Covid-19 Emergency: Advance treatment decisions and Palliative care

Resources to support North West London practitioners to undertake Anticipatory Care Planning (ACP) with patients

V3.0 02/04/2020

Collated by NW London Covid 19 Community response team – End of life workstream.

A wide consultation and review of existing national, regional and local resources was used to develop this resource pack.

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A collated list of National, Regional and NW London local good practice resources for community practitioners to use to support anticipatory care planning and palliative care during COVID-19 crisis

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Abbreviations: SOP – Standard operating procedure

<u>Still awaiting the following National and regional guidelines to be published.</u>

1) Pan London Ethical Decisions document
2) NSHE/I Guidance for Palliative care in COMMUNITY SETTING

Supporting practitioners with Anticipatory Care Planning (ACP): Covid-19 Crisis 2020

To note

A joint statement in relation to anticipatory care planning was issued on 30/03/2020 from the following organisations:

- British Medical Association (BMA)
- Care Provider Alliance (CPA)
- Care Quality Commission (CQC)
- Royal College of General Practice (RCGP)

The importance of having a personalised care plan in place, especially for older people, people who are frail or have other serious conditions has never been more important than it is now during the Covid 19 Pandemic.

Where a person has capacity, as defined by the Mental Capacity Act, this advance care plan should always be discussed with them directly. Where a person lacks the capacity to engage with this process then it is reasonable to produce such a plan following best interest guidelines with the involvement of family members or other appropriate individuals.

Such advance care plans may result in the consideration and completion of a Do Not Attempt Resuscitation (DNAR) or ReSPECT form. It remains essential that these decisions are made on an individual basis. The General Practitioner continues to have a central role in the consideration, completion and signing of DNAR forms for people in community settings.

It is unacceptable for advance care plans, with or without DNAR form completion to be applied to groups of people of any description.

These decisions must continue to be made on an individual basis according to need.

1. Introduction

This NW London resource pack is for GPs and other practitioners to undertake anticipatory care planning with their patients or to update a plan where it already exists, and record on Coordinate my Care (CMC).

It is well established that offering anticipatory care plan discussions to patients can increase the chances of patient-centred care, achieving preferred place of care and preferred place of death. Digital platforms such as **coordinate my care (CMC)** and the primary care medical record are enablers to sharing patients' wishes and achieving their goals. With this in mind, below is guidance on how to approach anticipatory care discussions with frail and elderly patient with complex comorbidity during the 2020 COVID-19 crisis. **Fundamental to this process is offering rather than imposing these conversations and having a patient focused approach**.

Clinicians are expected to make decisions in the same way that they would normally –in the best interests of the patient. We are now developing a better clinical understanding of covid-19 that needs to be applied to these decisions –if there has been significant lung damage, patients are likely to need to be on a ventilator for an extended period and that needs to shape clinicians' decisions about who is likely to benefit from ventilation and who is not. It has been observed that that ITU and HDU care are often not effective treatments for patients with COVID-19 who are frail and are dependent for many of their everyday needs. For this reason, these patients are not routinely offered ITU and HDU care.

In hospital, mildly frail patients may be offered CPAP (continuous positive airway pressure) rather than ventilation if they are deemed fit and there are no contraindications. It is important to use this guidance wisely, advising if appropriate in particularly frail patients that in hospital it is likely that only oxygen may be available to them rather than CPAP and ventilation. In these patients it may be prudent to be clear from the outset that these options may well not be available to them.

What does the pack include?

- Scripts to support an ACP conversation
- Resources to support a thorough ACP conversation and end of life resources under the following sections:
    1. Symptom management and care of the dying
    2. Communications and ethics
    3. CMC use and creation
    4. Care homes and high risk/vulnerable people
        - Examples of letters from GPs to care homes about need for ACP with residents which practises and PCNs can adapt for own use
        - Examples SOPs to enable GPs to work remotely with care homes which practices and PCNs can adapt for own use
    5. Information for patients and carers
    6. Care after death
    7. Additional resources

Please note: There is no standard NW London letter about anticipatory care discussions with frail and elderly patient with complex comorbidity during the 2020 COVID-19 crisis. PCNs/ Practices or practitioners can use or adapt the information in the example letters included in Section 3 of this pack to communicate with care homes, vulnerable patients and their relatives.

Who does it apply to?

- All residents in residential and nursing homes
- People living in their own homes with a care package
- People in supported living
- People in their own homes independently without a care package who are at risk of deteriorating physical health and would benefit from an ACP (identified by a healthcare professional or the UK government in response to Covid-19)

Who should discuss and document the ACP?

In most cases it will be the GP where the person is known to them or by an individual where the care plan has previously been developed.

For a number of residents in a care home setting it may be the senior Nurse, a Clinical Nurse Specialist (CNS) or other suitably qualified practitioners/ staff:

- Care home Nurses (general RN)
- CNS Palliative care
- CNS Respiratory
- CNS Cardiac
- Social Workers
- AHPs e.g. OT
- Social Prescribers

Where should the ACP be recorded?

Coordinate my Care (CMC) and a printed paper copy placed with the person at their usual place of residence.

Who is the Responsible Clinician (RC) to ensure the ACP is developed and implemented?

The patient's registered GP will be overall responsible, but will call upon other services to deliver the care to the person depending on their needs.

We would to extend acknowledgement and a huge thanks to all those who have contributed to this pack; including CCG Chairs, Macmillan and EOLC GP clinical leads, specialist palliative care from both acute and community trusts and hospices in NW London, as well as wider end of life care stakeholders for NW London.

All sources of information are listed on the contents page.

For any further information or for queries about this pack please contact: Nwlccgs.covid19community@nhs.net

Considerations and scripts to support Anticipatory discussions:

Longer 'script' to discuss Anticipatory Care Planning (ACP) with a patient: either face-to-face, during video consultations or on the telephone - then record on CMC

Ensure you record the information collected onto CMC – see section 3 for CMC resources to support you to do this.

1. **Clarify who is in the room, their roles, if the patient or family member acting for the patient (if patient lacks capacity) would like anyone else present:**
    a. Does the person have capacity to understand the content of this discussion at this time?
    b. Is there a Lasting Power of Attorney for Health and Wellbeing or Deputy, (and if there is can they provide the documentation which must be registered with the Office of the Public Guardian)
    c. Does the person need emotional support for this discussion
    d. Bearing in mind all of the above is now a suitable time for this potentially distressing conversation?
2. **Explore understanding and clarify what COVID-19 is**:
    a. *"What do you understand COVID-19 or corona virus to be? What do you know about it?"*
    b. Clarify that *"COVID-19, also known as corona virus, is an infectious disease that is spreading across the country from person to person. It causes a cough, fever, headaches, body aches, shortness of breath and sometimes bowel symptoms. There is currently no cure but most patients get better with supportive treatment or rest alone. It can cause mild illness in some people and very severe life-threatening illness in others. It is thought that older people with complex medical problems have a much higher risk of severe disease and death. As you may have heard in the media, many patients who get severely unwell may be offered a ventilator to breath for them".*
3. **Ask for permission to discuss the future:**
    a. "Please can I ask you questions about the future and your health?" "Are you someone who likes to plan ahead with your health or are you someone who likes to take each day as it comes?"
        i. If they say they like to take each day as it comes and they do not want to talk about their health offer once more by saying *"The reason I am asking this is that we often find that if we discuss the future and plan ahead we can help people choose their care and increase the chances of patients getting the care they want and where they want it"*
        ii. If after this they still say no, respect their decision and stop further anticipatory care discussions. You can offer if they would like a relative or other proxy to have these discussions on their behalf.
4. **Ask about their worries, hopes and fears:**
    a. "Have you thought about what might happen if you became infected with corona virus?"

   b. "At this time in your life what is it that makes you happy or you feel is important to you?"
   c. "What would you NOT want to happen? Is there anything that you worry about or fear happening?"

5. **Ask about care preferences:**
   a. *"If you were unwell with corona virus, and you had all options available to you, where would you prefer to be cared for?"* (home/hospital/hospice/care home).
   b. *"This is a distressing and difficult question. If you were critically unwell, and all options were available to you, and at the end of your life, where would you like to die?"* (options as above)

6. **Explore ceilings of care:**
   a. "This is a very difficult and potentially distressing question, so please feel free to stop me or take your time to answer. If you had severe life-threatening corona virus would you want to go to go to hospital to receive potentially life-saving care or would you like to receive best care at home without these potentially life-saving treatments?"
      i. You may wish to include in severely frail or for relatives of a patient with severe dementia: *"Although that going to hospital would give you access to potentially life-saving treatment, there is also the risk of getting ill from other infections or dying from other causes in hospital. Furthermore, due to your complex medical problems and reduced physical strength some treatments in hospital may not be helpful/offered to you and cause discomfort with little benefit to you or your survival. This risk is difficult to fully define but there is uncertainty as to how much some aggressive treatments will help you or be offered by doctors to you."*
      ii. You may wish to go into more detail: *"There are several ways the hospital may try and support you. These could be giving you fluid through a needle in your vein, giving you oxygen or helping you breath either through a high pressure face mask or a ventilator. If you are in hospital your family and friends would not be able to visit you. Oxygen may help you breath but it may not. If oxygen alone doesn't help you might be offered a high pressure facemask called CPAP (continuous positive airway pressure) or ventilation. These treatments are not offered to everyone because in particular patients who are very frail or have other health problems, they do not help sufficiently. The doctors would decide if these treatments were suitable for you. "*
         - It may be important to acknowledge that CPAP is quite uncomfortable for many patients
      iii. You may wish to reassure the patient or relative, that if they chose not to be admitted for life-saving treatment in hospital, supportive treatments at home could be given to keep the person comfortable and avoid suffering
   b. "This is again a very difficult question and feel free to stop me if you feel too uncomfortable or upset. A ventilator is a machine that breaths for you whilst you are unconscious. This is offered to some patients with life-threatening corona virus who are thought to have the resilience and strength to recover following a short period (days/weeks) on this very aggressive treatment. It is not offered to everyone and in hospital it may or may not be offered to you to save your life, should you have life-threatening breathing problems. Is this something you would

want or would you prefer the option of having supportive treatments to make you comfortable?" (emphasise if this is something they would want only if there is a chance this would be offered to them).

        i. Again you may wish to mention in a particularly frail patient or to a relative of a patient with severe dementia: *"Ventilation may not be a sensible option or offered to you as due to your complex medical problems and profoundly reduced strength it may be less likely that your body will breath again by itself following this aggressive treatment. In the event that you did survive ventilation your quality of life may be significantly reduced compared to what it is now. There is some uncertainty about this and again it is difficult to clearly define."*

        ii. *"People who need help with their breathing (a ventilator which does their breathing for them) are extremely ill and in some cases may not survive, no matter their age."*

    c. Ask about do not attempt cardiopulmonary resuscitation (DNACPR):

        i. *"Finally, I have one more difficult question and I apologise for the distressing nature of this conversation so far. Do you feel ok to continue? If your heart were to stop for any reason would you want healthcare professionals to attempt to bring you back to life using very aggressive methods including pressing down heavily on your chest and using tubes and other devices?"*

        ii. *"Thank you for sharing your thoughts. I apologise for the distressing nature of this discussion. Please can I share with you my medical opinion regarding this? As you may or may not be surprised to hear, the decision about whether to bring someone back to life or allow someone to die naturally is a decision taken by the doctor rather than patients or their relatives. However, the decision to allow a natural death has to be made in advanced and documented to be valid."*

        iii. For frail patients where there is complex comorbidity: "*In my medical opinion, due to your complex medical problems and low in-built strength, if your heart should stop for any reason, aggressive attempts to bring you back to life such as pressing against your chest would most likely be unsuccessful. In the unlikely event that they were successful, it is highly likely you would have an extremely low quality of life, being unable to enjoy many of the things you do now. Therefore it is my medical opinion that it would be in your best interests to have a certificate stating to healthcare professionals that they should allow you to pass away peacefully rather than starting to attempt to bring you back to life using the aggressive methods."*

7. **Discuss options as appropriate:**

    a. Hospice and palliative care support:

    b. Anticipatory medication:

        i. *"We can provide medication called 'Just in Case Medication'. These are medication that are locked away and only used in the event that you are terminally ill and unable to take medication by mouth. They are to reduce pain, breathlessness, sickness and anxiety. If you would like we can prescribe these medication and you can keep them at home just in case one day you need them. They are often difficult to get last minute during* *the weekend or at night, so it is useful to have these well in advance just in case. They are given to you when you need them by district nurses who can come to your house day and/or night to give you care."*

8. **Check understanding:**
    a. "I am sorry for the distressing content of this discussion but I hope it may help us plan ahead and help you get there care you would want in the future".
    b. "If you feel able and would like to, please could you summarise what we have discussed? Would you like me to summarise again for you?"
9. **Clarify how you can share their wishes:**
    a. *"There is a digital platform called Coordinate My Care (CMC) https://www.coordinatemycare.co.uk which is a confidential web-based way of recording care plans for patients. This enables your wishes, decision about where you would like to be cared for and medical problems to be seen by ambulance crews, GPs, hospital doctors and out-of-hours medical services. Would you like me to create one of these plans for you?"*
    b. For some patients: *"You can also create your own plan using the online myCMC option." https://www.mycmc.online/public/index.html#/home*
    c. If declining CMC ask if you can share the plan on paper in their home, with relatives and / or on the GP record
10. **Follow-up and closure:**
    a. Set when you are able to see the patient again or how you are available for support
    b. Check the patient is ok and if they would like any other person to be informed

Shorter ‘script’ for telephone calls to patients to discuss Anticipatory Care Planning (ACP) – then record onto CMC

Ensure you to record the information collected onto Co-ordinate My Care (CMC) – see section 3 for CMC resources to support you to do this.

Introduction

‘Hello my name is…’

Make sure you are talking to the right person

Ensure they can clearly hear and understand you

1. **Reassurance**

‘We are aware that a lot of patients may be worried to bother us in case we are too busy so we just wanted to contact you and make sure you are ok.

‘I know it may be worrying at the moment with all the endless news reports regarding Covid-19.

‘I just wanted to let you know we are here and that if you have any concerns or symptoms you can let us know’.

Is there anything worrying you at the moment or that you would like to ask me?’

2. **Contact Next of Kin/ or other with legal representation**

‘What support if any do you have at the moment? Do you have carers coming in, someone to do shopping/get any medications or things you might need during an extended time of staying at home? *(question may not be relevant for residents in care homes)*

‘It would also be a good time for me to check we have all your contact and next of kin details up to date? including any legal representation such as lasting powers of attorney?

3. **Conversation about patient’s wishes**

‘We really are living through an unprecedented time, and we know for some people it makes them start thinking about what they want and what they do not want when it comes to medical treatment if they were to become unwell. This is usually called a future, advance or anticipatory care plan.

I am sorry to bring this up and over the phone like this and if you prefer not to talk about it, that is completely fine.

However, if you feel you would like to talk about it, or let me know what those wishes are, so that everyone involved in looking after you knows and is aware e, then I would be very happy to discuss that now or another time soon if that is better for you’.

(Could reference a past care plan already recorded and use this as a discussion, or use the CMC platform to guide you through preferences and priorities of care)

There is a digital system that we have been using across London called Coordinate My Care. This is for GPs, the ambulance service and the hospitals to share your important medical information, your wishes and priorities and your next of kin details. Would you be happy for me to create a record for you on this system?

4. Vulnerability

‘Care home residents like yourself *(amend to the appropriate situation)* are potentially more vulnerable and are likely to have an increased risk of severe illness if you were to contract the Covid-19 virus.

Processes are in place to isolate all residents and limit visiting to reduce your likelihood of becoming ill’.

‘Should you become ill, your doctor will need to know of your wishes for care and treatment, and this is best managed before you are severely ill, when you may not be able to express your wishes’.

If you become ill, your symptoms could be managed in your usual place of residence and can we planned for in advance if you would like?

Any decision about you will continue to be made on an individual basis according to your needs.

5. Ethical decision making

The framework published in March intends to provide support to ongoing response planning and decision-making to ensure that ample consideration is given to a series of ethical values and principles when organising and delivering social care for adults. Guidance Responding to COVID-19: the ethical framework for adult social care Published 19 March 2020

When having the discussion with the resident, consider the following:

Respect: This principle is defined as recognising that every person and their human rights, personal choices, safety and dignity matters.

Reasonableness: This principle is defined as ensuring that decisions are rational, fair, practical, and grounded in appropriate processes, available evidence and a clear justification.

Minimising harm: This principle is defined as striving to reduce the amount of physical, psychological, social and economic harm that the outbreak might cause to individuals and communities. In turn, this involves ensuring that individual organisations and society as a whole cope with and recover from it to their best ability.

Inclusiveness: This principle is defined as ensuring that people are given a fair opportunity to understand situations, be included in decisions that affect them, and offer their views and challenge. In turn, decisions and actions should aim to minimise inequalities as much as possible.

Accountability: This principle is defined as holding people, and ourselves, to account for how and which decisions are made. In turn, this requires being transparent about why decisions are made and who is responsible for making and communicating them.

Flexibility: This principle is defined as being responsive, able, and willing to adapt when faced with changed or new circumstances. It is vital that this principle is applied to the health and care workforce and wider sector, to facilitate agile and collaborative working.

Proportionality: This principle is defined as providing support that is proportional to needs and abilities of people, communities and staff, and the benefits and risks that are identified through decision-making processes.

Community: This principle is defined as a commitment to get through the outbreak together by supporting one another and strengthening our communities to the best of our ability.

