief.
Review PRN dose administration after 4hrs and increase syringe driver infusion if required.

Chaplaincy & Spiritual Care (Acute Hospital Services) COVID-19 Outbreak

During Covid-19 access Chaplaincy Support by asking for the chaplain on-call via Switchboard

All routine and intentional visits suspended

Religious, spiritual, cultural need identified response required from Chaplaincy Teams

Chaplaincy & Spiritual Care support accessed through normal routes
During Covid-19, for urgent and non-urgent support:
contact Switchboard and ask for the chaplain on-call

Chaplain to contact clinical staff to confirm COVID-19 status and response required

No COVID-19 suspected

New / Ongoing / Urgent Support

Triaged & reviewed in partnership with ward / unit / IC staff

Spiritual Needs Assessment completed

Consider appropriate and safe response:

- Is telephone / Skype response possible?
- What infection control measures are necessary?
- Is generic or faith specific response required?
- Is an urgent response required?

Urgent / EoL

Visit and respond as agreed with clinical staff

Non urgent

Arrange appropriate response and consider telephone contact

Confirmed/Suspected COVID-19

New / Ongoing / Urgent Support

Triaged, reviewed in partnership with ward / unit / IC staff

Spiritual Needs Assessment completed

Consider appropriate and safe response:

- Is telephone / Skype response possible?
- Discuss infection control measures and requirements?
- Is generic or faith specific response required?
- Is an urgent response required?

Urgent /EoL

If visit agreed as urgent and necessary, appropriately trained staff utilise PPE

Non urgent

Visit not appropriate unless urgent. Utilise remote support options

- The individual needs of the patients, relatives, carers and members of staff will be appropriately assessed as part of a Spiritual Needs Assessment to take into consideration their religious, spiritual and cultural wishes.
- An initial risk assessment will be undertaken with a review before each subsequent visit.
- Chaplaincy teams 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.

Visiting palliative care / end of life patients
COVID-19 Outbreak

The public should be asked to limit visiting patients in hospital and to consider other ways of keeping in touch with those close to them, through phone calls and using facilities such as FaceTime, WhatsApp and Skype.

Visitors in clinical areas must be immediate family members or carers.

General principles

As of Tuesday 24th March, we will not be allowing visitors at our hospitals until further notice.

Anyone attending our hospitals for any reason should do so on their own, if practically possible.

Exceptions will be made for immediate family/partners of those at end of life

COVID-19 patients: negative

- end of life visiting and care continues as per latest visiting policy
- consideration regarding the number of visitors at the bedside at any one time should be guided by the individual situation, the facility and appropriate risk assessments
- no children under the age of 12 should be visiting without the nurse in charge's prior permission, but considerate, informed decision-making should be the rule of thumb

COVID-19 patients: suspected or positive

- visitors will wear PPE in the same way as the staff caring for the patient
- there should be no time limit on how long visitors can stay with a patient and relatives can, if they wish to do so, be involved in providing care
- mementoes in care after death can be provided, on the ward
  - mementoes should be placed in a sealed bag and the relatives must not open these 7 days
  - for all other care after death guidance please refer to the appropriate flowchart

Visitors should be restricted to essential visitors only, such as parents or carers of a paediatric patient or an affected patient's main carer. Visiting should also be restricted to those assessed as able to wear PPE (see risk assessment below). Visitors should be permitted only after completion of a local risk assessment which includes safeguarding criteria as well as the infection risks.

Visitors should be advised not to go to any other departments or locations within the hospital or healthcare facility after visiting.

The risk assessment must assess the risk of onward infection from the visitor to healthcare staff, or from the patient to the visitors. The risk assessment should include whether it would be feasible for the visitor to learn the correct usage of PPE (donning and doffing under supervision) and should determine whether a visitor, even if asymptomatic, may themselves be a potential infection risk when entering or exiting the unit. This must be clear, documented and reviewed.

Important considerations for care immediately before and after death
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. The palliative care and bereavement support team, mortuary teams and Coroners Offices can be contacted for additional support and guidance.

Clear and complete documentation

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

Before death

Decisions regarding escalation of treatment made on a case by case basis

If death is imminent and family wish to stay with their loved one staff must advise them that they should wear full PPE

Faith deaths – AWAITING CLARIFICATION

At the time of death

Inform and support family and /or Next of Kin

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

Appropriate Doctor completes MCCD as soon as possible

- COVID-19 is an acceptable direct or underlying cause of death for the purposes of completing the Medical Certificate of Cause of Death
- COVID-19 is not a reason on its own to refer a death to a coroner under the Coroners and Justice Act 2009
- that COVID-19 is a notifiable disease under the Health Protection (Notification) Regulations 2010 does not mean referral to a coroner is required by virtue of its notifiable status

If the deceased is to be cremated, doctors will not be able to physically see the deceased due to risk. AWAITING OF CONFIRMATION OF CREMATORIUM ACCEPTABLE RECOGNISED IDENTIFIERS

Where next of kin / possible informant are following self-isolation procedures, arrangements should be made for an alternative informant who has not been in contact with the patient to collect the MCCD and attend to give the information for the registration

If referral to HM Coroner is required **for another reason**, a telephone conversation should take place as soon as possible with HM Coroner's Office and guidelines within Care after Death policy should be followed alongside this guidance

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

Care after death
COVID-19 Outbreak

Clear and complete documentation

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

This advice is for cases where a COVID-19 is suspected or confirmed. If tested and no results, treat as high risk during care after death.

