Working together to improve end of life care

Community Palliative, End of Life and Bereavement Care in the COVID-19 pandemic

A guide to End of Life Care symptom control when a person is dying from COVID19 care for General Practice Teams,
prepared by the Royal College of General Practitioners
and the Association for Palliative Medicine

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Adapted from Northern Care Alliance NHS Group and the Association for Palliative Medicine of Great Britain and Ireland: COVID-19 and Palliative, End of Life and Bereavement Care in Secondary Care, Version 2

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This guidance is produced during the COVID-19 outbreak in order to support the care in the community of patients and those important to them, at the end of their lives or who are unwell as the result of COVID-19 or other life-limiting illnesses.

This document will be updated 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 public-facing pages of the RCGP COVID-19 Resource Hub and Association for Palliative Medicine website (https://apmonline.org/). Please check that you are referring to the most current version.

Also check COVID government updates: https://www.gov.uk/government/topical-events/coronavirus-covid-19-uk-government-response

For national examples of contingency medication list options for symptom control and resources to support carer administration (after considering any safe-guarding risks), please see RCGP COVID-19 Resource Hub - palliative care section.

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Supporting RCGP COVID-19 Community Palliative and End of Life Care resource list
https://elearning.rcgp.org.uk/course/view.php?id=373

The management of symptoms related to infection with COVID-19 including care at the end of life in the community

Primary care teams have responsibility to provide or refer for essential palliative and end of life care, both for those with a pre-existing health condition and those who may die as a consequence of infection with COVID-19. It is important to remember that most people infected with COVID-19 virus have mild disease and recover. Of the laboratory confirmed patients, approximately:

- 80% have had mild to moderate disease
- 15% require admission to hospital for severe disease. This population is a concern for GPs in the need to know how these patients will be managed in Primary care after hospitals reaches full capacity, and the burden of workload shifts to Primary Care
- 5% require admission to an intensive care unit and are critically ill.

Some people will become severely unwell in the community due to COVID-19 or due to unrelated illnesses whilst self-isolating due to the outbreak. When analysed by age, the mortality rate due to COVID-19 equates closely to the one-year mortality rate for the population of the same age.

Some terminally ill patients will enter the last stages of life and die in the community. Primary care teams need to be prepared and supported to manage this. Clinicians should have access to local specialist palliative care teams for additional advice and guidance if required. As the pandemic progresses, it is likely that both hospice-based and home-based specialist palliative care services will be difficult to access.

Discussions about care plans

Conversations about preferences and priorities, including advance decisions to refuse treatment, are part of advance care planning for anybody who has a progressive life-limiting illness. In the context of people who have severe COVID-19 disease, honest conversations about preferred place of care, goals of care and treatment escalation planning should be initiated as early as is practicable so that a personalised care plan can be documented and revised as the situation changes. Families and carers should be involved in these discussions as far as possible and in line with the person's wishes.

In the context of COVID-19, the person is likely to have become ill and deteriorate quickly, so the opportunity for discussion may be limited or lost. Families and carers may be shocked by the suddenness of these developments and may themselves be ill or required to self-isolate. As far as possible it remains important to offer these conversations. Equally, it is a person's right to not be forced to have these conversations. Being kept informed helps to reduce anxiety, even in highly uncertain situations and even if the conversations need to be conducted behind PPE or, by telephone or video consult. Primary care may consider opportunistic conversations with its most high-risk patients in advance of them being infected, where capacity allows.

If advance care planning conversations have already been documented, then colleagues involved in the person's care should be made aware of the person's wishes, where possible using shared electronic medical record systems and Electronic Palliative Care Coordination Systems (EPaCCS) so that other colleagues including out of hours and emergency services are able to understand the person's wishes as well as updating family and carers contact details to support their involvement in their care.