Special considerations for telephone consultations:

1. Acknowledge when you can hear the person upset or their voice changes and ask for clarification
2. Ask several times during the consultation if they understand and are happy to continue
3. Ask if they would like you to discuss anything again with another person or family member the same topics to help their understanding

Video Consultation options for completing Advance Care plan/ DNAR conversations:

- Zoom Video Consultation

See “How to Use Zoom” user guides

- Microsoft Teams – due to COVID-19 this is available free for NHS staff
- Whatsapp – IG community says acceptable to use whatsapp. Be aware to use video conferencing they have to save your contact number to then launch call to you (that acts as consent) so they return your number. If your service uses a single point of access you may not want them having individual mobile numbers.
- Accurx

https://www.accurx.com/video-consultation-for-nhs-trusts https://www.accurx.com/video-consultation-for-nhs-trusts%20

This is a web-based service via NHS mail. A link will be provided via NHS mail to a user agreement. You need to enter the patients NHS number and DOB then it sends a ticket to their smart phone and then the video starts. This has been released free during COVID-19 (usually there is a fee) Contact: becky@accurx.com

Other useful guidance:

- British Geriatric Society guidance on COVID-19 in care homes: https://www.bgs.org.uk/resources/covid-19-managing-the-covid-19-pandemic-in-care-homes
- https://www.gov.uk/government/publications/coronavirus-bill-summary-of-impacts/coronavirus-bill-summary-of-impacts#section-4--managing-the-deceased
- Local voluntary support for vulnerable patients: https://covidmutualaid.org/local-groups/
- The Scottish Quality Safety Fellowship have some helpful resources on their website to support difficult conversations with people and families, as well as provide information on stress coping and resilience for healthcare workers: https://learn.nes.nhs.scot/741/quality-improvement-zone

- Difficult conversations https://www.realtalktraining.co.uk/app/uploads/2020/03/COVID-19-Evidence-based-advice-for-difficult-conversations.pdf
- Prognostic indicator tools for frailty and other long-term conditions: https://www.spict.org.uk and https://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf

Section 1
Symptom management and care of the dying

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

First Edition March 2020

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

Collated for General Practice Teams by:
Dr Catherine Millington-Sanders and RCGP COVID-19 End of Life Care Advisory Group

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:
  - 37.5°C or greater (oral)
  - 37.2°C or greater (axillary)
  - 37.8°C or greater (tympanic)
  - 38°C or greater (rectal)
- Associated signs & symptoms:
  - shivering
  - shaking
  - chills
  - aching muscles and joints
  - other body aches

Non-pharmacological measures

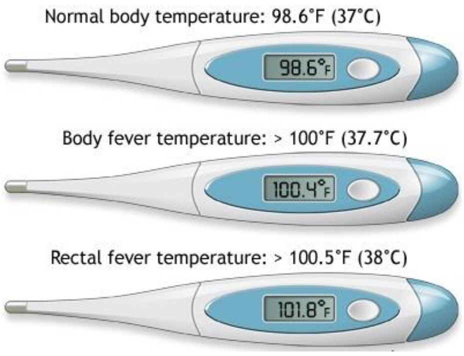
- Reduce room temperature but not to the point of inducing shivering
- Wear loose clothing
- Cooling the face by using a cool flannel or cloth
- Oral fluids
- Cooling the face by using a cool flannel or cloth
- Portable fans are **not** recommended for use during outbreaks of infection or when a patient 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

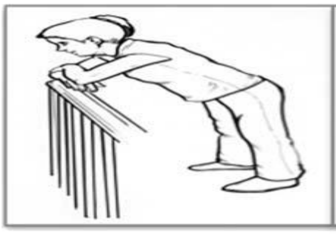
- Opioids may reduce the perception of breathlessness
    - Consider Oramorph 2.5-5mg prn (or equivalent opiate)
    - If needed, consider morphine modified release 5mg bd (titrate up to maximum 30mg daily if solely for breathlessness)
    - Morphine 1.25-2.5mg SC prn if unable to swallow titrated up 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.

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

Emotional/Spiritual/Religious needs of the deceased and their 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

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

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.

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.

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.**

CARE AFTER 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

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

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.**

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

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

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

COVID EOLC COMMUNITY CHARTER

Working together across the community, to give the best possible palliative and end of life care to people affected by COVID-19 Pandemic, we will seek to be guided by the following ethical principles:

1. Respect

- People should be kept as informed as possible.
- People should have the chance to express their views on matters that affect them.
- People's personal choices about their treatment and care should be respected as much as possible.
- Where a healthcare team's views on appropriate future treatments are at odds with those of an individual and those close to them, a second opinion should be sought.
- When people are not able to decide, those who have to decide for them should take decisions based on the best interests of the person as a whole rather than just based on their health needs.
- When people are vulnerable, safeguarding their rights and fulfilling our statutory responsibilities of care will remain our priority.

2. Minimise Harm

- By balancing the risks to patients, families, staff and staff families in a proportionate manner.

3. Fairness

- Everyone matters equally.
- People with an equal chance of benefiting from health or social care resources should have an equal chance of receiving them; however, it will not be unfair to ask people who could get the same benefit from an intervention at a later date to wait.
- People lacking capacity will have their best interests and support needs considered by those making decisions on their behalf.

4. Working Together

- Working together to plan for, and respond to the pandemic as issues arise.
- Helping one another.
- Being prepared to share information that will help others.
- Taking responsibility for our own behaviour, i.e by not exposing others or ourselves to unnecessary risk.

5. Reciprocity

- If people are asked to take increased risks, or face increased burdens, during the pandemic, they should be supported in doing so, but the risks and burdens should be minimised as far as possible.

6. Keeping Things in Proportion

- Those responsible for providing information will neither exaggerate or minimise the situation and will give people the most accurate information that they can.
- Decisions on actions that may affect people's daily lives, which are taken to protect people from harm, will be proportionate to the relevant risk and to the benefits that can be gained from the proposed action.

7. Flexibility

- Plans will be adapted to take into account new information and changing circumstances based on up-to-date latest evidence or expert consensus.
- People will have as much chance as possible to express concerns about or disagreement with decisions that affect them.

8. Good Decision-Making

i.Openness and transparency

Those making decisions will:

- Consult those concerned as much as possible in the time available.
- Be open about what decisions need to be made and who is responsible for making them.
- Be as open as possible about what decisions have been made and why they were made.
- Seek second opinions and cross-check decisions with peers in situations where up-to-date flowcharts and guidelines are not sufficient to guide next steps, and/or where patients/families are in disagreement.

ii. Inclusiveness

Those making decisions will:

- Involve people to the greatest extent possible in aspects of planning that affect them.
- Take into account all relevant views expressed.
- Try to ensure that particular groups are not excluded from becoming involved.
- Take into account any disproportionate impact of the decision on particular groups of people.

iii. Accountability

Those responsible for making decisions:

- Are answerable for the decisions they do or do not take and as far as possible will seek to document such decision processes.

iv. Reasonableness

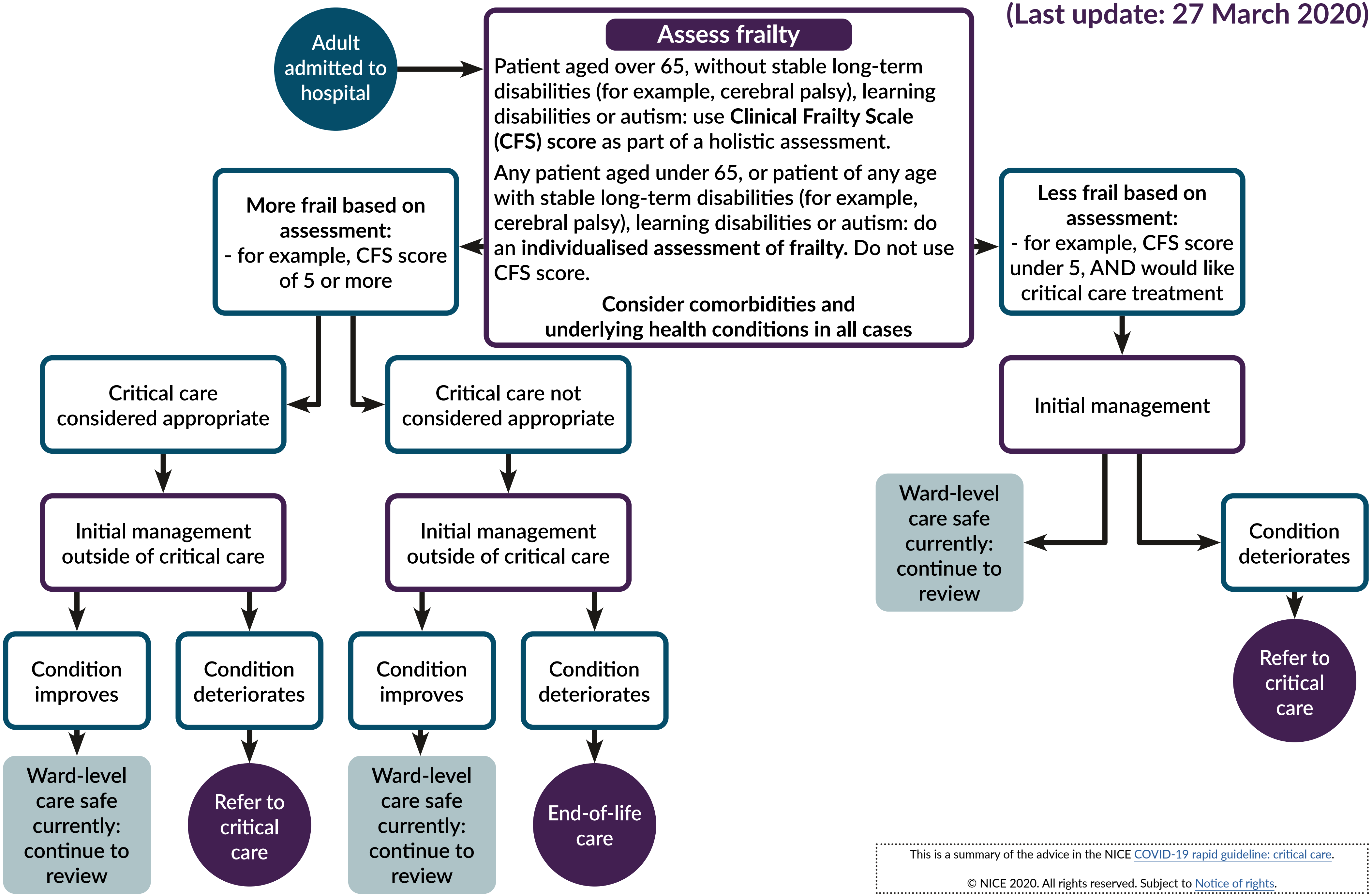
Decisions should be:

- Rational.
- Not arbitrary.
- Based on appropriate evidence.
- The result of an appropriate process, taking into account how quickly a decision has to be made and the circumstances in which a decision is made.
- Practical – what is decided should have a reasonable chance of working.
- Taken with respect to professionalism and compassion.

Adapted from:
Department of Health, November 2007, Responding to pandemic influenza – the ethical framework for policy and planning.

NICE National Institute for Health and Care Excellence

COVID-19 rapid guideline: critical care in adults
(Last update: 27 March 2020)



Adult admitted to hospital

Assess frailty

Patient aged over 65, without stable long-term disabilities (for example, cerebral palsy), learning disabilities or autism: use **Clinical Frailty Scale (CFS) score** as part of a holistic assessment.

Any patient aged under 65, or patient of any age with stable long-term disabilities (for example, cerebral palsy), learning disabilities or autism: do an **individualised assessment of frailty.** Do not use CFS score.

Consider comorbidities and underlying health conditions in all cases

More frail based on assessment:
- for example, CFS score of 5 or more

Critical care considered appropriate

Initial management outside of critical care

Condition improves

Ward-level care safe currently: continue to review

Condition deteriorates

Refer to critical care

Critical care not considered appropriate

Initial management outside of critical care

Condition improves

Ward-level care safe currently: continue to review

Condition deteriorates

End-of-life care

Less frail based on assessment:
- for example, CFS score under 5, AND would like critical care treatment

Initial management

Ward-level care safe currently: continue to review

Condition deteriorates

Refer to critical care

This is a summary of the advice in the NICE COVID-19 rapid guideline: critical care.

*COVID-19 management of End of Life symptoms – COMMUNITY SETTINGS (This patient is unable to swallow any oral medications safely)

29/3/2020 Version 1.5

	1st Line				**2nd line** replacement drugs when 1st lines are not available.				**3rd Line**
	Breathlessness / Pain (Chest pain seen in some COVID cases)	**Agitated delirium**	**Respiratory Secretions ‡**	**Anxiety** (Breathlessness, if not held with 3 drugs)	**Breathlessness / Pain**	**Agitated Delirium**	**Respiratory Secretions ‡**	**Anxiety** (Breathlessness if not symptom controlled with 3 drugs)	**All Symptoms**
Syringe Driver available**	**Morphine** 10-30mg/24hrs CSCI (2.5-5mg SC PRN Hourly x4/24hrs)	**Haloperidol** 5mg/24hrs CSCI (0.5-1.5mg SC PRN 4hourly x4/24hrs)	**Hyoscine butylbromide** 60-120mg/24hrs CSCI (20mg SC PRN 4hourly x3/24hrs)	**Midazolam** 10-30mg/24hrs CSCI (1.25-5mg SC PRN up to hourly x4/24hrs)	**Oxycodone** 10-20mg/24hrs CSCI (1.25-5mg SC PRN Hourly x4/24hrs)	**Levomepromazine** 25mg/24hrs CSCI (12.5-25mg SC PRN 4hourly x3/24hrs)	**Glycopyrronium** 600-1200mcg/24hrs (micrograms) CSCI (200-300mcg SC PRN 4hourly x4/24hrs)	**Levomepromazine** if not already on haloperidol. See also **Lorazepam** SL/Oral	Try 1st line and 2nd line suggestions on the relevant row. If drugs are not available then consider drugs further down (or up) each symptom column. If in doubt call palliative care or your Trust pharmacist for advice. Other replacement drugs may be available for each indication; however these will not be drugs you commonly use. All drugs should be written up on locally agreed Community Administration Orders. New pre-printed versions may be provided if legal and policy blocks are removed.
Healthcare Professional available but **no syringe drivers** available	**Fentanyl Patch** 12-25mcg/hr Replace 48hourly (**Morphine Inj.** 2.5-5mg SC PRN Hourly x4/24hrs)	**Haloperidol** 5mg SC Once Daily (1.5mg SC PRN 4hourly x4/24hrs)	**Hyoscine butylbromide** 40mg SC 12hourly Increase to 8hourly if symptoms persist (20mg SC PRN 4hourly x4/24hrs)	**Lorazepam tablet** Blue SL/White Oral 0.5-1mg 12hrly (0.5mg SL/Oral PRN 6hourly x2/24hrs)	**Buprenorphine Patch** 15-35mcg/hr Replace as per instructions or sooner. (If no Morphine, **Oxycodone** 2.5-5mg SC Hourly PRN x4/24hrs)	**Levomepromazine** 25mg **SC Once Daily** (12.5-25mg SC PRN 4hourly x3/24hrs)	**Glycopyrronium** 400mcg SC 8hrly (micrograms) (400mcg SC PRN 4hourly x3/24hrs)	**Diazepam** enema 5-10mg Once Daily (5mg PR As required 4hourly x2/24hrs)	
Lay carer only, willing to give SC injections	As row above. **No syringe drivers available. Clinical teams not able to guarantee their availability for giving as required injections or regular injections.** If you are not sure about the need for giving an As Required injection at any time then please telephone for advice/support from the community or hospice team supporting you, local palliative care team or patient's GP practice.								
Lay carer available but unable to give SC meds	**Fentanyl Patch** Dose as above. A fan if tolerated. (**ORAL Morphine 20mg/ml** up to 1ml [0.5ml in each cheek] PRN 2hourly x4/24hrs)	**Levomepromazine** Oral [1 tablet crushed, with a little water] 25mg Once Daily (12.5mg As Required 4hourly x3/24hrs)	**Hyoscine hydrobromide patch** 1mg/day size Replace 48 hourly Repositioning see LINK to guidance.	See above	**Buprenorphine Patch** Dose as above	**Olanzapine Oro-dispersible** 10mg OD Buccal (5mg Buccal As required 4hourly X4/24hrs)	**Atropine 1% eye drops** 1-2 drops SL 6-8 hourly	Seek advice	
	Increase doses only when advised by a health professional.								
Lay carer available and willing to give rectal meds #	**#Morphine MR Tablet** 10-30mg Twice Daily **PR** (Morphine Supp. 5-10mg PR As Required 2hourly X4/day).	See above	See Above	**# Diazepam Enema** 5-10mg Once Daily PR (5mg As required 4hourly x2/24hrs).	**#Oxycodone MR Tablet** 5-15mg Twice Daily **PR** (Oxycodone oral liquid 5-10mg PR As Required X4/day)	See Above	See Above	**# Diazepam Tablet** 5-10mg Once Daily **PR** (5mg As required 4hourly x2/24hrs)	
	Increase doses only when advised by a health professional. *Evidence document* – **www.futureplanning.org.uk\COVID_EoLdrugchart**								

* All drugs in this table are used "off-label" as is accepted practice for most End of Life drug use.

**If 4 drugs are required in the syringe driver then SHFT/Solent policy does allow this in "extreme" circumstances. COVID-19 is extreme. Please D/W palliative care or your community matron if concerned. We will not be able to afford to tie up 2 syringe drivers with one patient just because of a policy.

‡ In all cases consider positioning and other non-pharmacological measures. Seek physio **advice** if required.

These suggestions are made assuming all other medications are unavailable, inappropriate or contraindicated. Also, recognising the slow onset of pain relief and titration with Opioid transdermal patches. If a patient is breathless and/or in pain and the facility to setup a Syringe Driver or give SC PRNs is not available, then better to use an unusual treatment, which we are not used to, but should work, rather than nothing. Time will tell!