Mementoes / keepsakes (e.g. locks of hair, handprints, etc) should be offered and taken <u>at the time of care after death.</u> These <u>cannot be offered or undertaken at a later date</u>

- mementoes in care after death can be provided, on the ward
  - mementoes should be placed in a sealed bag and the relatives must not open these before 7 days

Full PPE should be worn for performing physical care after death.

Moving a recently deceased patient onto a hospital trolley for transportation to the mortuary might be sufficient to expel small amounts of air from the lungs and thereby present a minor risk - a body bag should be used for transferring the body and those handling the body at this point should use full PPE

The outer surface of the body bag should be decontaminated immediately before the body bag leaves the anteroom area. This may require at least 2 individuals wearing PPE

Registered nurses on ward to complete Notification of Death forms fully including details of COVID-19 status and place in pocket on body bag along with body bag form, ID band with patient demographics placed through loops in body bag zip, body bag wiped over with, for example, Chlorclean & porters contacted to transfer to mortuary

- the deceased's property should be handled with care as per policy by staff using PPE and items that can be safely wiped down such as jewellery should be cleaned with, for example, Chlorclean
- clothing, blankets, etc., should ideally be disposed of. If they must be returned to families they should be double bagged and securely tied and families informed of the risks
- any hospital linen should be treated as Category B laundry

Property bags should still be used for property that has been properly cleaned / bagged

Organ / tissue donation is highly unlikely to be an option as per any other active systemic viral infection

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

Mortuary transfer and care
COVID-19 Outbreak

Clear and complete documentation

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

Porters, wearing full PPE, PPE collects patient from ward and transfers to Mortuary by way of the process in place for safe removal

Patient walked down to mortuary

Usual booking in procedures at the Mortuary

Trolley used to transfer the deceased to the mortuary and the electric trolley used in the mortuary must both be cleaned with, for example, Bioguard disinfectant on receipt of the deceased

If a pacemaker or defibrillator is in situ these patients will **need to be buried not cremated** due to unnecessary risk to mortuary staff to facilitate removal

No Visits to reduce any risk to staff and family
Skype / FaceTime / photos may be possible on a case by case basis if families wish – mortuary staff / Bereavement Nurses will advise

Families that do wish to visit their loved one should be advised that this may be pursued via their chosen Funeral Director

Mortuary Technicians to do checks on the name tags on body bag tag, body bag **NOT** to be opened

On release of the deceased, Funeral Director to bring coffin into Mortuary, deceased to be placed into coffin and coffin sealed and cleaned prior to being placed in Funeral Director's transport

The trolley and fridge tray that the deceased has been on must be cleaned after release to funeral directors with, for example, Bioguard disinfectant

If a post mortem examination is required, staff to follow Royal College of Pathologists guidelines (Osborn *et al*, 2020)

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

Registering a death
COVID-19 Outbreak

All deaths must continue to be registered by an informant. This information has been provided by local Registry Offices in Leicester, Leicestershire & Rutland.

Clear and complete documentation

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

- where next of kin / or a possible informant are following self-isolation procedures, arrangements should be made for an alternative informant who has not been in contact with the patient to collect the MCCD and attend to give the information for the registration
- where there is no alternative informant available, a member of Bereavement Service staff can register the death as an "occupier".

Wherever possible, the following information is required to be given to the Registrar by whoever is registering the death:

- NHS number
- date of death
- full name at death
- details of any other names that the deceased has been known by
- maiden name if applicable
- date of birth
- place of birth
- occupation and if deceased retired
- marital status
- full Name of spouse / civil partner if applicable
- spouse / civil partner occupation and if retired
- full address and postcode of deceased
- for statistical information date of birth of spouse and the industry they work / worked in and if they supervised staff

Green "release" paperwork can be taken to chosen Funeral Director

- should a member of Bereavement Service staff need to register the death on behalf of the family, payment by card can be arranged via the General Office
- the member of staff registering the death can then request the cash from General Office
- a receipt must be obtained by the staff member from the Registry office to go with the petty cash slip as evidence of payment

Bereavement Offices

The bereavement office at UHL can offer bereavement support through its team of bereavement nurses.

Spiritual Care Teams: The bereavement services at UHL are linked to the UHL chaplaincy (see above)

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

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