Adult Safeguarding

Even in the midst of a pandemic, clinicians should be aware of and follow the Mental Capacity Act 2005 principles:

1. The patient must be assumed to have capacity
2. The patient must be given all possible support to make decisions
3. The patient can make unwise decisions [subject to restrictions for infection control which apply to everyone]
4. Any decision taken about a person without capacity must be in their best interest [Subject to considerations of justice in the use of limited resources]
5. Any decision taken about a person without capacity should be the least restrictive

Any concerns about an adult being harmed or neglected must be escalated through the normal safeguarding adult pathways.

Domestic violence and abuse (DVA), perpetrated by one (or multiple) adult family members against another can be physical, emotional, sexual and/or financial. Risk factors for DVA include social isolation, frail health, and increased dependence on another for care. The COVID-19 pandemic will cause an increase in deaths at home and face-to-face support may be more limited, increasing the risk of abuse not being identified. Good communication will be needed between healthcare teams with safe, timely information recording any concerns about DVA on the patient electronic medical record.

For more information, read the full guidance on Domestic Violence and Abuse in the context of end of life care in the COVID-19 pandemic on the RCGP COVID-19 Resource Hub.

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:

Local palliative care guidelines already exist for other symptoms commonly experienced by people with advanced serious illness. The following symptom flow charts take the general approach of:

- correct the correctable
- non-drug and drug approaches

Examples of supportive treatments for correctable causes include:

- antibiotic treatment for a secondary bacterial infection may improve fever, cough, breathlessness and delirium
- optimising treatment of comorbidities such as chronic obstructive airways disease or heart failure may improve cough and breathlessness.

Typical starting dose of drugs are given. However, these may need to be adapted to specific patient circumstances. Some reports are highlighting that for some people dying of COVID-19 the end can be rapid with severe breathlessness. We have a duty to assess and ensure patients, receive appropriate symptom control, to relieve distress without delay. It may be necessary to rapidly titrate symptom relieving drugs by intravenous or subcutaneous injection to relieve distress.

It is important to regularly assess the symptoms of individual patients dying of COVID-19 symptoms and these may vary in severity for each patient. The frequency and dosing must be assessed on an individual basis and adjusted according to their need. For example, severe COVID-19 symptoms, may require higher or more frequent doses, which may include increasing the starting doses or having a low threshold to titrate quickly. Clinicians should access local specialist palliative care teams for advice and guidance if required.

Please note that all routes of administration of drugs should be considered and the choice depends on availability of equipment such as syringe drivers and of staff that are able to administer drugs via different routes. Consider other routes such as buccal, rectal, transdermal. Discuss with the patient's family or carers ways they may administer of medications.

When prescribing medications, as always in end of life care, consider how large a supply may be needed and avoid distress in acute deterioration. Local pharmacy planning measures should be considered to support recovery of unused drugs rather than destroying them, to avoid national shortages. It may also be helpful to work with your local pharmacy teams to enable health care professionals to carry a locked supply drugs for recorded, emergency use in the community.

Management of fever Primary care
COVID-19 Outbreak

Consider accessing local specialist palliative care teams for advice and guidance if required

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

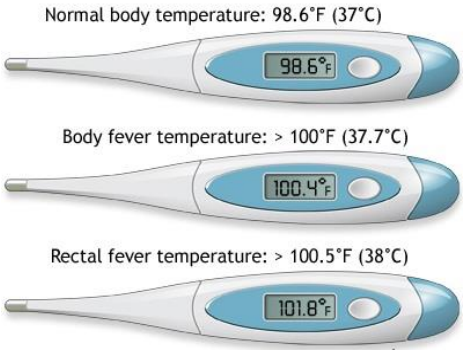
- Reduce room temperature but not to the point of inducing shivering
- Wear loose clothing
- Cooling the face by using a cool flannel or cloth
- Oral fluids
- Cooling the face by using a cool flannel or cloth
- Portable fans are **not** recommended for use during outbreaks of infection or when a patient is known or suspected to have an infectious agent but if self-isolating this may not be so relevant

Pharmacological measures

- Paracetamol 1g PO / PR QDS

It is not advised to use NSAIDs in patients who may recover from COVID-19

- In the dying patient who is not expected to recover from Covid -19 it maybe appropriate to use ibuprofen orally or diclofenac to control fever via a s/c driver