Lorazepam blue tablets – Genus brand will dissolve in a moist mouth if placed alongside/under the tongue - SL

SC – Subcutaneous
SL – Sublingual
Lay Carer – relative/friend/care assistant
CSCI - Continuous SubCutaneous Injection (syringe driver)
Supp. – Suppository
PR – Per rectum
As required or *PRN* – only give if patient becomes symptomatic
X2, x3 or *x4/24hrs* - seek advice if this number of As Required or PRN doses is exceeded in a 24hr period.

Patches - patients with fever are likely to absorb the drug more rapidly, hence the suggestion to change earlier than usual practice. Also, EoL patients may be unable to report their patch becoming less effective after 2 days.
- usually only for stable pain and will take 12-24hours to reach effective blood levels. In spite of fever absorption may be poor in very cachexic patients.

Wessex Palliative Care Physicians March 2020

March 2020 - Symptom Control in the last days of life during COVID-19 pandemic

Guidance for community professionals on medications that can be administered by traditional and alternative routes (i.e. non-oral / non-subcutaneous) routes for symptom control

Key principles:

- Patients entering the last days of life often require medications to control pain, nausea, respiratory tract secretions and agitation, which are normally administered orally or subcutaneously.
- Local Palliative Care / symptom control guidelines on care and medication to use in this situation should continue to be followed wherever possible.
- However, in the presence of the COVID-19 pandemic, there will be an increase in the number of patients dying, an increased burden on healthcare staff whose exposure to COVID-19 should be minimised, and the potential for a lack of syringe drivers.
- In this situation, those important to the patient will have an increasing role in administering medication for symptom control in the last days of life, with virtual professional support from GPs / district nursing / specialist palliative care teams.
- Healthcare professionals involved in a patient’s care continue to have responsibility for advising those important to the patient how to use the medications that they have recommended / prescribed
- Where possible, it is safest for those important to the patient to administer medications via the oral route for as long as possible, and when this is not possible, to use a non-oral, non-subcutaneous i.e transdermal, buccal, rectal route.
- The evidence base and experience in the non-oral, non-subcutaneous route of administration is limited, and therefore increases the risk.
- In exceptional circumstances a decision may be taken to train and support those important to the patient to administer subcutaneous medications.
- Local Medication and Administration records (MAAR) should continue to be used to record and administer such medication
- In preparation for this situation, the NHSE/I (London region) End of Life Care Clinical Network has drawn up
  1. a list of medications that can be administered via a non-oral, non-subcutaneous route to control symptoms in the last days of life. This list has been reviewed by two paediatric palliative care teams (Great Ormond Street and Royal Marsden) who use this route more commonly
  2. a proforma that Palliative Care teams can use to document their preferred oral / subcutaneous / non-oral, non-subcutaneous medications for local use. (we have also included a completed proforma as an example)
  3. a quick guide to train and support those important to the patient to administer subcutaneous medications

Proforma – Medications for use in the last days of life – COVID-19 pandemic (XXXXX Specialist Palliative Care team)

Symptom	**Non-pharmacological approaches**	**Starting doses in opioid naïve patients (if patients are not responding consider titrating within dose and range and seek advice)**			
		Oral route	**Subcutaneous route**	**Syringe driver doses**	**Medications via alternative routes**
Pain					
Nausea & Vomiting					
Agitation / anxiety					
Respiratory secretions					
Breathlessness	**NB:** Fan therapy is *not* advised due to infection control risks for others				
Fits					
Fever					

EXAMPLE Proforma – medications for use in the last days of life – COVID-19 pandemic (completed by YYYY Specialist Palliative Care team)

Symptom	Non-pharmacological approaches	Starting doses in opioid naïve patients (if patients are not responding consider titrating within dose and range and seek advice)			
		Oral route	**Subcutaneous route**	**Syringe driver doses**	**Medications via alternative routes**
Pain	Heat pads over affected areas Massage	Morphine sulphate immediate release 2.5-5mg PO PRN hourly and titrate to response or Morphine sulphate modified release 5mg PO BD and titrate to response In renal failure, consider Oxycodone – seek advice from Palliative Care	Morphine sulphate 2.5-5mg (1.25mg if elderly, frail, low weight) S PRN hourly and titrate to response In. renal failure, consider Oxycodone – seek advice from Palliative Care	Morphine Sulphate 10mg/24 hours and titrate according to response In renal failure, consider halving dose or oxycodone – seek advice from Palliative Care	Buprenorphine transdermal patches starting at 5-10mcg/hr every 7 days Concentrated oral morphine solution (20mg/ml) at dose of 2.5-5mg (0.125-0.25mls) administered buccally (draw up in syringe then inject into side of mouth and rub cheek to enable absorption). Seek advice from palliative care team
Nausea & Vomiting		Varies by cause: Metoclopramide 10mg PO TDS Domperidone 10mg PO QDS Cyclizine 50mg PO TDS Haloperidol 0.5-1mg PO BD Levomepromazine 6.25mg PO	Haloperidol 0.5-1.5mg SC PRN hourly	Haloperidol 3-10mg/24 hours	Olanzepine 5-10mg tablets orodispersible PRN Or Hyosicne hydrobromide patches (scopoderm) 1mg 72 hours (can use 2 patches)
Agitation / anxiety	Consider relaxation CDs, breathing exercises (extend 'out' breath) etc	Lorazepam 500mcg-1mg sublingually QDS	Midazolam 2.5-5mg SC PRN hourly	Midazolam 10mg/24 hours and titrate according to response (reduce to 5mg/24 hours if eGFR <30)	Prefilled midazolam buccal solution (Buccolam 10mg/2ml) administer 0.5-1ml PRN hourly
Respiratory secretions	Positioning Reassurance for carers	N/A	*Glycopyrronium 200-300mcg SC hourly (max 1.2mg/24 hrs)	*Glycopyrronium 0.8-1.2mg/24 hours	Hyoscine hydrobromide patches (Scopoderm) 1mg 72 hourly (can use 2 patches) Glycopyrronium injection applied buccally 200-300mcg SC hourly (max 1.2mg/24 hrs)
Breathlessness	Cool flannel around the face and nose Draught from an open window	Morphine sulphate immediate release 1-2mg PO PRN hourly and titrate to response or Morphine sulphate modified release 5mg PO BD and titrate	Morphine sulphate 1-2mg SC PRN hourly and titrate to response	Morphine sulphate 10mg/24 hours and titrate according to response In renal failure, consider halving dose or oxycodone –	Buprenorphine transdermal patches starting at 5-10mcg/hr every 7 days Concentrated oral morphine solution (20mg/ml) at dose of 2.5-5mg (0.125-0.25mls) administered buccally (draw up in

	NB: Fan therapy is *not* advised due to infection control risks for others	to response In renal failure, consider Oxycodone – seek advice from Palliative Care	In. renal failure, consider Oxycodone – seek advice from Palliative Care	seek advice from Palliative Care	syringe then inject into side of mouth and rub cheek to enable absorption). Seek advice from palliative care team
Fits		As per individual normal prescribed medication	Midazolam 5-10mg SC stat	Midazolam 20-30mg/24 hours if unable to take oral anti epilepsy medication	Prefilled midazolam buccal solution (Buccolam 10mg/2ml) administer 1-2mls stat
Fever	Cool flannel	Paracetamol 1g PO QDS	N/A	N/A	Paracetamol suppositories 1g QDS PR

Section 2
Communication and ethics

NHS
Education
for
Scotland

Delivering the news of a death by telephone

Before the phone call

- Consider which team member is best placed to make the call
- Find a quiet place and minimise any potential disruption
- Establish who is to be contacted and whether they have indicated what times of day they would want to be phoned; and in response to what type of event
- Gather information and consider what you are going to say

During the phone call

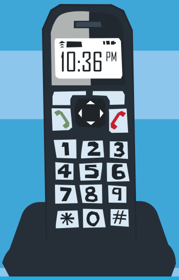
- Introduce yourself and where you're calling from
- Establish that you are speaking to the right person and ask if this is an okay time to talk
- Consider asking if there is anyone with them and whether they would prefer to come and talk face to face
- Avoid euphemisms and try not to rush

Difficult questions

- "**Has he/she died?**" – you could say *"I'm so sorry to tell you this, but he/she became very unwell this evening and sadly, yes he/she has died. I'm so sorry to tell you this news over the phone"*
- If you don't know the answer to a question don't be tempted to guess. E.g. if asked "**Why did they die?**" and if you aren't sure, you could say *"I don't know what the exact cause was, but I understand that it's important to you, so I will make sure the team know that you wish to talk about this when you arrive"*

How will they react?

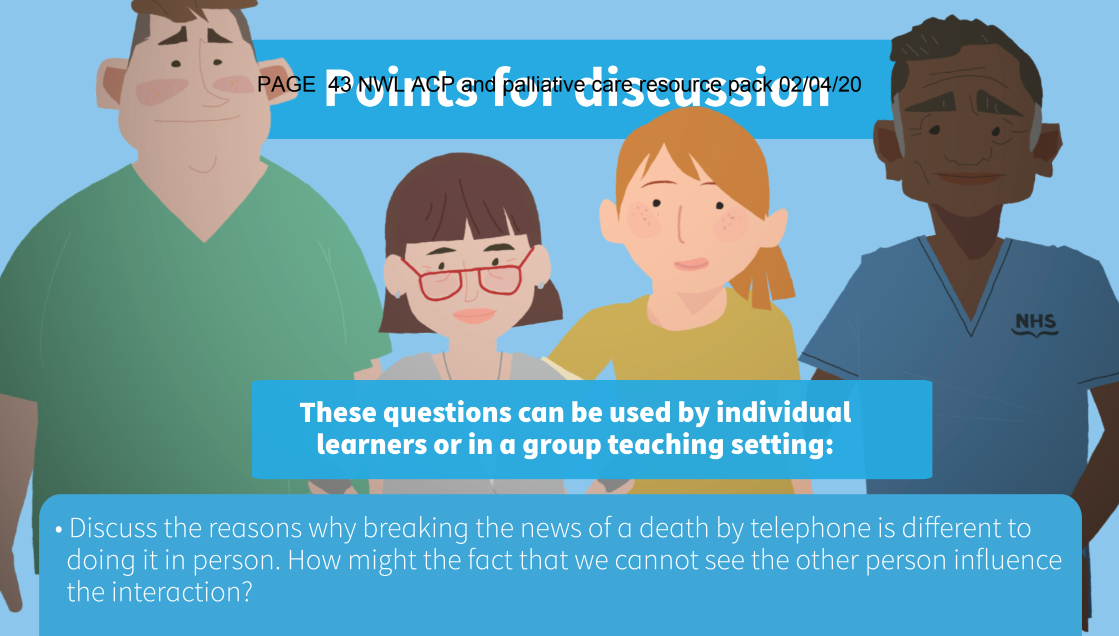
- People may have a wide range of different responses, which may not be related to the way that you have delivered the news
- It may be hard to establish how someone is reacting
- Do not feel as though you must fill any silences but if you wish you could say *"I appreciate that this must be a shock"* or *"I appreciate that this must be very difficult to take in"*



After the phone call

Take time to care for yourself and seek support – these conversations can be difficult and emotionally challenging

www.sad.scot.nhs.uk **supportarounddeath@nes.scot.nhs.uk** **@NES_Bereavement**



Points for discussion

These questions can be used by individual learners or in a group teaching setting:

- Discuss the reasons why breaking the news of a death by telephone is different to doing it in person. How might the fact that we cannot see the other person influence the interaction?

- Consider the types of feelings we experience when a person dies. How might this influence how we feel when we break bad news? How might our feelings influence conversations?

- Discuss the use of the word “sorry” in breaking bad news like this. How does it make you feel? What role does it have in this conversation?

- How might any periods of silence feel to you and the other person?

- Consider what you would do if the person answered the telephone and wasn’t in a position to talk privately or was alone. What might you do or say?

- When talking to a family on the telephone, consider the consequences of indicating that a person hasn’t yet died when actually they have

- If you have experience of breaking the news of a death by telephone, consider what helped you to feel prepared to deliver the news?

- Are there any key principles about how to deliver the news of a death that might help you break other bad news on the telephone e.g. that a person has been involved in an accident or that their condition has deteriorated?

Please visit **www.sad.scot.nhs.uk** to watch a short animated film on this topic and for other educational resources on death, dying and bereavement for health and social care professionals

NHS Education for Scotland

Transcript of ‘Delivering the News of a Death by Telephone’ video

Our responsibilities as healthcare professionals don’t end when a patient dies. One of the hardest jobs we have is breaking the news to those who were closest to them. We would all prefer to do this face-to-face, especially if it’s unexpected, but it is perfectly acceptable - and sometimes necessary - to tell someone about a death by telephone.

This news should, where possible, be given by someone who knows the patient and understands the care they have received. With your colleagues, consider who is best placed to make this call; this could be any member of the team. Find somewhere quiet and consider what you’re going to say.

Usually, you should phone as soon as possible, having first clarified who is to be contacted. Typically, this is the next of kin, but sometimes it may not be. It may also be documented what the patient’s family or friend would want to be told over the telephone and what times of the day or night they would want to be contacted.

It's not unusual to feel anxious about making a call like this. Remember to take your time, and when you’re ready:

> “Hello?”
>
> “Hello, this is Dr Hughes calling from Ward 12 of the City Hospital.”

Pay attention to the speed and tone of your voice. This can communicate just as much as the words you say.

> “Am I speaking with Mr Singh?”
>
> “Yes, speaking.”
>
> “Hello Mr Singh, I know we haven’t met before. I’m sorry to call you at this time of night. Is it okay for you to talk just now?”
>
> “Yes, I’m just watching the telly, one sec.”
>
> “Is there anyone there with you, Mr Singh?”
>
> “Yes, my daughter’s here with me.”
>
> “I’m calling to speak about your wife. Would you like to come into the hospital, or are you okay to talk on the phone?”

Usually they will want to know what has happened straight away, although some people may prefer to come in. In this case, you might suggest that they bring someone with them, and remind them to travel safely. Sometimes people may interrupt you to ask whether a person has died. This can be unsettling, but we must answer honestly. Try to avoid the use of euphemisms such as ‘passed away’.

> “Adia – has she died?”

“I’m so sorry to tell you this, but she became very unwell this evening, and sadly, yes, she has died. I’m very sorry to give you this news over the phone.”

It can be difficult to establish how a person is reacting to this news when speaking by phone. Don’t feel you need to fill any silences. Offer the opportunity to come in to have another conversation face-to-face. Those who are newly bereaved and in shock are unlikely to remember all that has been said.

They may also take solace in spending time with the person who has died. Confirm that the family know where to come and inform staff so they are met promptly. At the end of the call, ensure that they know what will happen next and consider restating your name and providing your contact details.

“Thank you, doctor. We’re on our way.”

“Of course, Mr. Singh. We’ll see you soon.”

Document the conversation in the patient’s notes and update the relevant team with any outstanding issues.

Communicating by phone can add additional complexity to already challenging conversations. Even when the news of a death is delivered with sensitivity and empathy, people can have a wide range of reactions. Try to ensure that you attend to your own wellbeing, and consider if you would benefit from some support or time to yourself. If a colleague witnessed you delivering bad news over the phone, perhaps seek their feedback on what you did well. Encouraging and supporting members of your team may help you all manage similar situations in the future.

The film was produced in April 2019 and can be found at www.sad.scot.nhs.uk or https://vimeo.com/328655124

For more information visit www.sad.scot.nhs.uk or contact supportarounddeath@nes.scot.nhs.uk

Ethical dimensions of COVID-19 for front-line staff

31 March 2020

Royal College of Physicians

Setting higher standards

Ethical dimensions of COVID-19 for front-line staff

31 March 2020

Supported by:

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The Faculty of Intensive Care Medicine

RCoA Royal College of Anaesthetists

RC PSYCH ROYAL COLLEGE OF PSYCHIATRISTS

The Royal College of Emergency Medicine

The ROYAL COLLEGE of OPHTHALMOLOGISTS

RC GP Royal College of General Practitioners

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HEALTH THROUGH SPORT AND EXERCISE

ROYAL COLLEGE of PHYSICIANS of EDINBURGH

RCR The Royal College of Radiologists

ROYAL COLLEGE OF PHYSICIANS AND SURGEONS OF GLASGOW

In response to the growing urgency of the COVID-19 pandemic, the Committee on Ethical Issues in Medicine of the Royal College of Physicians (RCP) has developed the following guidance for front-line staff.

Presently there is no specific treatment or prophylaxis option for COVID-19. As seen with previous pandemics, this can change over time. The practical ethics will change as such options emerge. This should be taken into account when reviewing this document and making ethical decisions based on the advice presented here. This guidance has benefited from multiple stakeholder input, including the General Medical Council (GMC), the Faculty of Intensive Care Medicine, the Intensive Care Society, royal colleges and faculties. It provides guidance for the difficult ethical issues that front-line staff will face while caring for their patients during the pandemic. The Committee on Ethical Issues in Medicine reserves the right to change this advice at any time to reflect the current situation with the COVID-19 pandemic.

Ethical framework that informs the guidance

Pandemics present difficult logistical, medical and ethical challenges to the medical workforce. Pandemics require incorporating public health ethics with clinical ethics. Distributive justice is the most often cited ethical principle during a pandemic; however, we suggest that, for the clinical workforce in particular, fairness is a better way of understanding and approaching the ethical problems that the workforce will encounter and are encountering. Fairness is often part of disaster or emergency medicine ethics, and presents a useful ethical approach for clinicians to COVID-19. The principal values that inform this guidance are that any guidance should be accountable, inclusive, transparent, reasonable and responsive.[1]

By these we mean:

Value	Description
Accountability	Measures are needed to ensure that ethical decision-making is sustained throughout the crisis, ideally nationally.
Inclusivity	Decisions should be taken with stakeholders and their views in mind.
Transparency	Decisions should be publicly defensible.
Reasonableness	Decisions should be based on evidence, principles and values that stakeholders can agree are relevant to health needs, and these decisions should be made by credible and accountable members of staff.
Responsiveness	Flexibility in a pandemic is key. There should be opportunities to revisit and revise decisions as new information emerges throughout the crisis, as well as mechanisms to address disputes and complaints.