Management of cough Primary care
COVID-19 Outbreak

Consider accessing local specialist palliative care teams for advice and guidance if required

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 a closed waste bin
- Clean hands with soap and water, alcohol hand rub or hand wipes after coughing, sneezing, using tissues

Non-pharmacological measures

- Oral fluids
- Honey & lemon in warm water
- Suck cough drops / hard sweets
- Elevate the head when sleeping
- Avoid smoking
- Humid air may help if it is possible to provide this

Pharmacological measures

- Treat underlying causes such as superadded bacterial infection
  or uncontrolled COPD, HF or asthma- this may help symptoms even in the dying person
- Simple linctus 5-10mg PO QDS
  if ineffective
- Codeine linctus 30-60mg PO QDS
  or
- Morphine sulphate immediate release solution 2.5mg PO 4 hourly

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

- use of sodium cromoglicate 10 mg inhaled 4 times a day (can improve cough in people with lung cancer within 36-48 hours)
- if severe / end of life: morphine sulphate injection 10mg via a syringe driver over 24 hours and 2.5–5mg SC 4 hourly PRN

Management of pain
COVID-19 Outbreak

Consider accessing local specialist palliative care teams for advice and guidance if required

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 1:
  - start **regular** paracetamol (usual dose 1g four times a day)
  - dose reduction is advisable in old age, renal impairment, weight <50kg, etc
- Step 2:
  - persistent or worsening pain: stop paracetamol if not helping pain
  - start codeine 30-60mg four times a day **regularly**
- Step 3:
  - maximum paracetamol and codeine, persistent or worsening pain: stop paracetamol if not helping pain
  - stop codeine
  - commence strong opioid (e.g. oral morphine)

****NSAIDS contraindicated in COVID-19****

Commencing strong opioids

- start either an immediate-release (IR) or a modified-release (MR) preparation
- ALWAYS prescribe an immediate-release morphine preparation prn
- starting dose will depend on existing analgesia – calculate dose required
- monitor the patient closely for effectiveness and side effects
- always prescribe laxatives alongside strong opioids
- always prescribe an antiemetic regularly or prn

Suggested starting doses

- opioid-naïve/frail/elderly
  - morphine 2.5-5mg PO IR 4 hourly
- previously using regular weak opioid (e.g. codeine 240mg/24h)
  - morphine 5mg PO IR 4 hourly or MR 20-30mg BD
  - frail/elderly: use lower starting dose of 2.5mg PO IR 4 hourly or MR 10-15mg BD
- eGFR <30
  - seek advice

Titrating oral opioid dose

- if adjusting the dose of opioid, take prn doses into account
- check that the opioid is effective before increasing the 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 unacceptable side effects occur
- if pain control achieved on IR consider conversion to MR opioid (same 24-hour total dose)
- seek specialist advice if analgesia titrated 3 times without achieving pain control / 3 or more prn doses per day / total daily dose of oral morphine over 120mg / day unacceptable side effects

When the oral route is not available

- if analgesic requirements are stable - consider transdermal patches (e.g. buprenorphine, fentanyl)
- if analgesic requirements are unstable consider initiating subcutaneous opioids
- seek specialist advice if necessary
- morphine is recommended as the first line strong opioid for subcutaneous use for patients, except for patients who have been taking oral oxycodone or those with severe renal impairment
- if constant pain, prescribe morphine 4 hourly SC injections or as 24-hour continuous infusion via a syringe driver (McKinley T34)
- conversion from oral to SC morphine: oral morphine 5mg ≈ SC morphine 2.5mg
- wide inter-individual variation exists and each patient should be assessed on an individual basis
- prn doses of 1/10 to 1/6 of regular 24-hour opioid dose should be prescribed 2-4 hourly SC prn

If first line medications are unavailable, consider local guidance on contingency 2nd / 3rd line options

Consult your local pharmacy guidelines for guidance. National examples can be found on the RCGP COVID-19 Resource Hub

Minimise stock wastage. If available, consider if a syringe driver is helpful

If subcutaneous administration not possible, consider alternative routes e.g. buccal, rectal, transdermal

Management of breathlessness
COVID-19 Outbreak

Consider accessing local specialist palliative care teams for advice and guidance if required

Breathlessness is the subjective sensation of discomfort with breathing and is a common cause of major suffering in people with acute, advanced and terminal disease. In assessing breathlessness, you may want to consider respiratory rate, observation of breathing, use of accessory muscles, evidence of cyanosis and difficulty in completing sentences. 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

COVID -19 often causes breathlessness in its own right and this should be managed with supportive and symptomatic treatment however for many patients there may be other reversible causes contributing.

- Reversible causes should be identified and treated where possible. This would include treatment of superadded bacterial infection, and adequate management of underlying conditions such as COPD, asthma or heart failure.
- Even in the dying patient symptoms may be improved with treating these conditions and it should be considered

Non-pharmacological measures

- Positioning (various advice depending on position: sit upright, legs uncrossed, let shoulders droop, keep head up; lean forward)
- Relaxation techniques
- Reduce room temperature
- Cooling the face by using a cool flannel or cloth
- Portable fans are <u>not</u> recommended for use during outbreaks of infection or when a patient is known or suspected to have an infectious agent but if someone isolated at home this may not be relevant
- Mindful breathing techniques, distraction and psychological support can all reduce the sensation of breathlessness.

Pharmacological measures

- Opioids may reduce the perception of breathlessness
  - Consider Oramorph 2.5-5mg prn (or equivalent opiate)
  - If needed, consider morphine modified release 5mg bd (titrate up to maximum 30mg daily if solely for breathlessness)
  - Morphine 1.25-2.5mg SC prn if unable to swallow titrated up if needed
  - Midazolam 2.5-5mg SC prn for associated agitation or distress
- Anxiolytics for anxiety
  - lorazepam 0.5mg SL prn
- Consider administration via s/c
- Consider oxygen (no evidence of benefit in the absence of hypoxaemia)
- Consider anti-emetic + laxative for morphine/opiate side

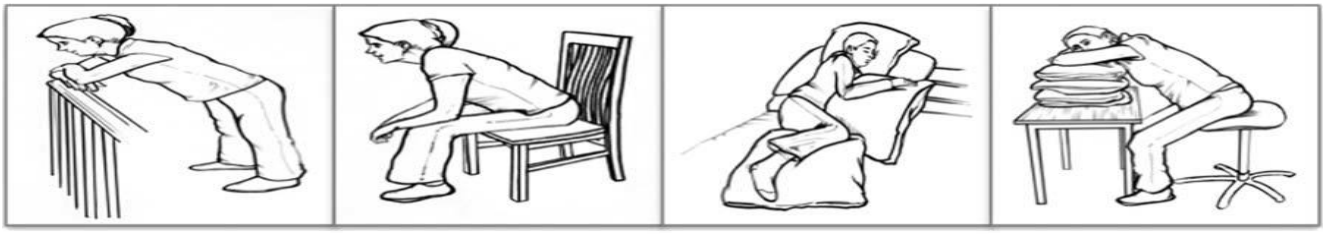
Pharmacological measures – Acute Respiratory Distress Syndrome

Patients can rapidly deteriorate with ARDS COVID-19 symptoms - these can be extremely distressing for the patient and family. **In individual circumstances and depending on the degree of distress, starting doses of medications to help manage breathlessness may need to be increased by up to 50%.** e.g. Morphine (or equivalent opiate), midazolam. If repeating doses, remember subcutaneous medications can take at least 20 minutes to build effect.

o Morphine 2.5-5mg SC prn. Can be titrated to resolution of symptoms and repeated when symptoms begin to recur.

o Midazolam 2.5-5mg SC prn for associated agitation or distress. Can be titrated to resolution of symptoms and repeated when symptoms begin to recur. Higher doses for severe uncontrolled distress at the end of life may be required in patients rapidly dying of COVID-19. IV administration may be indicated - severe cases in extremis