Good stewardship, guided by a doctor's duty to care is key to good ethical practice in a pandemic. The above values promote action and decisions that are fair, reciprocal, respectful, and equitable.[2,3] Adopting this approach will support the workforce as they cope with the increased demand, while maintaining good ethical processes in their care, and continuing to promote the ethical values they already maintain in their current practice.

Specific recommendations for ethical practice and decision-making during the pandemic

Developed from the above values and principles, the following offers specific guidance for the kinds of situations that front-line staff may find themselves in as the pandemic progresses. This advice takes into consideration the recent joint statements released by the GMC, the NHS and the chief medical officers in the UK. We hope that this practical advice will be of use to the workforce if and when they are faced with difficult situations. This advice will be added to and adjusted, in accordance with the value of responsiveness, as more is learned about the pandemic.

With all the guidance below, the usual principles of good care still apply:

Any decisions made to begin, withdraw or withhold care must also comply with the shared decision-making policies of the NHS. This means that these decisions should include the patient and their wishes (as much as is feasible for the given situation) and, if appropriate, the patient's carers. This is true regardless of whether the patient has COVID-19.

Ensuring fair and equitable care

Front-line staff, policymakers, management and government have a responsibility to patients to ensure that any system used to assess patients for escalation or de-escalation of care does not disadvantage any one group disproportionately. Treatment should be provided, irrespective of the individual's background (eg disability), where it is considered that it will help the patient survive and not harm their long-term health and wellbeing.

Caring for COVID-19 vs non-COVID-19 patients

Decision-making should not be disease specific – ie the presence or absence of COVID-19 should not be a limiting factor in treatment decisions. Where care between a COVID-19 patient and another patient in need of care is in question, care should be prioritised based on national guidance. Resources will be inevitably stretched, with doctors having to make decisions about whether patients can or cannot receive necessary treatment.

However, efforts must be made to ensure that the public (patients, carers and those not yet ill) understand the purpose of any treatment guidelines being used. Patients and their families must understand how the guidance is applied, so they are able to trust that it is consistently and fairly applied. This will help to avoid fears in the public that doctors and nurses are allowed to 'ignore' certain patients, which is not and will not be the case.

Making difficult decisions

For reasons of practical and moral support, it is advisable that assessment and prioritisation decisions are carried out by more than one clinician colleague, where feasible. Decisions to escalate care to ITU should have input from ITU doctors. As is normally the case it is recommended that, where appropriate, decisions within ITU involve the multidisciplinary team. This is particularly so if a decision is taken to withdraw treatment from existing patients in critical care. While it is ethically equivalent to withdraw treatment instead of withholding treatment, the stakes will undoubtedly be seen and felt by all to be very much higher when it comes to withdrawing treatment. These decisions must be made with the patient and, if appropriate, their carers.

All decisions must be appropriately documented, to ensure accountability and for the legal protection of front-line staff. Again, any decision to start, withdraw or withhold treatment must be made in accordance with existing national guidance.

Accountability for decision-making

During a pandemic, all accountability for decisions still holds. While doctors may have to work outside their usual location or specialty, they will still be held accountable for their decisions, just as they would during their regular practice. Decisions, regardless of whether they are COVID-19 related, should be made according to protocol and justified where required, as per good clinical practice. To provide accountability across the pandemic, documentation of the decision-making process is very important. As far as possible, conclusions should be in writing, and the reasons for any decision should be clearly set out.

Support with difficult decisions

Medical ethicists (sometimes referred to as bioethicists) can help front-line staff with difficult decisions, particularly where there is significant disagreement or a stakeholder might wish some form of external appeal other than a second opinion. Hospitals may wish to engage medical ethicists, or form clinical ethics committees to help with such situations.

Teamwork and mutual support across the whole healthcare team are essential to making difficult decisions. Working together and consulting colleagues regularly, including MDTs where appropriate, recognises that everyone is working in very stressful situations, in different ways and may be exhausted. Support and solidarity with all our colleagues is so important in this time.

Discussing care wishes with patients

Many front-line staff will already be caring for patients for whom any escalation of care, regardless of the current pandemic, would be inappropriate, and must be properly managed. We strongly encourage that all front-line staff have discussions with those relevant patients for whom an advance care plan is appropriate, so as to be clear in advance the wishes of their patients should their condition deteriorate during the pandemic.

Prioritising ITU beds and resources

ITU beds, in fact all hospital beds and resources, should continue to be allocated based on appropriate assessment methods. This assessment should be continual as new cases present, to ensure that those patients in most need of care are continually prioritised and cared for. As is always the case in critical care, there will be some patients (with or without confirmed COVID-19) for whom admission to ITU would be inappropriate. National Institute for Health and Care (NICE) guidance on how to assess these patients for care during the pandemic has been issued and can be found here.

Working outside of specialty

Doctors are bound by their duty of care for patients in the pandemic. In a pandemic, this duty of care is part of equitable, reciprocal practice that shows solidarity while protecting the public from harm. To uphold this duty of care, doctors will need to be flexible, and may need to work in locations or clinical areas outside their usual practice. This will be especially true for those doctors who find their elective clinics and procedures cancelled during the COVID-19 crisis. Doctors should be prepared and supported to work outside their normal practice, but not obligated to work outside their competency. There should be overt support of the clinicians – preferably by the government, but at the very least by the trusts/health boards employing the clinicians. Doctors working out of remit should be provided with appropriate training and personal protective equipment (PPE) to work competently in their new role.

Doctors with pre-existing conditions or over the age of 70

The government has advised that there is an increased risk of severe illness from COVID-19 in those aged over 70 or under 70 with certain underlying health conditions. Some of our workforce will come under one or both of these categories, and should consider these risks if they choose to continue working.

Doctors have a duty to protect the public from harm, an extension of which is the right to protect themselves from harm so they can continue to care effectively. In this respect, it is ethical for those doctors who would be harmed by contracting the virus to refrain from treating patients with (or suspected) COVID-19. In line with the above recommendation that doctors need to be flexible during a pandemic, it may be necessary to reassign these doctors to roles that do not involve contact with these patients (eg as NHS 111 responders or teleconsultation services), so that their expertise can help with the pandemic, while keeping these individuals safe. In addition, those doctors with care responsibilities for vulnerable family members should also be given the option of stepping back from front-line care of patients with COVID-19, as part of their duty of care to that family.

PPE for front-line staff

In order to fulfil their duty of care to their patients, front-line staff must be appropriately shielded from harm, regardless of the source of that harm. Caring for patients with or suspected COVID-19 requires appropriate PPE, and all front-line staff should have constant access to PPE during the pandemic, as specified in the current Public Health England guidance. If asked to care without appropriate PPE, doctors should immediately report this to the relevant director of that clinical service. If possible, please also report it via the RCP reporting system.

Specialty-specific advice

We recognise that other colleges have developed more tailored advice on ethical issues for their members. When made available, links to this advice will be available here.

The Royal College of General Practitioners is producing specific GP guidance that is forthcoming.

References

1 Daniels N. Accountability for reasonableness. *BMJ* 2000;321: 1300–1. https://doi.org/10.1136/bmj.321.7272.1300

2 Thompson AK, Faith K, Gibson JL *et al*. Pandemic influenza preparedness: an ethical framework to guide decision-making. *BMC Med Ethics* 2006;7:12. https://doi.org/10.1186/1472-6939-7-12

3 UK Government. *Guidance: Pandemic flu*. 2017. www.gov.uk/guidance/pandemic-flu#ethical-framework. [Accessed 29 March 2020].

Further reading

Badano G. If you're a Rawlsian, how come you're so close to utilitarianism and intuitionism? A critique of Daniels's *Accountability for reasonableness*. *Health Care Anal* 2018;26:1–16. https://doi.org/10.1007/s10728-017-0343-9

Bensimon CM, Smith MJ, Pisartchik D, Sahni S, Upshur RE. The duty to care in an influenza pandemic: A qualitative study of Canadian public perspectives. *Soc Sci Med* 2012;75:2425–30. https://doi.org/10.1016/j.socscimed.2012.09.021

Daniels N, Sabin JE. Accountability for reasonableness: an update. *BMJ* 2008;337:a1850. https://doi.org/10.1136/bmj.a1850

Daugherty Biddison EL, Faden R, Gwon HS *et al*. Too many patients…a framework to guide statewide allocation of scarce mechanical ventilation during disasters. *Chest* 2019;155:848–54. https://doi.org/10.1016/j.chest.2018.09.025

Faden R. Social justice and pandemic planning and response. In *Institute of Medicine (US) Forum on Microbial Threats. Ethical and Legal Considerations in Mitigating Pandemic Disease: Workshop Summary*. Ethical Issues in Pandemic Planning and Response: Washington (DC): National Academies Press (US) 2007, p172. www.ncbi.nlm.nih.gov/books/NBK54169/ [Accessed 30 March 2020].

Kinlaw K, Barrett DH, Levine RJ. Ethical guidelines in pandemic influenza: recommendations of the Ethics Subcommittee of the Advisory Committee of the Director, Centers for Disease Control and Prevention. *Disaster Med Public Health Prep* 2009;3 Suppl 2:S185–92. https://doi.org/10.1097/DMP.0b013e3181ac194f

Lor A, Thomas JC, Barrett DH *et al*. Key ethical issues discussed at CDC-sponsored international, regional meetings to explore cultural perspectives and contexts on pandemic influenza preparedness and response. *Int J Health Policy Manag* 2016;5:653–62. https://doi.org/10.15171/ijhpm.2016.55

General Medical Council. Joint statement: Supporting doctors in the event of a Covid-19 epidemic in the UK, 11 March 2020. www.gmc-uk.org/news/news-archive/supporting-doctors-in-the-event-of-a-covid19-epidemic-in-the-uk [Accessed 13 March 2020].

Sokol DK. Ethics and epidemics. *Am J Bioeth* 2008;8:28–9. https://doi.org/10.1080/15265160802318121

Upshur REG, Faith K, Gibson JL *et al*. *Stand on guard for thee: Ethical considerations in preparedness planning for pandemic influenza*. A report of the University of Toronto Joint Centre for Bioethics Pandemic Influenza Working Group. November 2005. www.jcb.utoronto.ca/people/documents/upshur_stand_guard.pdf [Accessed 31 March 2020].

WHO. *Ethical considerations in developing a public health response to pandemic influenza*. 2007. www.who.int/csr/resources/publications/WHO_CDS_EPR_GIP_2007_2/en

Section 3

Care Homes & High Risk/Vulnerable patients

Decisions about Cardiopulmonary Resuscitation (CPR)

Information for patients and those close to them

This leaflet is about Cardiopulmonary Resuscitation (CPR) and how decisions are made about it. This leaflet may not answer all your questions, so please talk to a member of the healthcare team looking after you if there is anything you don't understand, or if you would like more information.

July 2016

Original wording of model leaflet produced by the Resuscitation Council (UK)

What is CPR?

CPR is a treatment that is used to try to restart someone’s heart and breathing when one or both of these has stopped. When the heart stops this is called a cardiac arrest and when the breathing stops it is a respiratory arrest. If one stops, the other usually stops soon afterwards (cardiorespiratory arrest).

CPR includes:

- repeatedly pushing down very vigorously on the centre of the chest;
- blowing air or oxygen into the lungs, using either a mask over the nose and mouth or a tube inserted into the throat or windpipe; and often
- using electric shocks to try to restart normal heartbeats.

What is the chance of CPR restarting my heart and breathing?

There is no simple answer to this, because everybody is different. The chance of CPR restarting your heart and breathing will depend on:

- why your heart and breathing has stopped;
- any illnesses or medical problems you have (or have had in the past);
- the overall condition of your health.

Many attempts at CPR do not restart the person’s heart and breathing despite the best efforts of everyone involved. For example, when CPR is attempted in hospital, on average about 2 out of 10 patients survive to leave hospital. In places other than a hospital, the chances of survival are usually even lower. For some people the chance of survival will be much better than this and for others there will be no chance of benefit from CPR.

If you want more information, your healthcare team can usually explain more clearly what the likelihood of CPR working for you would be if your heart or breathing were to stop.

Is CPR tried on everybody whose heart and breathing stop?

No. It’s important that CPR is not tried on everybody whose heart and breathing stop. For example, when someone is coming to the end of their life as a result of an advanced, irreversible illness, and the heart and breathing stop as part of the natural process of dying, CPR will not prevent their death.

If CPR does restart the heart and breathing in these circumstances it can leave a dying person with more distress or worse health in the last hours or days of their life. For others, receiving CPR would deprive them of dignity during the very last moments of their life. For these reasons many people choose not to receive CPR when they know that they are coming close to the end of their life.

Such a decision not to attempt CPR is often called a ‘Do Not Attempt CPR’ or ‘DNACPR’ decision. Nowadays, if possible, many healthcare teams will try to discuss with individual people their wishes about CPR and to record when CPR would still be wanted, as well as when it isn’t wanted or wouldn’t work.

Do people make a full recovery after CPR?

Although many people do make a full recovery, some recover but still have poor health, and some people will be left in worse health after resuscitation from cardiorespiratory arrest. The likelihood of full recovery depends largely on:

- why the heart and breathing has stopped;
- the overall condition of a person’s health;
- how quickly CPR is started.

Those who are resuscitated by CPR are often still very unwell and need more treatment, usually in an intensive care unit (ICU) or sometimes a cardiac care unit. In some cases a person may be left with permanent brain damage or in a coma.

CPR can cause unwanted effects such as bruising, broken ribs and (infrequently) damage to internal organs such as the lungs or liver. When there is a real chance that CPR could bring a person back to a length and quality of life that they would want, the risk of these unwanted effects is not usually enough for them to decide that they don't want CPR.

Will I be asked whether I want CPR?

This will depend on your circumstances:

- Usually, if your heart and breathing are unlikely to stop, health professionals will not discuss CPR with you unless you ask them to. Where no decision has been made in advance about whether or not CPR should be performed, it will be assumed that CPR should be attempted if cardiorespiratory arrest occurs unexpectedly. If that may not be what you want, it's important to discuss your wishes with your healthcare team.
- If there is a chance your heart and breathing will stop and that CPR might be successful your views on CPR, your medical condition and the likely outcome of attempting CPR are all very important in deciding whether CPR is the right choice for you. The health professionals looking after you will want to know what you think and make a shared decision with you.
- If CPR will not prevent your death should your heart and breathing stop, your healthcare team will make a decision not to attempt CPR. They will explain to you the decision and the reasons for it, unless they believe that telling you will cause you physical or psychological harm.

If you wish, your family or close friends can be involved in these discussions. If you disagree with a decision about CPR, you can request a second opinion.

What will happen if no decision has been made?

In an emergency, when someone collapses and their heart and breathing stop without warning, health professionals will try to restart the heart and breathing if:

- there is a chance that CPR will work, and
- the person is not known to have decided against receiving CPR.

What if I don't want to discuss CPR?

You don't have to talk about CPR if you don't want to, or you can ask to delay the discussion until you are ready for it.

In these situations, the health professional in charge of your care will have to make a decision in your best interests about what to do if your heart or breathing stops, taking into account your general views and wishes.

Does it matter how old I am or that I have a disability?

No. What is important is:

- your views and wishes;
- your state of health; and
- the likelihood of the healthcare team being able to achieve what you want.

What if I am unable to take part in a decision about CPR?

If you cannot take part in making a decision about CPR or about other types of treatment, because you are too unwell to understand information, to make a considered choice, or to communicate your wishes, these decisions will be made for you.

In England and Wales:

- You can plan ahead for this situation by choosing somebody who you want to be involved in future decisions if you are unable to take part. You do this by arranging to give them a "Lasting Power of Attorney" (LPA) for your health and welfare.
- The Court of Protection may also appoint a "Deputy" with similar powers.
- If, like many people, you do not have a LPA or Deputy, the health professional in charge of your care will make a decision about what is best for you, taking into account your previously expressed wishes. They will ask your family or close friends for information about these. If you have no family or friends to ask, an "Independent Mental Capacity Advocate" may be asked to help.

More information on how healthcare decisions are made in England and Wales, when people are unable to take part in decisions, can be found under “Mental Capacity (What is the Mental Capacity Act)” at www.nhs.uk

In Northern Ireland:

The health professional in charge of your care will make a decision about what is best for you, taking into account your previously expressed wishes. They will ask your family or close friends for information about these.

In Scotland:

- You can plan ahead for this situation by choosing somebody who you want to be involved in future decisions on your behalf You do this by making them your “Welfare Attorney”.
- The Sheriff may also appoint a “Welfare Guardian” with similar powers.
- If you do not have a Welfare Attorney or Guardian, the health professional in charge of your care will make a decision about what will benefit you, taking into account your previously expressed wishes. They will ask your family or close friends for information about these.

More information on how healthcare decisions are made in Scotland, when people are unable to take part in decisions, can be found under “Adults with Incapacity (Adults with Incapacity Act)” at www.mwcscot.org.uk/

Can my family decide for me?

Your family and friends are not allowed to decide for you (unless they have been appointed as your legal attorney, deputy or guardian). Whenever possible, the healthcare team looking after you will ask them about your known or likely wishes.

If there are people who you do or do not want to be told about your condition or asked about your care and treatment, you should let your healthcare team know.

I know that I don’t want anyone to try CPR on me. How can I make sure they don’t?

If you don’t want CPR, you can refuse it and if they know of this refusal the healthcare team must follow your wishes. It is very important to ensure that your wishes are recorded clearly and that you make them known to your family or other carers and to your healthcare team. Healthcare professionals called to you in an emergency will need immediate access to any document recording your wishes.