If first line medications are unavailable, consider local guidance on contingency 2nd / 3rd line options
Consult your local pharmacy guidelines for guidance. National examples can be found on the RCGP COVID-19 Resource Hub
Minimise stock wastage. If available, consider if a syringe driver is helpful
If subcutaneous administration not possible, consider alternative routes e.g. buccal, rectal, transdermal



Forward lean 1 | Forward lean 2 | Adapted forward lean for lying | Adapted forward lean for sitting

Management of delirium Primary care
COVID-19 Outbreak

Consider accessing local specialist palliative care teams for advice and guidance if required

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

Identify and treat underlying causes

- Identify and manage the possible underlying cause or combination of causes and treat these
- These include:
  - superadded infection,
  - drugs,
  - dehydration
  - constipation
  - urinary retention
  - hypoxia
- The delirium may be a direct symptom of COVID-19 therefore treatment options may be limited

Non-pharmaceutical measures

- 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
- Ensure adequate care and supervision from family, friends and carers to help with this
- Ensure that people and those looking after them have adequate access to medical input
- Avoid moving people within and between rooms or care settings where possible and keep stimulation at a minimum
- Ensure adequate lighting
- Sometimes providing reassurance that delirium can be a typical symptom of infection can be helpful

Pharmacological measures: mild to moderate to severe

Haloperidol is generally the drug of choice for both hyper- and hypo-active delirium:

- start with 500 microgram / 24h CSCI or PO/SC at bedtime and q2h prn
- if necessary, increase in **0.5−1mg increments**
- median effective dose 2.5mg/24h (range 250 microgram - 10mg / 24h
- consider a higher starting dose (1.5-3mg PO/SC) when a patient's distress is severe and / or immediate danger to self or others

If the patient remains agitated, it may become necessary to add a benzodiazepine, e.g.

- lorazepam 500 micrograms-1mg PO bd and prn
  or
- midazolam 2.5-5mg SC prn 1-2 hourly

Pharmacological measures: end of life (last days / hours)

Use a combination of levomepromazine and midazolam in a syringe driver
Levomepromazine (helpful for delirium)

- start 25mg SC stat and q1h prn (12.5mg in the elderly)
- if necessary, titrate dose according to response
- maintain with 50-200mg / 24h CSCI
- alternatively, smaller doses given as an SC bolus at bedtime, bd and prn

Midazolam (helpful for anxiety)

- start with 2.5-5mg SC/IV stat and q1h prn
- if necessary, increase progressively to 10mg SC/IV q1h prn
- maintain with 10-60mg / 24h CSCI

If the above is ineffective, seek specialist palliative care advice

If first line medications are unavailable, consider local guidance on contingency 2nd / 3rd line options. National examples can be found on the **RCGP COVID-19 Resource Hub**

Management of this symptom, which is distressing for both relatives 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.

- Prevention of delirium is better than cure, so meticulous adherence to delirium prevention strategies (orientation, prevention of constipation, management of hypoxia, etc) is essential
- Adoption of daily screening, using Single Question in Delirium (SQiD) and / or 4AT rapid test for delirium (https://www.the4at.com/) to detect early and treat cause

Care immediately before and after death

A proportion of people who have severe COVID-19 will die of the infection or complications. This guidance includes a flow chart of what needs to be done and how best to support people in this situation, throughout this period. Bereavement support will be essential particularly for those with existing mental health conditions. In most parts of the country, bereavement services already exist and it will be important to understand your local support options. It is also important to consider the role of compassionate communities and supportive networks within them available. Experience in previous disaster situations tells us that community support and local group initiatives will be most valuable on the path to recovery for bereaved and traumatised.

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.

Staff should be aware that this guidance is subject to change as developments occur. Check for updates on the RCGP COVID-19 Resource Hub. Additional information can be found here; https://www.gov.uk/government/topical-events/coronavirus-covid-19-uk-government-response. Funeral directors and Coroners offices can be contacted for additional support and guidance.

Important considerations for Care immediately before and after Death where COVID-19 is suspected or confirmed

(Information to do with certification apply to England and Wales – information about Scotland and Northern Ireland is in the box at the bottom of the flowchart)

Clear and complete documentation

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

BEFORE DEATH

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

If death is imminent and family wish to stay with their loved one, they should be advised regarding infection risk and should wear full PPE

Consider the patient's spiritual or religious needs; if appropriate, signpost to whatever resources are available in your local area.

VERIFICATION OF DEATH

Inform and support the family and/or next of kin. Consider their spiritual or religious needs and signpost to appropriate resources in your local area.

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

Verification of death process should be completed as per local policy/guidelines.

Any equipment used in the Verification of Death process should be either disposed of or fully decontaminated with Chlorclean solution

Emotional/Spiritual/Religious needs of the deceased and their family/significant other/s

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.

Staff should be aware that this guidance is subject to change as developments occur. Check for updates on the RCGP COVID-19 Resource Hub. Additional information can be found here; https://www.gov.uk/government/topical-events/coronavirus-covid-19-uk-government-response. Funeral directors and Coroners offices can be contacted for additional support and guidance.

MEDICAL CERTIFICATE OF CAUSE OF DEATH

Clear and complete documentation

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

Emotional/Spiritual/Religious needs of the deceased and their family/significant other/s

Appropriate Doctor completes Medical Certificate of Cause of Death 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. A swab is not necessary if the doctor feels that to the best of their knowledge and belief, Covid-19 is the cause of death.
Covid-19 is notifiable but it is not a reason on its own to refer a death to a coroner under the Coroners and Justice Act 2009.

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The body does not need to be seen for cremation paperwork, unless the patient has not seen a doctor in the 28 days before death.

↓

Where next of kin/ or a possible informant are following self-isolation procedures or ill or unavailable, arrangements can be made for the funeral director to act as an informant. Documents should be signed, scanned and sent by secure email and the originals posted or kept safe for collection at a later date, depending on local arrangements. See further section on "Registering the

↓

If referral to HM Coroner is required **for another reason**, notification should take place as soon as soon as possible and is legally required in writing.

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.

Staff should be aware that this guidance is subject to change as developments occur. Check for updates on the RCGP COVID-19 Resource Hub. Additional information can be found here; https://www.gov.uk/government/topical-events/coronavirus-covid-19-uk-government-response. Funeral directors and Coroners offices can be contacted for additional support and guidance.

CARE AFTER DEATH

Clear and complete documentation

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

If deceased has been tested for covid-19 and no results please treat as high risk.

Full PPE should be worn for performing physical care after death. Information on PPE can be found in the "PPE requirements" table on the final page of this document.

Mementoes/keepsakes e.g. locks of hair, handprints etc. must be offered and obtained during physical care after death by person/s wearing full PPE, as they will not be able to be offered at a later date. They should be placed in a sealed plastic bag and families advised to NOT open for 7 days.

The act of moving a recently deceased patient 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

Registered nurses to complete Notification of Death forms fully including details of COVID-19 status (NEW SECTION) and place in pocket on body bag along with body bag form, ID band with patient demographics placed through loops in body bag zip.

The outer surface of the body bag should be decontaminated (see environmental decontamination https://www.gov.uk/government/publications/wuhan-novel-coronavirus-infection-prevention-and-control/wuhan-novel-coronavirus-wn-cov-infection-prevention-and-control-guidance#decon) immediately before leaving the clinical area. This may require at least 2 individuals wearing PPE (check your local PPE guidance), in order to manage this process.

Ensure that anyone involved in moving the body is aware of confirmed or suspected COVID-19

If someone has died in a care setting, the deceased's property should be handled with care as per policy by staff using PPE. Items that can be safely wiped down such as jewellery should be cleaned with Chlorclean and securely bagged before returning to families.
Clothing, blankets etc. should ideally be disposed of or treated as per local policy. If they must be returned to families they should be double bagged and securely tied and families informed of the risks

Consider bereavement support for the family and/or carers of any confirmed or suspected COVID-19 deaths and refer on as appropriate

Emotional/Spiritual/Religious needs of the deceased and their family/significant other/s

NB - ORGAN/TISSUE DONATION IS HIGHLY UNLIKELY TO BE AN OPTION AS PER ANY OTHER ACTIVE SYSTEMIC VIRAL INFECTION

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.