You can make a ‘living will’ (sometimes called an ‘Advance Statement’) to put in writing your wishes about any type of care or treatment that you would or wouldn’t want to be considered for if you are not able to decide for yourself at the time. Although not legally binding, this can be important to guide health professionals who may not know you well but are having to decide what treatment would be in your best interests

In England and Wales, you can also make an “Advance Decision to Refuse Treatment” (ADRT). This must be signed by you and by a witness and is legally binding. To refuse CPR it must state that you refuse it even if your life is at risk.

If you have made an ADRT or any other type of ‘living will’, you should make sure that your healthcare team knows about it and puts a copy of it in your records. You should also make sure that people close to you know about it and where you keep it, so that they can find it easily in an emergency and show health professionals what decisions or preferences you have recorded.

If it is decided that CPR won’t be attempted, what then?

This is often called a “Do Not Attempt Cardiopulmonary Resuscitation” or “DNACPR” decision. Together with the reasons for the decision, it is usually recorded on a special form that makes it easy for health professionals to recognise.

Increasingly, similar forms are used to record both a decision whether or not CPR should be attempted, and decisions made in advance about other types of care and treatment that a person may or may not want to be considered for, especially as they approach the end of their life. For example, these choices may include decisions about wanting to have treatment at home and not be admitted to hospital, or choices about wanting hospital treatment but not wanting to be considered for admission to an intensive care unit.

Most decisions recorded on such forms will be reconsidered if your condition changes or if you are transferred, for example from hospital to home, to a nursing home or hospice, or from one hospital ward to another. The form should travel with you, so that it is always readily available to guide any health professional if your condition worsens.

What about other treatment?

A DNACPR decision is about CPR *only* and you will receive all the other treatment that you need. If you have recorded a refusal of other treatments that will also be used to guide decisions about your care if your health deteriorates and you are unable to make clear choices at the time.

If it has not been suggested already, you may want to discuss with your healthcare team and plan with them what other types of care and treatment you would or would not want to be considered for if your health deteriorates.

What if I want CPR to be attempted, but the healthcare professional in charge of my care says it won’t work?

When a decision is made that CPR will not work because a person is dying from an advanced and irreversible condition it will usually have been discussed and agreed among several members of the healthcare team. If you are not willing to accept the explanation and advice that they have given you, they will arrange a second opinion for you if you would like one.

It is important to remember that you are not entitled to demand treatment that is not being recommended or offered. However, health professionals will not refuse your wish for CPR if there is any real possibility of it working successfully.

If CPR might restart your heart and breathing, but is likely to leave you in very poor health, your opinion about whether these chances are worth taking is very important.

The healthcare team should listen to your opinions and anyone close to you that you want to be involved in the discussion. In most cases, health professionals and their patients agree about treatment where there has been good communication.

What if I change my mind or my situation changes?

Your healthcare team will keep the decision about CPR under review, in particular if your condition changes, if you move to a different care setting or go home, or if you want to change your mind.

Can I see what’s written about me?

Yes. You can see what’s written about you.

You can ask the healthcare team to show you your records and, if there is anything in them that you do not understand, they will explain it to you.

Who else can I talk to about this?

In addition to the healthcare team looking after you, there are other people you may want to talk to about CPR, for example:

- patient support groups
- spiritual advisers
- independent advocacy services

Use this space to write down any questions that you may want to discuss with anyone, including your healthcare team.

Dear nursing home managers and leads,

We have looked at contingency planning within The Argyle Care Home Service and Ealing Community Partners, and how to manage both regular and urgent GP input for your residents, in the context of rising cases of COVID19. There is concern that GPs and our staff could potentially be a vector of transmission, as well as the possibility of homes being quarantined/isolated at some stage restricting our access to you.

In order to maximise patient safety, but also continue business as usual as far as possible, we anticipate needing to move in the next few days towards remote assessment of patients using telephones and increased video capability. This will apply to both regular rounds and ad-hoc visits, including in the evenings and over the weekends and continue for the foreseeable future.

In preparation for this, we therefore need all homes to prepare to do the following:
1) to have available at least one mobile handset that can have signal throughout the building with WhatsApp (as an encrypted service) available on it that staff/nurses can take to patient's rooms as required. It will clearly need to be able to be cleaned/wiped down too. We will then be able to assess patients visually if needed. The staff will need to know what the number of the handset is so that clinicians can call it!
2) to start to provide lists for GP rounds via email **in advance** (on the morning of the scheduled round) where this does not already happen;
3) It would also be helpful for homes (most of you already have most of this kit) to be able to take **basic clinical observations** (temperature with a no-touch thermometer, BP, P and preferably oxygen saturations - all kit needs to be able to be wiped down) where needed. Where nurses are confident they have the competence to examine eg chest or abdomen, please inform us.

For the time being we will continue to provide our usual phlebotomy and INR services but this may also be subject to revised arrangements. Other services provided by Ealing Community Partners and West London NHS Trust will be subject to their own plans.

Please could all homes confirm to us that this has been read and actioned as far as possible. We attach a copy of our Standard Operating Procedures (SOP) relating to this way of working.

Any queries, please let us know

Regards

Dr Anna Down
Clinical Lead, The Argyle Care Home Service
The Argyle Care Home Service Team

For your own individual planning purposes that will allow maximum access to healthcare professionals if required, it would be useful for every home to designate a room near the entrance to the building (outside of any areas occupied by patients and outside of any areas potentially closed to access) that can be used to put on/off PPE and for people to change/decontaminate. This room should be able to be deep cleaned.

Standard Operating Procedure for remote GP rounds (Information for clincians)

Please note, the TACHS SPA number 0203 700 3105 and the email address argyle.carehome@nhs.net remain operating as usual and should be used as normal by the homes

This SOP is designed to allow business as usual as far as possible in terms of timing of rounds and their content, but via TELEPHONE AND DIGITAL channels

On call rotas and diverting to mobiles will continue as normal though actions once a call is received will be as per this SOP

Homes have been advised that returning calls to any other number (even if they have temporarily been made available by a clinician or AHP) will result in clinical risk and should not be done. These may not be from usual handsets that are always on.

Regular/planned GP rounds

1. For planned/regular rounds, the home will email over the list of residents to be seen as usual to argyle.carehome@nhs.net. This needs to be sent before 9:30 for morning rounds and 12:30 for afternoon rounds. It will be forwarded to the relevant GP as soon as possible.
2. List must include patient details, what is to be discussed, and clinical observations
3. List will be sent to regular clinician as per the rota. They will review and set a time to call the home (or first unit) to discuss the list. Home will need to ensure that the relevant person, with knowledge of the patients, is available. Home to be prepared to get repeat or additional clinical observations at the time
4. Homes to consider if patient could be moved to a quiet area or their room if required during the round, if necessary
5. Clinician will decide if video review of patient is required. When this is agreed, the home staff will provide the number of their allocated handset and GP will initiate WhatsApp video call
6. Home will need to be able to pass on call to other units, or ensure that the next unit is ready to receive a call at the allotted time
7. There may be occasions where it is both recommended and safe for face to face clinical review by a clinician – this can be assessed and agreed by the clinician at the time but will not be routine practice
8. Clinical notes will be emailed to the home after the round is completed

Ad-hoc/urgent clinical requests/on-call procedures

1. For any ad-hoc or urgent requests, nursing homes are to call the usual SPA on 0203 700 3105
2. Call will be placed on NH triage list as usual and allocated to appropriate team
3. For clinical requests/queries, initial call back will be by telephone as usual. We have advised that it is essential that we have the correct number to call back on. Home will need to ensure that the relevant person, with knowledge of the patient, is available.
4. Clinician will decide if video review of patient is required. When this is agreed, the home staff will provide the number of their allocated handset and GP will initiate WhatsApp video call

5. There may be occasions where it is both recommended and safe for face to face clinical review by a clinician – this can be assessed and agreed by the clinician at the time but will not be routine practice

Regular/planned Pharmacy review

1. For planned/regular medication review, the pharmacist will have sent a list of residents to the home in advance
2. The pharmacist will agree a time to call the home (or first unit) to discuss and review. Home will need to ensure that the relevant person, with knowledge of the patients, is available.
3. Pharmacist will decide if video review is required. When this is agreed, the home staff will provide the number of their allocated handset and pharmacist will initiate WhatsApp video call
4. Home will need to be able to pass on call to other units, or ensure that the next unit is ready to receive a call at the allotted time
5. Relevant notes will be emailed back to the home after the round is completed

Standard Operating Procedure for remote GP rounds

Please note, the TACHS SPA number 0203 700 3105 and the email address argyle.carehome@nhs.net remain operating as usual and should be used as normal.

This SOP is designed to facilitate routine and adhoc requests as far as usual, though the clinician should not be expected to be visit your site in person

Returning calls to any other number (even if they have temporarily been made available by a clinician or AHP) will result in clinical risk and should not be done. These may not be from usual handsets that are always on.

Regular/planned GP rounds

1. For planned/regular rounds, the home will email over the list of residents to be seen as usual. Email to argyle.carehome@nhs.net. This needs to be sent before 9:30 for morning rounds and 12:30 for afternoon rounds.
2. List must include patient details, what is to be discussed, and clinical observations
3. List will be sent to the regular clinician. They will review and set a time to call the home (or first unit) to discuss the list. Home will need to ensure that the relevant person, with knowledge of the patients, is available. Please be prepared to get repeat or additional clinical observations at the time
4. Please consider if patient could be moved to a quiet area or their room if required during the round, if necessary
5. GP will decide if video review of patient is required. When this is agreed, the home staff will provide the number of their allocated handset and GP will initiate WhatsApp video call
6. Home will need to be able to pass on call to other units, or ensure that the next unit is ready to receive a call at the allotted time
7. GP notes will be emailed back to the home after the round is completed

Ad-hoc/urgent clinical requests

1. For any ad-hoc or urgent requests, staff are to call the usual SPA on 0203 700 3105
2. Call will be placed on NH triage list as usual and allocated to appropriate team
3. For clinical requests/queries, initial call back will be by telephone as usual. It is essential that we have the correct number to call back on. Home will need to ensure that the relevant person, with knowledge of the patient, is available.
4. GP will decide if video review of patient is required. When this is agreed, the home staff will provide the number of their allocated handset and GP will initiate WhatsApp video call
5. There may be occasions where it is both recommended and safe for face to face clinical review by a clinician – this can be assessed and agreed by the clinician at the time but will not be routine practice

Regular/planned Pharmacy review

1. For planned/regular medication review, the pharmacist will have sent a list of residents to the home in advance
2. The pharmacist will agree a time to call the home (or first unit) to discuss and review. Home will need to ensure that the relevant person, with knowledge of the patients, is available.

3. Pharmacist will decide if video review is required. When this is agreed, the home staff will provide the number of their allocated handset and pharmacist will initiate WhatsApp video call
4. Home will need to be able to pass on call to other units, or ensure that the next unit is ready to receive a call at the allotted time
5. Relevant notes will be emailed back to the home after the round is completed

Information prepared by Dr Anna Down – The Argyle Care Home Service Mar 2020

Guidance for GPs looking after care home residents during Covid 19

It is crucial that any potential outbreak of COVID19 within a care home/residential setting is identified early so that appropriate isolation advice and PPE can be used early. Within London currently there is NO swabbing of care home residents remaining at home, so all suspected diagnoses need to be made clinically.

Clinical case definition:
Either:
New persistent cough
OR
T>37.8C

For any patient presenting with either of these symptoms the working diagnosis is of COVID19 and **isolation rules** apply. Please code as suspected COVID19 – the majority of cases in the community will never be swabbed and PHE are keen that we make clinical positive diagnoses.
In order to maximise the isolation of people to reduce spread of COVID19, and very little information on how often it is coincident with another diagnosis (seems to be increasingly common as a concurrent diagnosis), ALL patients with T>37.8C should be advised to follow isolation rules even if there is another diagnosis possible.

- Any resident with symptoms should be isolated for 7 days from the onset of symptoms.
- In line with other household isolation guidance, all residents in close contact (ie on the same unit) that have not shown symptoms should be isolated for 14 days

Working with PHE we have developed a recommendation that **any home/unit with 2 or more residents placed into isolation (for cough or fever, however mild) within 7 days should be considered as an outbreak** and is for escalation to PHE via email to both PHE.nwl@nhs.net and LCRC@phe.gov.uk . For homes within Ealing, please also cc Wendy Meredith (DPH): MeredithW@ealing.gov.uk , Kerry Stevens (DASC): Stevensk@ealing.gov.uk, Social care: spteam@ealing.gov.uk, PHE: MaddenV@ealing.gov.uk

For homes with a single GP provider this is easier to establish than those with multiple GP providers. Please ask the home if any other residents (under any GP) are in isolation and then it is required that the HOME escalates to PHE as above. There are also other local authority reporting systems in place for homes to report symptomatic residents.

For homes where patients have tracheostomies or where they are carrying out other aerosol generating procedures, please note that PPE requirements are different for suspected COVID19 cases:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/874411/When_to_use_face_mask_or_FFP3.pdf

Key messages to care homes

- Residents who have symptoms of coronavirus infection (COVID-19), however mild, must be isolated in their own room for 7 days from when symptoms started.
- This action will help protect others in the home whilst they are infectious.
- Residents should be encouraged to wash their hands regularly for 20 seconds, each time using soap and water.
- It is important that those with symptoms stay away from others in the home and any visitors to the home
- you do not need to call the GP to put a resident into isolation. We would advise that you take this action first then call their GP discuss the resident and concerns. If they are worsening then please call the GP or 111*6 before calling 999

Reporting potential outbreaks

- Working with PHE we have developed a recommendation that any home/unit with 2 or more residents placed into isolation (for cough or fever, however mild) within 7 days should be considered for escalation to PHE via email to both PHE.nwl@nhs.net and LCRC@phe.gov.uk . For homes within Ealing, please also cc Wendy Meredith (DPH): MeredithW@ealing.gov.uk , Kerry Stevens (DASC): Stevensk@ealing.gov.uk, Social care: spteam@ealing.gov.uk, PHE: MaddenV@ealing.gov.uk

Will my resident be tested if we think they have COVID-19

- We do not have access to testing from the GP surgery. The NHS will NOT be testing those self-isolating with mild symptoms or those remaining at home. At the current time that includes care home residents but this may change

How long do we need to isolate a resident for?

- Any resident with symptoms should be isolated for 7 days from the onset of symptoms.
- In line with other household isolation guidance, all residents in close contact (ie on the same unit) that have not shown symptoms should be isolated for 14 days. The 14 days represents the potential incubation period (the time it takes for symptoms to show if you have been infected).

Managing the resident in isolation

- Residents should stay in a well-ventilated room with a window that can be opened. Try to keep the window open as much as possible to enable ventilation and air flow as this will help to keep clean air moving through their room.
- The door to their room should be closed.
- Meals and all personal care should be given in the residents room.

- PPE will be needed for all interactions with the resident including but not limited to personal care and for mealtimes etc. Please follow guidance from your home manager and line manager as usual.
- We would suggest nominating one nurse and one carer to attend to the isolated patient on any given shift (reducing the number of people that go into the room)
- Ensure the resident is using their own eating and drinking utensils (including cups and glasses in the bathroom and bedroom), dishes, drinks, towels, washcloths or bedlinen.

If the resident needs to be moved around the home

- Minimise the time the resident is in contact with other people and shared spaces
- Aim to keep them 2 metres (3 steps) away from other people.
- For shared toilet and bathroom, it is important that they are cleaned after the resident has used them every time (e.g. wiping surfaces). For shared bathrooms, consider taking the isolated resident last, before thoroughly cleaning the bath, sink and toilet.

Appointments

- All routine medical and dental appointments should be cancelled whilst a resident is isolated. For advice call their GP as usual

Facemasks

- Putting a mask on a resident eg during personal care may help reduce the risk of transmission to carers but is not in place of carers and staff using full appropriate PPE

Visitors

- Visitors should be discouraged from entering the room of any residents in isolation. If they do enter, then they must use PPE to avoid transmission to themselves or any other residents

Ending isolation

- Residents should remain isolated until 7 days after the onset of their symptoms. After 7 days, if they are better and no longer have a high temperature, they can return to normal routine.
- Cough may persist for several weeks in some people, despite the coronavirus infection having cleared. A persistent cough alone does not mean they must continue to be isolated for more than 7 days but please seek advice for any concerns

What you can do to practically care for someone who is in their last days and hours of life

It is important to be aware of what to expect and how to make the experience as comfortable as possible.

Communication and environment

When approaching the end of life, people often sleep more than they are awake and may drift in and out of consciousness.

Try to imagine what the person you are caring for would want. Provide familiar sounds and sensations, a favourite blanket for example, or piece of music. Keep the environment calm by not having too many people in the room at once and avoid bright lighting. This can reduce anxiety even when someone is unconscious. Even when they cannot respond, it is important to keep talking to them as they can most probably hear right up until they die.

Feeling sick

Sometimes people can feel nauseated or sick when they are dying.

If vomiting, and unable to sit up, turn the person on their side to protect their airway. There are medicines that can be given to help relieve this.

Moving

The person will require washing at least once a day and regular turning every 2-4 hours to protect their skin from developing pressure sores.

Alternate their position from lying on their back to each side. You can use pillows or rolled up towels to support them and also to support under their arms and between and under their legs. When you are washing the person, look for signs of redness, or changes in the colour or appearance of their skin. Check the back of the head and ears, the shoulder blades and elbows and the base of the spine, hips and buttocks, ankles, heels and between the knees.

Your health team will advise you on the medications that can help with controlling symptoms experienced at the end of life.

Pain

Some people may be in pain when they are dying. If they are less conscious they may grimace or groan to show this. There are medicines that can be given to ease pain.

Always check their positioning in bed to see if this can also help. They may be too weak to move and this can cause discomfort. Consider if they have any areas that are known to hurt, for example a bad back, and remember this when positioning them.

Going to the toilet

Towards the end of life, a person may lose control of their bladder and bowel. Even though we expect someone to go to the toilet less as they eat and drink less, contact the health care team that is looking after them if they have not passed any urine for 12 hours or more as it can be uncomfortable.

Keep the person comfortable by regularly washing them and changing pads if they are wet or soiled.

Mouth care

While people rarely complain of thirst at the end of life, a dry mouth can be a problem due to breathing mostly through their mouth.

It's important to keep lips moist with a small amount of un-perfumed lip balm to prevent cracking. Regularly wet inside their mouth and around their teeth with a moistened toothbrush whether he or she is awake or has lost consciousness. Check for sore areas and white patches on the tongue, gums and inside the cheek which can be sore. If this happens tell the person's healthcare professionals as it can be treated easily.

Breathlessness and cough

Breathlessness and cough can be another cause of agitation and distress and it can make it difficult to communicate. Don't expect the person to talk and give them time and space to respond. Reassure them that the unpleasant feeling will pass.

You can offer reassurance by talking calmly and opening a window to allow fresh air in. If possible, sit the person up with pillows rather than lying flat as this can help the sensation of not being able to breathe.

Before someone dies their breathing often becomes noisy. Some people call this the 'death rattle'. Try not to be alarmed by this, it is normal. It is due to an accumulation of secretions and the muscles at the back of the throat relaxing. There are medicines that can be given to help dry up secretions if it is a problem.

Agitation or restlessness

Some people can become agitated and appear distressed when they are dying. It can be frightening to look after someone who is restless. It's important to check if the cause is reversible like having a full bladder or bowel which can be reversed by using a catheter to drain the urine or medicines to open the bowels. Your health team can assess if this is necessary.

Check if their pad is wet to see if they are passing urine or if they are opening their bowels. If it's not either of these things, there are things you can do and give to help. Try to reassure the person by talking to them calmly and sitting with them. Touch can be effective in doing this too. There are also medicines that can be given to help settle and relax someone.

Looking after yourself

Caring for a dying person can be exhausting both physically and emotionally. Take time out to eat and rest. Try to share the care with other people when possible and remember it is OK to leave the person's side to have a break.

Washing

Sometimes it may be too disruptive for the person to have a full wash. Just washing their hands and face and bottom can feel refreshing.

To give a bed bath, use two separate flannels, one for the face and top half of the body and one for the bottom half. Start at the top of the body, washing their face, arms, back, chest, and tummy. Next, wash their feet and legs. Finally, wash the area between their legs and their bottom. Rinse off soap completely to stop their skin feeling itchy. Dry their skin gently but thoroughly. Only expose the parts of the person's body that are being washed at the time – you can cover the rest of their body with a towel. This helps to keep them warm and maintains their dignity.

Eating

As the body shuts down it no longer needs food and fluid to keep it going. When a person is dying they often lose their desire to eat or drink and finally their ability to swallow. They can lose weight rapidly.

This is often difficult to accept because we often equate food with health and feeding people as an act of love. However, hunger and thirst are rarely a problem at the end of life.

Continue to offer a variety of soft foods and sips of water with a teaspoon or straw for as long as the person is conscious (but allow them to refuse it). It's important not to force food or drink onto someone who no longer wants it. Remember to sit them up when offering food and fluids to avoid choking.

When a person is no longer able to swallow some people want them to have fluids via other routes like a drip, but at the end of life this offers little, if any, benefit. The body cannot process the fluid like a healthy body can and it can be harmful to artificially feed and hydrate. Risks include infection at the insertion site or in the blood, and fluid overload resulting in swelling or even breathing problems.

Please find below example letters and templates for communicating with care homes, patients and relatives/carers regarding ACP

The Confederation

The Confederation, Hillingdon CIC
Belmont House,
Belmont Road,
Uxbridge, UB8 1HE

☎ 01895 547386
www.hillingdonprimarycare.co.uk

The Confederation is a member of
Hillingdon Health and Care Partners

MESSAGE FROM CARE HOME SUPPORT TEAM MATRONS RE. COVID-19

Dear Care Home and Extra Care Facility Staff,

We are in a very difficult and frightening time at the moment and acknowledge you may be feeling very isolated in the care homes. We recognise you are caring for those who are considered most vulnerable to possibly contracting Covid 19 Virus at a time when support and resources are being streamlined and particular groups of at risk patients are being prioritised.

As Care Home Matrons we want to offer as much support as possible; however we unable to visit on a regular basis, as we wish to minimise any potential risk to spread the virus. We will continue to perform our morning triage call and are happy to discuss any anxieties or concerns you may have. You are advised to contact us during the course of the day with any concerns via mobile or email. You may be aware the Care Home Matrons have been collecting data to update/create Coordinate My Care records (CMC) for all residents in the care home setting, so you and all other essential services – LAS, GP's,111, A and E, DN's have a record of resident's wishes surrounding their preferred choices of care and DNACPR status. Although not ideal but essential at this time we will be phoning relatives to have these discussions. We will then update you and their CMC record. Please ensure all staff have read and clearly understood the plan for all residents as we have received feedback this week that residents have been admitted to hospital despite their CMC Record clearly stating "Not for Hospitalisation".

With the unprecedented demand on all services we need to think carefully before phoning for an ambulance as hospital is not the ideal place for your residents at the moment. Can we manage their symptoms with support from community services? Sadly the reality is that those who are most frail with numerous comorbidities will not survive ventilation or a resuscitation attempt. We will be explaining to families the risk of residents being transferred into hospital and it may be more appropriate to facilitate with support of services, a more dignified death in the care home, in a familiar environment with staff they know. In the community setting we still have access to Rapid Response, Your Life Line and District Nursing Services; although we are aware they will be under immense pressure.

We presume that relatives will be allowed to visit those who are dying in your care home; this may not be the case in hospital.

We appreciate this is a bleak and frightening picture, but we are forced to be realistic with what we will be facing.

We have included information that we hope will be of use, many may already be aware, in that case use it as a refresher and ask are we adhering to this.

Do the staff ALL know the plan for each resident.

Reducing the infection

Before performing hand hygiene:

- expose forearms (bare below the elbows);

- remove all hand and wrist jewellery (a single, plain metal finger ring is permitted but should be removed (or moved up) during hand hygiene);

- ensure finger nails are clean, short and that artificial nails or nail products are not worn;

- cover all cuts or abrasions with a waterproof dressing.

Personal Protective Equipment
It is vitally important understand about PPE and what they are trying to avoid, it is not just a case of wearing the equipment. Safe removal and disposal is as, if not more important to stop the spread of the virus and protect staff and residents.

Recommended Guidelines

Use safe work practices to protect yourself and limit the spread of infection

- Keep hands away from face and PPE being worn.
- Change gloves when torn or heavily contaminated.
- Limit surfaces touched in the patient environment.
- Regularly perform hand hygiene.
- Always clean hands after removing gloves.

NB Masks and goggles are not routinely recommended for contact precautions. Consider the use of these under standard infection control precautions or if there are other routes of transmission.

The type of PPE used will vary based on the type of exposure anticipated, and not all items of PPE will be required.
The order for putting on PPE is Apron or Gown, Surgical Mask, Eye Protection (where required) and Gloves.
The order for removing PPE is Gloves, Apron or Gown, Eye Protection, Surgical Mask.

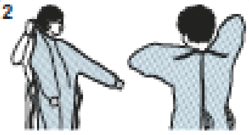
1. Putting on Personal Protective Equipment (PPE).

- **Perform hand hygiene before putting on PPE**

1

Apron
Pull over head and fasten at back of waist.

2



Gown/Fluid repellent coverall
Fully cover torso neck to knees, arms to end wrist and wrap aroundthe back. Fasten at the back.

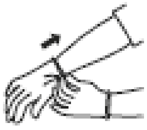
3

Surgical mask (or respirator)
Secure ties or elastic bands at middleof head and neck.Fit flexible band to nose bridge.Fit snug to face and below chin.Fit/check respirator if being worn.

4

Eye Protection (Goggles/Face Shield)
Place over face and eyes and adjust to fit.

5



Gloves
Select according to hand size.Extend to cover wrist.

2. Removing Personal Protective Equipment (PPE)

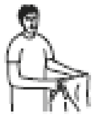
6

Outside of gloves are contaminated. Grasp the outside of the glove with the opposite gloved hand; peel off.

7

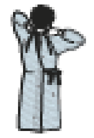
Hold the removed glove in the gloved hand. Slide the fingers of the ungloved handunder the remained glove at the wrist. Peel the second glove off over the first glove. Discard into an appropriate lined waste bin.

8



Apron
Apron front is contaminated. Unfasten or break ties.Pull apron away from neck and shoulders touching inside only. Fold and roll into a bundle. Discard into an appropriate lined waste bin.

9



Gown/Fluid repellent coverall
Gown/Fluid repellent coverall front and sleeves are contaminated.Unfasten neck, then waist ties.

10

Remove using a peeling motion; pull gown/fluid repellent coverall fromeach shoulder towards the same hand.

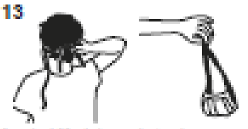
11

Gown/fluid repellent coverall will turn inside out. Hold removed gown/fluid repellent coverall away from body, roll into a bunde and discard into an appropriatelined waste bin or linen receptacle.

12

Eye Protection (Goggles/face shield)
Outside of goggles or face shield are contaminated.Handle only by the headband or the sides.Discard into a lined waste bin or place into a receptacle for reprocessing/ decontamination.

13



Surgical Mask (or repiratory)
Front of mask/respirator is contaminated - do not touch. Unfasten the ties - first the bottom, then the top. Pull away from the face without touching front of mask/respirator. Discard disposable items into an appropriate lined waste bin. For reusable respirator place in designated receptacle for processing/ decontamination.

- **Perform hand hygiene immediately on removal.**
- **All PPE should be removed before leaving the area and disposed of as healthcare waste.**

Treatment of linen

Disposable gloves and an apron should be worn when handling infectious linen.
All linen should be handled inside the patient room. A laundry receptacle should be available as close as possible to the point of use for immediate linen deposit.

When handling linen do not:
● rinse, shake or sort linen on removal from beds/trolleys;

- place used/infectious linen on the floor or any other surfaces e.g. a locker/table top;
- re-handle used/infectious linen once bagged;
- overfill laundry receptacles; or
- place inappropriate items in the laundry receptacle e.g. used equipment/needles

Healthcare laundry services should be used to launder staff uniforms. If there is no laundry facility available, then uniforms should be transported home in a disposable plastic bag. This bag should be disposed of into the household waste stream.
Uniforms should be laundered:

- separately from other household linen;
- in a load not more than half the machine capacity;
- at the maximum temperature the fabric can tolerate, then ironed or tumbled-dried.

NB. It is best practice to change into and out of uniforms at work and not wear them when travelling.

Cleaning of rooms

"Frequently touched" surfaces such as medical equipment, door/toilet handles and locker tops, patient call bells, over bed tables and bed rails should be cleaned at least twice daily and when known to be contaminated with secretions, excretions or body fluids.
Domestic/cleaning staff performing environmental decontamination should:
be allocated to specific area(s) and not be moved between COVID-19 and non infected areas.

When symptoms have resolved, or a resident has died rooms should be deep cleaned. (This includes removal and laundering of all curtains and bed screens)

Discharge of Residents from hospital

With the incredible demand on patient beds in hospital Care Homes will be asked to take residents home at short notice.
NICE Guidelines state

"Patients can be discharged before resolution of symptoms provided they are deemed clinically fit for discharge and should be isolated on returning to the care homes.".

Treatment of residents with Covid 19 Virus

Each morning when we triage we will ask if there are any residents who are deteriorating, so we can ensure we have all they need in place, including anticipatory medication.

Signs and symptoms

- Fever a temperature of 37.8c or skin hot to touch.
- A **new** continuous cough
- Shortness of breath or difficulty breathing
- Fatigue
- Headaches
- Sore throat
- Aches and pains

Treatment

- Administer four times a day Paracetamol, ensure all residents have this written up on their MAR chart.
- Administer all usual remedies for sore throats and coughs, ie honey and lemon, cough medicine, throat lozenges if safe to do so.
- Although it is a virus, symptoms are very similar to a chest infection so antibiotics will still be given if there is any doubt
- Keep residents temperature down with cold compresses, reduced bedlinen and night clothes and a well ventilated room
- DO NOT USE A FAN as this spreads the virus around.
- Encourage fluids as much as able, if not ensure frequent mouthcare.
- Isolate resident in room with the door shut, if this is not possible create an area that is restricted to infected residents and limit staff in the area, even stopping them walking through for breaks, equipment etc. Staff working in that area should wear PPE at all times.

Severely ill residents

- Ensure residents have anticipatory medication and administer as prescribed
- Residents who are struggling to breath will become very distressed, requiring Morphine/Oramorph and Midazolam.
- The virus creates very thick mucus so unless residents are coughing up wet mucus Glycopyrronium will not help the symptoms.
- Contact District Nurses or YLL to administer if you are in a residential setting.

Please remember to keep up to date documentation, especially if you have identified a residents but are unable to isolate them, perhaps due to challenging behaviour.

We hope this is of use, once again please do not hesitate to contact us.
You are all doing an amazing job at such a horrendous time.

Kind Regards

Care Home Matrons

Beverley, 07563555862, bclement@nhs.net
Sarah, 07563555163, sarah.brown48@nhs.net
Lorraine, 07563555317, lorraine.fitzgerald3@nhs.net
Chipo, 07563555744, chipo.mubwandarikwa3@nhs.net

COVID-19 and Care planning for hospital admissions

Date : 27/3/20

Dear Patients and Relatives,

You are receiving this letter because you are a Patient or a relative of a patient in a care home in Hillingdon that is registered for NHS GP and Community services.

We need to ensure that patients have an up to date care plan in place. Many patients already have care plans in place regarding their wishes/their power of attorney's views on further care and hospital admission. But this is not the case for all of our patients. We want to make every effort to plan for and follow the wishes of you and your loved ones. We are in the process of reviewing your/your relative's notes, underlying medical conditions, and care plans, including existing resuscitation decisions.

If you are unsure if you or your relative has such a care plan in place or your views have changed since this was last discussed, please could you put this in writing. Please state if you are the patient, relative, or power of attorney for health and welfare, and whether these are your views as a relative/carer/friend. Please state the name and date of birth of the patient in your email and send it to -------(Anil do you want a central coordination contact here)?.

In normal practice these are discussions that we would have with you in a face to face meeting at a time and place convenient to you. Unfortunately, this is not possible at the moment. If you have any concerns or would like to discuss this further please contact one of the nursing home staff who will arrange for us to be in touch. We have a team of specialist expert nurses working with us. They are here to document your wishes and plans, and they may also call you to talk through these issues.

You will be aware that there is a global COVID-19 pandemic. NHS services are extremely stretched and this will continue for some time to come. We have been receiving reports from hospitals, both locally and nationally, that elderly patients and those with underlying medical conditions or frailty, who are infected with COVID-19, will very sadly, in many cases, become very unwell, despite hospital care.

We apologise for any distress that this letter may have caused. We hope that you understand why this has been necessary. We are making every effort to ensure that our patients have the best possible health outcomes from the NHS and the care that modern medicine can offer them.

Recommended wording to communicate DNACPR decisions for relative of patients who lack capacity and live in nursing homes / residential homes.

Dear XXX (name of Resident / Relative),

We are writing this letter at an unprecedentedly difficult time. You will be aware that there is a national Coronavirus Emergency and that this is taking a significant toll on the NHS Ambulance, Primary Care, Hospital, and Intensive Care services.

We have been receiving reports from hospitals, both locally and nationally, that elderly patients and those with other medical conditions or frailty, who are infected with Covid -19, will very sadly, in many cases, become very unwell. We also know that elderly patients, especially those with other co-morbidities and frailty do not benefit from aggressive hospital treatment.

We are, therefore, having to make difficult decisions regarding the benefit of sending our elderly patients to hospital and the appropriateness of attempting to re-start their hearts if they were to stop beating (CPR or cardiopulmonary resuscitation). The decision about this treatment is a medical one, but it is one in which we must inform patients and / or their relatives of the conclusion made.

We have reviewed your relative's notes and feel that CPR would be very unlikely to be successful or be beneficial for them, if their heart was to stop beating - especially in the context of a serious covid-19 infection. If this were to happen, we feel it would be more appropriate to allow a natural death and have completed a 'Do Not Attempt Cardio Pulmonary Resuscitation' form for them.

In normal practice this is a decision that we would like to explain to patients and families in a calm, non-time pressured environment. Unfortunately, this is not possible in the current climate. If you have any concerns or would like to discuss any of the above further please contact one of the practice team on or discuss it further with the nursing home staff.

We are very sorry for any distress that this decision may cause, but I hope you understand why this has been necessary in view of the current situation we all find ourselves in.

Yours Sincerely

Dear GPs

In order to ensure the acute trusts are not overwhelmed with admissions for patients who would not benefit from further management /resuscitation we would ask you review the following

1- Any patient with a CMC record to ensure DNACPR /Treatment escalation plan is in place and appropriate

2- Identify and care plan, using CMC any appropriate patients e.g. –COPD/Heart failure as -most of you will have a list of these from the Quality Improvement activity for EoLc. Publish the plan in a timely manner

3- Secondary care colleagues have asked if all CMC records could have performance score/functional status and a relative contact name and number (I have attached a resource for this)

4- Support care home matrons to ensure plans are reviewed and published in timely manner

I have attached a small paragraph which you could convert to an accurx template to invite the relative/patient to update the care plan via phone/ video link.

ARGYLE
Health Group

NHS
Ealing Community
Partners

The Argyle Care Home Service
128 Argyle Road
London
W13 8ER

Tel: 0203 700 3105
Email: argyle.carehome@nhs.net

Re: COVID-19 and Care planning for hospital admissions

Date : 27/3/20

Dear Patients and Relatives,

These are exceptional times and we apologise for writing to you in this manner. However, we need to quickly share information with you. You are receiving this letter because you are a patient or a relative of a patient in a care home in Ealing that is registered for NHS GP and community services from the Argyle Health Group and Ealing Community Partners.