Staff should be aware that this guidance is subject to change as developments occur. Check for updates on the RCGP COVID-19 Resource Hub. Additional information can be found here; https://www.gov.uk/government/topical-events/coronavirus-covid-19-uk-government-response. Funeral directors 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 other/s

REGISTERING THE DEATH

All deaths must be registered by an informant and it is now expected that this will be done remotely

Where the deceased's next of kin or a possible informant are following self-isolation procedures, ill or unavailable a funeral director can act as an informant on behalf of the family. Where there is no alternative informant available, a member of Bereavement Service/Office 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

USEFUL CONTACT INFORMATION AND RESOURCES

Public Health England https://www.gov.uk/government/topical-events/coronavirus-covid-19-uk-government-response
Public Health Wales. https://phw.nhs.wales/topics/latest-information-on-novel-coronavirus-covid-19/
Health Protection Scotland https://www.hps.scot.nhs.uk/a-to-z-of-topics/covid-19/
HSC Public Health Agency Northern Ireland https://www.publichealth.hscni.net/news/covid-19-coronavirus
Public health declaration of Covid-19 as a notifiable disease https://www.legislation.gov.uk/nisr/2020/23/made
Mental capacity legislation www.legislation.gov.uk/nisr/2019/190/pdfs/nisr_20190190_en.pdf

Emotional/Spiritual/Religious needs of the deceased and their family/significant other/s

Holistic Care - Psychosocial, Spiritual, Religious and Cultural beliefs of patients and families

In these unprecedented times, the spiritual care of our patients will become increasingly important as people grapple with spiritual questions regardless of whether they have a faith or none. As primary care clinicians we need to acknowledge these questions as part of our care and be able to signpost people to where they can receive ongoing support. In some areas, Primary Care Chaplaincy will be vital to support us in these conversations giving an opportunity to consider what makes life meaningful and how to find inner hope and strength during the time of personal and national crisis. Our practices may have links with community faith groups which will help the specific communities in which we work. Although this may be an area of care that we are less familiar with, it is increasingly important we consider it as an integral part of holistic end of life care. The Association of Chaplaincy in General Practice offers useful advice and support http://acgp.co.uk/

It is important that we are able to link with existing compassionate neighbourhood and community initiatives which help people, families and neighbourhoods to support each other, in terms of the practical help of shopping, cooking, cleaning etc and the emotional support of friendship and care. Going into the future, there will be the need for peer support bereavement groups/cafes to help deal with the psychological aftermath of the COVID-19 pandemic. Each GP surgery can offer support simply knowing and being able to advise where to find information about local groups, so that patients and families can be linked with them. Our community connector roles will provide vital links between our patients, the practice and existing community services and supportive networks within our communities.

- National example of GP Surgery Bereavement leaflet - https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2020/03/NHS-Bereavement-Leaflet.pdf
- COVID CRUSE - Grief and Trauma - https://www.cruse.org.uk/coronavirus/trauma
- A collaborative guide to COVID-19 care - https://covid-at-home.info/

Looking after yourself and colleagues

As we sadly anticipate many community deaths from Covid-19 it is important we consider how to provide effective palliative care that meets the physical, social, psychological and spiritual needs of our patients, not just at the end of their lives but at different points along the trajectory of this disease. We will also be providing care and support for the families of our patients in circumstances that will make preparing for death more difficult.

In addition, the uncertainty of the progression of the illness, the pressure that we will be working under and the sheer scale of the pandemic and subsequent deaths will mean that we, as primary care clinicians, will be working in unfamiliar, emotional territory.