We are writing this letter at an unprecedentedly difficult time. This is not an easy letter to write. As a team we have spent over 7 years providing the highest standards of care for patients in care homes across Ealing. We have made every effort to ensure that each and every patient has the best level of healthcare that the NHS can offer.

You will be aware that there is a global COVID-19 pandemic. NHS services are extremely stretched and this will continue for some time to come. **We will not abandon you or your loved ones** but we do need to be frank with you about the impact of COVID-19.

We have been receiving reports from hospitals, both locally and nationally, that elderly patients and those with other medical conditions or frailty, who are infected with COVID-19, will very sadly, in many cases, become very unwell, even when in hospital. We also know that elderly patients, especially those with other co-morbidities and frailty do not benefit from aggressive hospital treatment. Our patients and our service are particularly vulnerable.

My colleagues and I have to make difficult decisions on a daily basis using our expertise and knowledge regarding the benefit of sending our elderly and frail patients to hospital and the appropriateness of attempting to re-start their hearts if they were to stop beating (CPR or cardiopulmonary resuscitation). The decision about CPR is a medical one, but it is one in which we must inform patients and / or their relatives of the conclusion made.

We are in the process of reviewing your/your relative’s notes and looking at existing CPR decisions and where we have none recorded. We will carry out an assessment of each patient’s current symptoms and underlying medical conditions. If we conclude that Cardio Pulmonary Resuscitation (CPR) would be very unlikely to be successful or not benefit the patient, especially if the patient has a serious COVID-19 infection, we will allow a natural death. We would therefore complete a ‘**Do Not Attempt Cardio Pulmonary Resuscitation**’ form for such patients.

Many patients already have care plans in place regarding their wishes/their power of attorney's views on further care and hospital admission. But this not the case for all of our patients. We want to make every effort to plan for and follow the wishes of you and your loved ones.

I have to stress again that we and the wider NHS will make every effort to ensure the health and wellbeing of all our patients, and provide the best supportive treatment that we can. But we do need to be frank with you regarding realistic outcomes if anyone has COVID-19. Unfortunately, for many of our care home patients, if they fall unwell and require ventilator therapy (a breathing machine) it is unlikely that they will survive. Please note this has been and will remain an individual holistic medical decision for each patient. This is not a blanket decision.

We need to implement a care plan. If you are unsure if you or your relative has such a care plan in place or your views have changed since this was last discussed, please could you put this in writing (stating if you are a patient, relative or power of attorney for health and welfare, or whether these are your views as a relative/carer/friend). Sending these wishes via email to argyle.carehome@nhs.net. Please state the name and date of birth of the patient in your email. We can then take these wishes into account alongside all the underlying health conditions.

In normal practice these are discussions that we would have with you in a face to face meeting at a time and place convenient to you. Unfortunately, this is not possible at the moment. If you have any concerns or would like to discuss this further please contact one of the nursing home staff who will arrange for us to be in touch. We have a team of specialist expert nurses from Marie Curie working with us. They are here to document your wishes and plans, and they may also call you to talk through these issues.

We once again apologise for any distress that this letter may have caused. We hope that you understand why this has been necessary. We are making every effort to ensure that our patients have the best possible health outcomes from what the NHS and modern medicine can offer them.

Yours Sincerely

Dr Anna Down
The Argyle Care Home Service

Dr Arjun Dhillon

Template for Accurx

We are in the process of reviewing your/your relative's notes, underlying medical conditions, and care plans, including existing resuscitation decisions. We are inviting you to review this with us. In normal practice these are discussions that we would have with you in a face to face meeting at a time and place convenient to you. Unfortunately, this is not possible at the moment. If you are unsure if you or your relative has such a care plan in place or your views have changed since this was last discussed, please could you respond to this message with you contact details and we will contact you .

Section 4
Coordinate My Care (CMC)

Resource pack to support implementation of Coordinate My Care plans at pace.

Document purpose	This resource pack has been collated to respond to the frequently asked questions in order to assist local health and care systems to increase use of Coordinate My Care (CMC).
Target audience	Commissioning and Transformation leads for End of Life, Urgent Care and Primary Care. CMC Strategic Commissioning Group members. Administration staff working in Primary care, Community Services and Acute Trusts. This pack is not aimed at front line staff. However, local leads may choose to use relevant information to support the local response to COVID-19.
Communication channels	CMC Strategic Commissioning Group members CCG End of Life leads Relevant Clinical Networks CMC Stakeholder newsletter
Background	Coordinate My Care is an accepted record of advance care plans and referenced in the Primary Care and Community Respiratory Resource pack for use during COVID-19 (issued on the 27th March (Appendix 1). CMC is a recognised source of information to aid decisions about ambulance conveyance or admission avoidance.

Frequently Asked Questions:

How can we rapidly create CMC plans for people at high risk of severe illness?

1. Practices should identify those patients who are at very high risk of severe illness from COVID-19 because of an underlying health condition (Appendix 2)
2. GP practices are able to run searches on the EPR to identify patients who:
    a. Are on their palliative care registers
    b. A moderate or severe frailty flag
    c. Using READ and SNOMED codes (Appendix 3).
    d. A new EMIS Search has been published to help identify those who are likely to be in the last year of their life and not on the palliative care register: https://www.england.nhs.uk/london/london-clinical-networks/our-networks/end-of-life-care/end-of-life-care-key-publications/
3. GP practices can invite patients by text, e-mail or letter to start their own myCMC plan. www.mycmc.online A template letter is available here: https://www.coordinatemycare.co.uk/wp-content/uploads/2020/03/my-cmc-letter-template-for-gps.docx
4. If a patient creates a myCMC plan, most of CMC fields are completed. An email will be sent to the registered GP practice notifying the practice that a patient has created a myCMC plan. The plan then just needs to be reviewed by a senior clinician and published.
5. Users can log-in to CMC either directly through their health IT systems that are configured via in-context link or by logging in with N3/HSCN access: nww.coordinatemycare.net

6. Offer those at risk of serious illness, should they contract Covid-19, the ability for relevant care and support information to be made visible to urgent and emergency services via a CMC plan.
7. Both clinical and non-clinical staff are able to create and add clinical details to a CMC plan (using information from established advance care plans recorded on their EPRs or in other formats). However, a senior clinician needs to review and publish this information.
8. Consider extending user access to CMC in nursing and care homes. For the duration of the COVID pandemic, the requirement for nursing and care homes to be DSPT compliant and have an information sharing agreement with CMC in place has been relaxed under COPI legislation. The DPIA relating to this was agreed by the London COVID-19 Information Governance group on the 31st of March 2020. Nursing and care homes staff should apply for log-ins using the online portal: https://www.coordinatemycare.co.uk/joining-cmc/
9. A CMC plan can be created very quickly. The minimum requirements necessary for a CMC care plan are:
    a. **Consent**: If a patient has a past/previous care plan on your IT System, consider if the consent includes using CMC to share this information.
    b. **Diagnosis**: The most significant diagnosis and purpose for creating the CMC plan
    c. **Prognosis:** If in doubt select “years”.
    d. **WHO performance status:** Select one**.**
    e. **Preferred Place of care:** Select “not discussed/not willing” if unknown.
    f. **Preferred Place of death:** Select “not discussed/not willing” if unknown.
    g. **CPR Discussions**: CPR is a medical decision. If it is medically not appropriate please discuss with patient/family. If, as a clinician, you are unsure if CPR should be commenced you can select “not discussed/not willing” or for full CPR.
    h. **Emergency treatment plan**: Select the appropriate recommendation/ceiling for clinical treatment. Provide free text to support emergency treatment decisions.
    i. **Medications and allergies:** Only allergies are absolutely necessary.
10. The overall clinical responsibility for decisions about CPR, including DNACPR decisions, rests with the most senior clinician responsible for the person’s care as defined explicitly by local policy. This could be a consultant, general practitioner (GP) or suitably experienced and competent nurse supported by local policy. It is recommended that anyone at Band 6 and below should not be making such decisions in isolation in any circumstance.

How can we rapidly update records for people in high risk groups?

11. Identify those patients that already have a CMC care plan. Practices can see a list of their patients who have a CMC plan on the CMC portal. This list can be filtered to view those plans that are still draft, or other relevant criteria. (Appendix 5)
12. CMC have been commissioned to create an excel spreadsheet for each CCG to identify those patients that have a CMC plan. The search will contain: CMC plan status published/draft, CPR status and last date published. **Using e-mail to share this list is NOT standard practice**. To enable this flow of data, a short form Data Protection Impact Assessment (DPIA) has been agreed by the London COVID-19 IG group under the COPI legislation.
    Please e-mail Murrae.tolson@swlondon.nhs.uk to provide the e-mail of the person for each CCG who should receive this list. This list can be used to identify and act on the following:
    a. Review and **publish DRAFT CMC plans**. Please note DRAFT CMC plans are NOT visible to urgent care services.
    b. Review CMC plans that were published a long time ago – they may no longer be accurate. In addition there may be further information including **symptom control**

guidance and access to anticipatory medication in the home which is important to add to the record.

c. Check that the patient and **carer contact** details are correct. Administrators are able to edit and publish non clinical items like demographic details on the CMC plan.
d. Add **professional contacts** such as community palliative care teams contact details. This will enable those attending to contact professionals in an emergency situation for advice.
e. Cross reference with local search identifying vulnerable in order to identify those who do not have a CMC plan. Consider comparing this with community or social service case lists. (Return to point 1&2)

How can we increase the number of CMC plans that are viewed?

13. Some Acute and Community Services have very few staff with CMC log-ins. The practice of viewing CMC plans may not be embedded in their usual operations. Large organisations that require access for more than 50 people can collate a list of staff who should have access to CMC and submit their details using the **batch log-in** request. Note that each member of staff needs to supply their unique e-mail address. https://www.coordinatemycare.co.uk/joining-cmc/. (Appendix 5.)
Some Trusts have arranged CMC log-ins for ED administrators and FY1s and FY2s. E-mail the attached list to coordinatemycare@nhs.net by 9am Monday morning for log-ins to be issued by close of Tuesday, or by 9am Thursday morning for log-ins to be issued by close of Friday.
14. Some Trusts have arranged for clinicians and non-clinicians to check if patient presenting at ED have a CMC plan. Attached quick guide explains how the CMC urgent care summary can be printed in order to attach to the admission notes. (Appendix 6)

Appendix 1: Primary Care and Community Respiratory Resource pack for use during COVID-19

PDF

Primary Care and
Community Respirat

Appendix 2: Those considered to be at increased risk:

- Aged 70 or older (regardless of medical conditions)
- Under 70 with an underlying health condition listed below (i.e. anyone instructed to get a flu jab as an adult each year on medical grounds)
- Chronic (long-term) respiratory diseases, such as asthma, chronic obstructive pulmonary disease (COPD), emphysema or bronchitis
- Chronic heart disease, such as heart failure
- Chronic kidney disease
- Chronic liver disease, such as hepatitis
- Chronic neurological conditions, such as Parkinson’s disease, motor neurone disease, multiple sclerosis (MS), a learning disability or cerebral palsy
- Diabetes
- Problems with spleen – for example, sickle cell disease or have had your spleen removed
- A weakened immune system as the result of conditions such as HIV and AIDS, or medicines such as steroid therapy or chemotherapy
- Being seriously overweight (a body mass index (BMI) of 40 or above)

- Those who are pregnant.

Appendix 3: READ and SNOMED codes relating to resuscitation.

READ codes relating
to resuscitation.docx

Appendix 4: CMC Practice list functionality

CMC Quick guide
Practice search.pdf

Appendix 5: CMC Batch log-in request (50+ users)

CMC
BATCH-LOGIN-UAF-

Appendix 6: How to find and print the CMC urgent care summary

CMC Find and print
urgent care summary

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CMC top tips

CMC remains the only IT platform to share important information regarding our patients with health and social care colleagues both in and out of hours.

The 2 most valuable areas completed on a CMC for LAS are;

1. **Escalation Treatment Plans / Crisis Plans**
2. **Contacts – both personal and professional**

LAS use CMC as a guide to help manage our patients. Any information is helpful, even if the care plan has not been discussed in its entirety or a patient and their family are not willing to discuss certain elements, this information in itself is incredibly valuable and the care plan still be published. It is a live document which can be added to as and when our patients are seen and their condition and presentation changes.

Escalation Treatment Plans / Crisis Plans

Add details of the problems or symptoms this patient frequently suffers with or is likely to contact emergency services regarding.

i.e COPD patient who is for full active treatment including CPR. Symptom of breathlessness. Patient has their own nebuliser, remind them of breathing techniques, have they started their rescue medication.

i.e Dementia patient who is for treatment of reversible symptoms at home. Symptom of delirium. Frequently suffers with UTI's. Please screen for infection with urine dip, examination. Should have antibiotics and soluble paracetamol at home to commence. Please alert GP.

It is invaluable to involve and ensure Family, Carers, NOK and anyone else involved in the patients care (i.e District Nurses) are aware of the CMC care plan. This can be printed along with the DNAR decision and left in a patient's home.

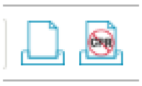
Contacts

Information regarding specialist nurses, hospital consultants, NOK or preferred relative or carer to be contacted can be very useful. Anyone who is involved in this patients care who may be able to support LAS/111 when they are contacted regarding your patient.

TOP TIP's

DNAR decision moving between care settings

A documented DNAR decision on CMC is valid in the community you do not need a hand written red bordered form. You can simply complete on CMC and print direct from the published care plan. (Helpful when patients are discharged from Hospital with a DNAR which needs reviewing in the community, simply create/ review on CMC).

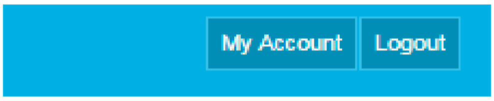


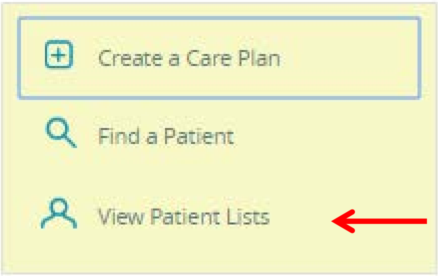
What to record on a CMC record

Share any intelligence which may be helpful to colleagues who do not know your patient. Explain their social situation including relationship with family, recent admissions or contact with you and their current baseline provides a good indication of what their normal is. Documenting you have not discussed or patient is not willing to discuss place of care, death, ceilings of treatment is very helpful to the LAS so they are aware. Explaining the purpose for creating the CMC i.e to share the patient's diagnosis and medications, is already an immediate benefit to the patient and whoever is viewing the care plan.

Viewing and Re-viewing all CMC care plans for you and your practice

If you wish to view all CMC care plans associated with you or your organisation you can log into CMC via their website www.coordinatemycare.co.uk and click on top right blue button 'access CMC' . On the home page top right there is a drop down to select all patients known to my organisation or left hand side view patient list.



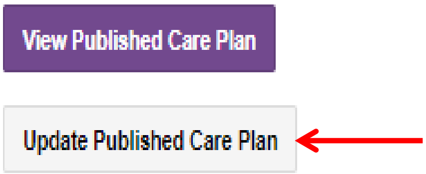


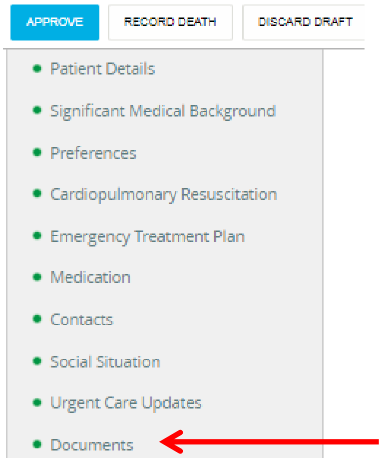
I would recommend logging in regularly (monthly to 3 monthly) to review any care plans which may be pending. And use this as an opportunity to review and update the care plans.

You could use this list on your CMC to discuss with your palliative care, district nursing or complex patient MDT's.

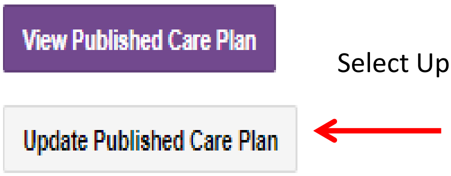
Uploading documents

Uploading documents is only available if you log in via the coordinatemycare.co.uk website access not through direct EMIS. (Keep a record of your username and password somewhere safe, you can easily request a new password either through the 24/7 support line 02078118513 or through the log in page on the website.





Recording patient death

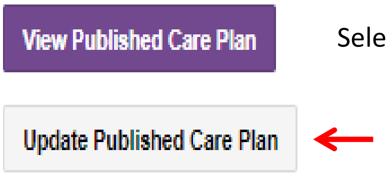


Select Update Published Care Plan next to a named CMC plan

Then select record a death at the top left of the screen.