In order to care effectively for our patients and their families, we must care for the physical, social, psychological and spiritual needs of our colleagues and ourselves. Firstly, we need to recognise our own vulnerabilities and the effect of our emotions upon our behaviours. It is important to develop within our team safe spaces, psychologically and physically, to talk about these and the effect upon our wellbeing.
We must develop mindful and deliberate compassion towards each other which involves noticing and being present in each other's suffering as well as creating flexible time to cope with suffering, buffering each other from overload as outlined in the GMC document, "Caring for doctors, Caring for patients". https://www.gmc-uk.org/-/media/documents/caring-for-doctors-caring-for-patients_pdf-80706341.pdf

We all will have anxieties, we will feel the burden of risk, we will be faced with suffering and death and at times will be limited in what we are able to do. We will feel tired and overwhelmed. We will not be failing our patients or our teams by feeling these things.

We will need to come alongside each other in our daily teams, or virtually, to identify with others who will be feeling the same. At times we will be able to be steady and calm in the face of the great suffering. At times we will seek this compassion from others. It is a time to show we value each other and confer dignity to each other. We need to be reaching out and establishing these networks of support now. Start by asking someone you work with how they really are.

Resources

Resources for looking after ourselves and each other during this very difficult time.

UK: Support with mental wellbeing, finance, housing and unemployment
https://www.mentalhealth.org.uk/coronavirus

England: NHS Practitioner Health provides https://www.practitionerhealth.nhs.uk/covid-19-workforce-wellbeing

Northern Ireland: www.nidirect.gov.uk

Scotland: section on Mental Wellbeing: https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19

Wales
For doctors in training: Professional Support Unit HEIW.ProfessionalSupport@wales.nhs.uk
For all doctors: Health for Health Professionals www.hhpwales.co.uk

RCN – COVID and your mental wellbeing
https://www.rcn.org.uk/get-help/member-support-services/counselling-service/covid-19-and-your-mental-wellbeing

These websites provide professionals with direct links to health, wellbeing and other referral sites for doctors in need.

BMA Wellbeing support services - Open to all doctors whether BMA (British Medical Association) members or not and is staffed by professional telephone counsellors 24 hours a day, 7 days a week. They are all members of the British Association for Counselling and Psychotherapy and are bound by strict codes of confidentiality and ethical practice. You can even choose to remain anonymous when you call.

DocHealth - A self-referral service available to all doctors, UK wide, and aims to provide confidential, specialist-led support for those suffering with stress-related depression or anxiety. The programme will initially run as a 24-month pilot, and aims to complement existing support services such as BMA Counselling and the Doctor Advisor Service. It is a joint venture from the RMBF and BMA. DocHealth is exclusively self-referral, with no report writing unless specifically requested by the doctor using the service. Fees are based on a sliding scale relating to the grade and circumstances of the doctor.

Doctors Support Network - A self-help group for doctors with mental health concerns, including stress, burnout, anxiety, depression, bipolar affective disorder, psychoses and eating disorders. All doctors in the group have been troubled at some stage in their lives. There are regular meetings around the UK, a newsletter and an email forum.

GMC (General Medical Council) online guide 'Your health matters' - Provides the first step in this support, helping to provide timely information for doctors who may for health reasons be involved in the GMC's fitness to practise procedures. The content was written with the help of Practitioner Health Programme, the Doctors' Support Network and the British Medical Association.

Practitioner Performance Advice (formerly NCAS) - Allows you to self refer, if you are returning to work after a period of absence, or you have health problems which may be impacting on your performance, and they will provide expert advice about the steps you can take and where you can go for help.

Royal Medical Benevolent Fund - A UK charity for doctors, medical students and their families. They provide financial support, money advice and information when it is most needed due to age, ill health, disability or bereavement.

Sick Doctors Trust - A proactive service for actively addicted doctors that is structured to provide an early intervention programme. The trust facilitates treatment in appropriate centres, arranges funding for inpatient

treatment and provides advocacy and representation when required. A charitable trust controlled by a board of trustees and staffed by doctors in recovery.

Samaritans - supporting anyone through branches across the UK and Republic of Ireland

Support for doctors - Academy of Medical Royal Colleges - A listing of websites that can offer support

Managing mental health challenges faced by healthcare workers during covid-19 pandemic
BMJ 2020;368:m1211
https://www.bmj.com/content/368/bmj.m1211