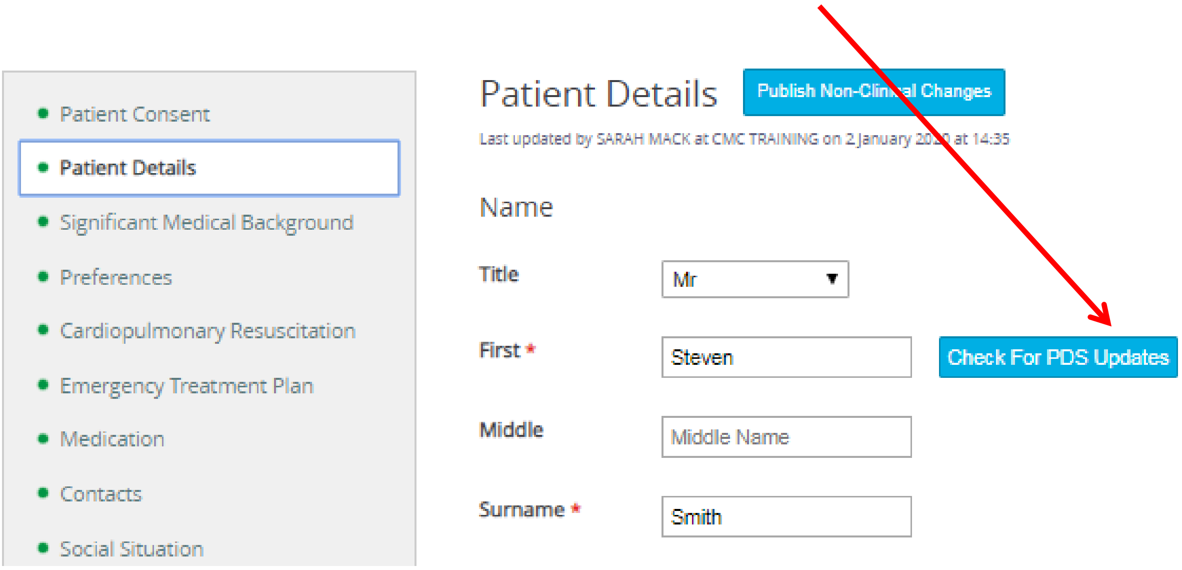
It is important to record a patient’s death on CMC, not only for quality data collection but for yourselves in monitoring and managing your list of CMC care plans.

How to update patient address as they are no longer associated with your organisation



Select update a Edit Draft Care Plan next to a named CMC plan

Then select Check For PDS Updates which allows you to identify the



Last updated by SARAH MACK at CMC TRAINING on 2 January 2020 at 14:35

Name

Title: Mr

First *: Steven

Middle: Middle Name

Surname *: Smith

new address

MyCMC

Patients are able to begin their own care plans on coordinatemycare@nhs.net

There is a brilliant video explaining CPR/DNAR. Once a patient has completed this process they will contact you and you simply log into CMC and will see the care plan pending approval.

Training

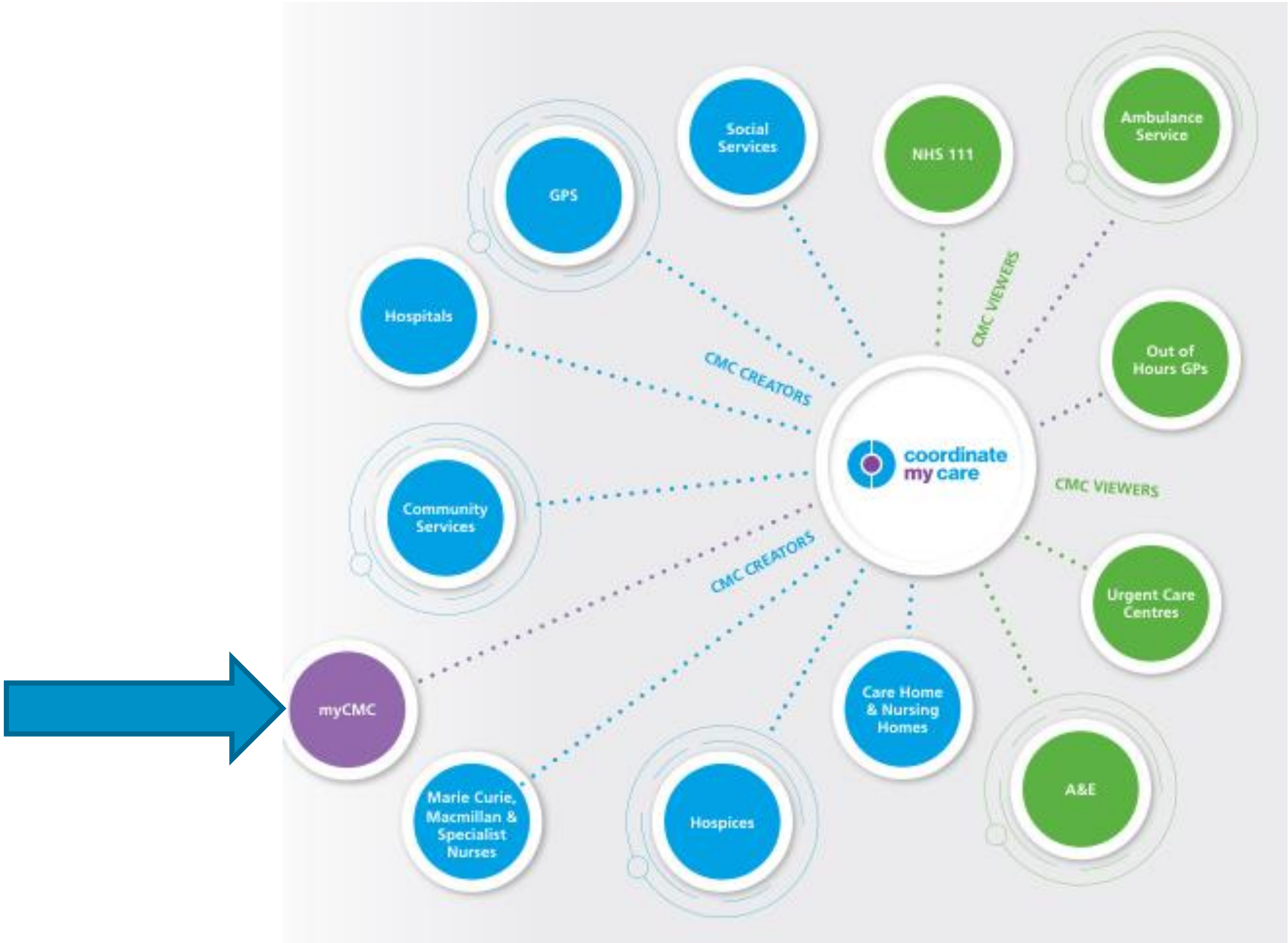
Face to Face: You can request this through coordinatemycare@nhs.net or via your End of Life Care Clinical Lead locally. For Brent as of January 2020 this is Dr Lyndsey Williams: lyndseywilliams@nhs.net. These can be undertaken at practice, PCN, CCG or STP collaborative.

Webinars: Under the 'Training' Tab on coordinatemycare.co.uk

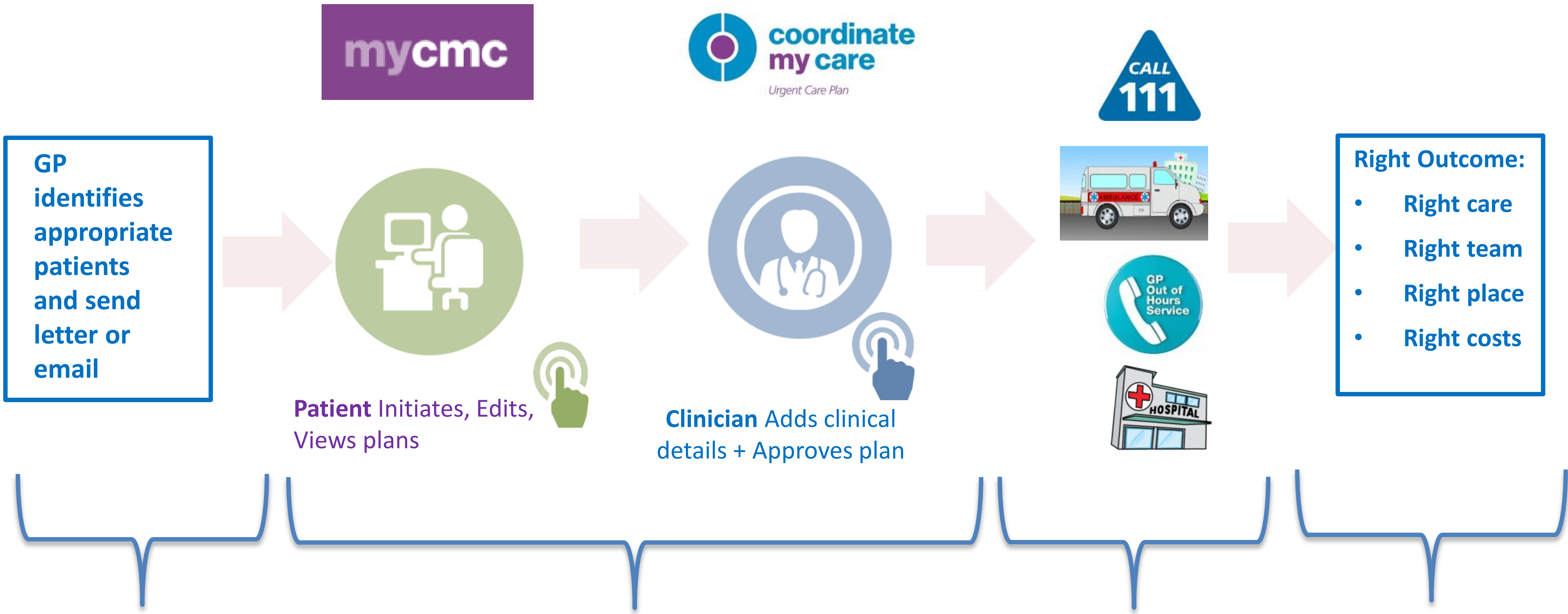
Online: Under the 'Training' Tab on coordinatemycare.co.uk. At the bottom of the page are excellent youtube tutorials on mental capacity and DNAR/CPR decision.

What is CMC?	Co-ordinate My Care is a London wide online digital Urgent Care Plan. It is created by Healthcare professionals (N3) for people who may need their care plans shared with an acute service (e.g LAS, OOH GP's,111). It can also be created by patient themselves – MyCMC - https://www.coordinatemycare.co.uk/mycmc/
What is CMC in context or configuration?	It is a link to CMC from within other IT systems such as EMIS/SystemOne/Adastra etc. You can access it when you open a patient's medical records. It is a small CMC logo (top left). Unfortunately this is not full integration but it is a step towards it. To set up your IT system's CMC in context link go to: https://www.coordinatemycare.co.uk/for-healthcare-professionals/links-to-other-nhs-it-systems/ You can contact coordinatemycare@nhs.net and they will advise you on how to 'configure' your IT system with CMC.
For Individuals to access CMC	3 forms need to be completed 1. Information sharing agreement (ISA) by the Caldecott guardian or governance lead of the practice or organisation: https://www.coordinatemycare.co.uk/joining-cmc/ 2. Submit the form online and tick the disclaimer/training waiver option or batch log-in request. Batch log ins need to be submitted by 9am Thursday for issue of log-ins close of Friday. Or submit by 9am Monday for issue of log-ins by close of Tuesday. https://www.coordinatemycare.co.uk/user-access/ 3. Training completion or Waiver training form if you have not had training. Without the waiver form or CMC training CMC will not provide you with a login
Training on CMC	On the coordinate my care website there is a 'Training' tab. It lists all the training that is available. Local End of Life Care Leads and other EOLC stakeholders such as local hospices may also be able to support you https://www.coordinatemycare.co.uk/for-healthcare-professionals/training/ There is a 5 minute video. There are also short PDF guides on how to log in, creating a new care plan, viewing a care plan, working from within another IT system, reviewing, updating and recording death and managing patient lists.
SMART card Login	If you provide CMC with your SMART card ID they will link it with your CMC user login. The first time you access CMC either via the web or through your IT system you will be asked for your login but then never again. Email coordinatemycare@nhs.net to link your SMART card.
HELP	02088118513 is the 24/7 helpline http://coordinatemycare.co.uk/healthcare-professionals coordinatemycare@nhs.net

Letting the patients do the hard work in the privacy of their own home. myCMC enables patients to record their key contacts, wishes and preferences. It supports them to think through concepts such as resuscitation (aided by videos online). This helps clinicians because patients will have started thinking through difficult decisions with their family and friends before coming to the surgery for their consultations to complete their CMC plan.



How myCMC works



GP identifies appropriate patients and send letter or email

Patient Initiates, Edits, Views plans

Clinician Adds clinical details + Approves plan

Right Outcome:

- **Right care**
- **Right team**
- **Right place**
- **Right costs**

Identification

Prospective through AI, MDTs or individual selection

Shared Decision Makers

Shared Information

Shared Benefits

Step 1

Practice **IDENTIFIES** patients and sends a **LETTER** or **EMAIL** to patients; frail, end of life care, heart failure, COPD……

PRACTICE ADDRESS
date

Dear XXX

You have been identified by your GP as someone who might benefit from having an Urgent Care Plan. This is a plan where you express your personal wishes about your care, you tell us who to contact in an emergency and you help the urgent care services to know about you.

If you are interested in starting a plan, please go on line to www.mycmc.online and start your questionnaire. Once you have completed it, press the submit button and your plan will come to the GP surgery. Then make a telephone appointment with your GP and we will complete your plan by adding your diagnosis, medications you take and what to do in an emergency. Your plan is then approved and it is called a Coordinate My Care (CMC) plan . Your CMC plan is immediately available for all the urgent care services to see when they need to. This includes 111, the out of hours GPs, the ambulance service and the Emergency Departments across London.

CMC is what it says on the tin – it coordinates the care around you.

You may like to print off the leaflet attached so you can read through it and discuss it with your family before you get started. https://www.coordinatemycare.co.uk/wp-content/uploads/2019/11/CMC_Patient_Flyer_Artwork_v11.pdf

For more information about Coordinate My Care you can access a step-by-step guide on our website at coordinatemycare.co.uk. Click on the myCMC tab and then look for the purple button which reads ‘View step-by-step guide’.

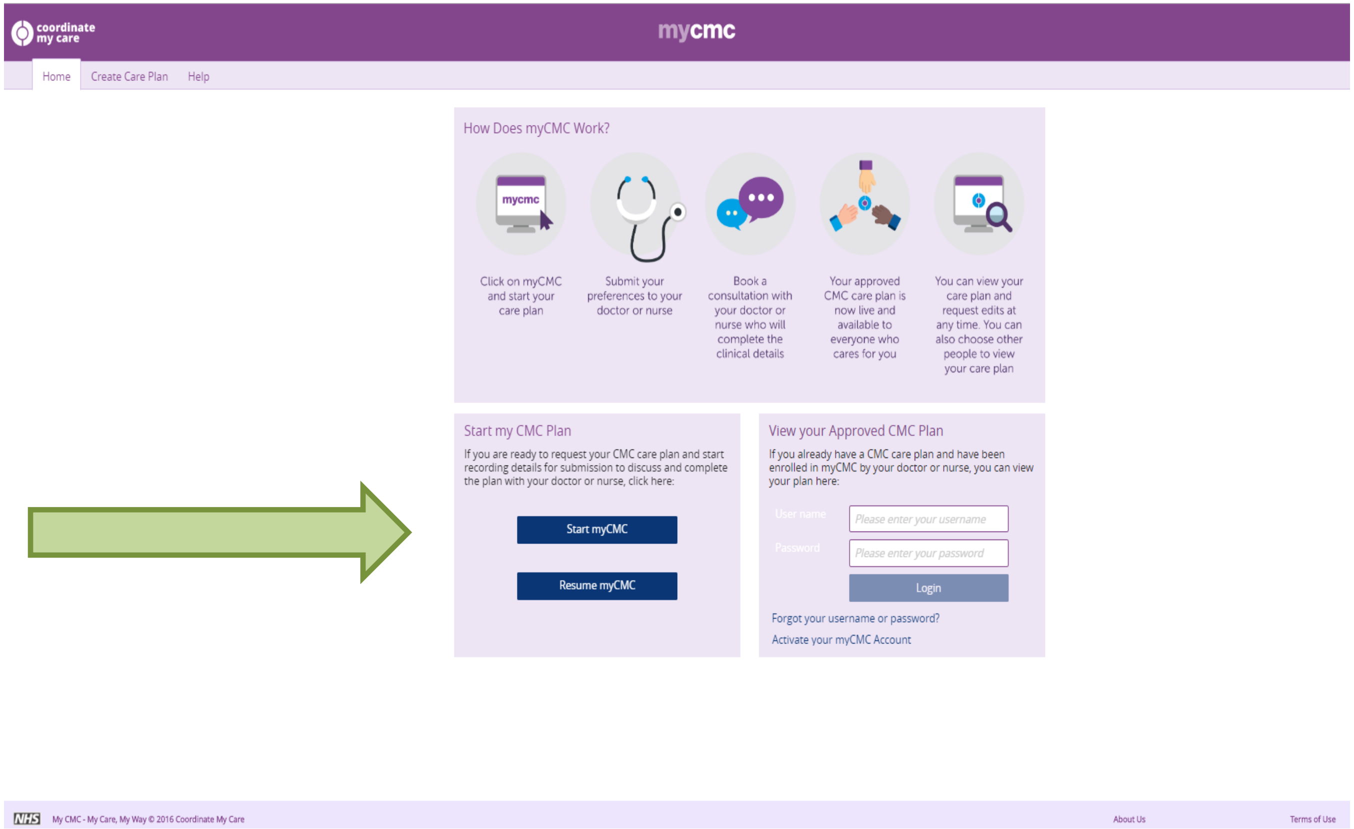
At times when the surgery is closed, if you need help and you call 111, 999 or the out of hours GP services they will all be able to access your CMC plan and know how to help you in an emergency.
If you have any queries please do not hesitate to call the surgery.

Step 2

Patient goes online

mycmc

Patient goes online to www.mycmc.online



How Does myCMC Work?

- Click on myCMC and start your care plan
- Submit your preferences to your doctor or nurse
- Book a consultation with your doctor or nurse who will complete the clinical details
- Your approved CMC care plan is now live and available to everyone who cares for you
- You can view your care plan and request edits at any time. You can also choose other people to view your care plan

Start my CMC Plan

If you are ready to request your CMC care plan and start recording details for submission to discuss and complete the plan with your doctor or nurse, click here:

View your Approved CMC Plan

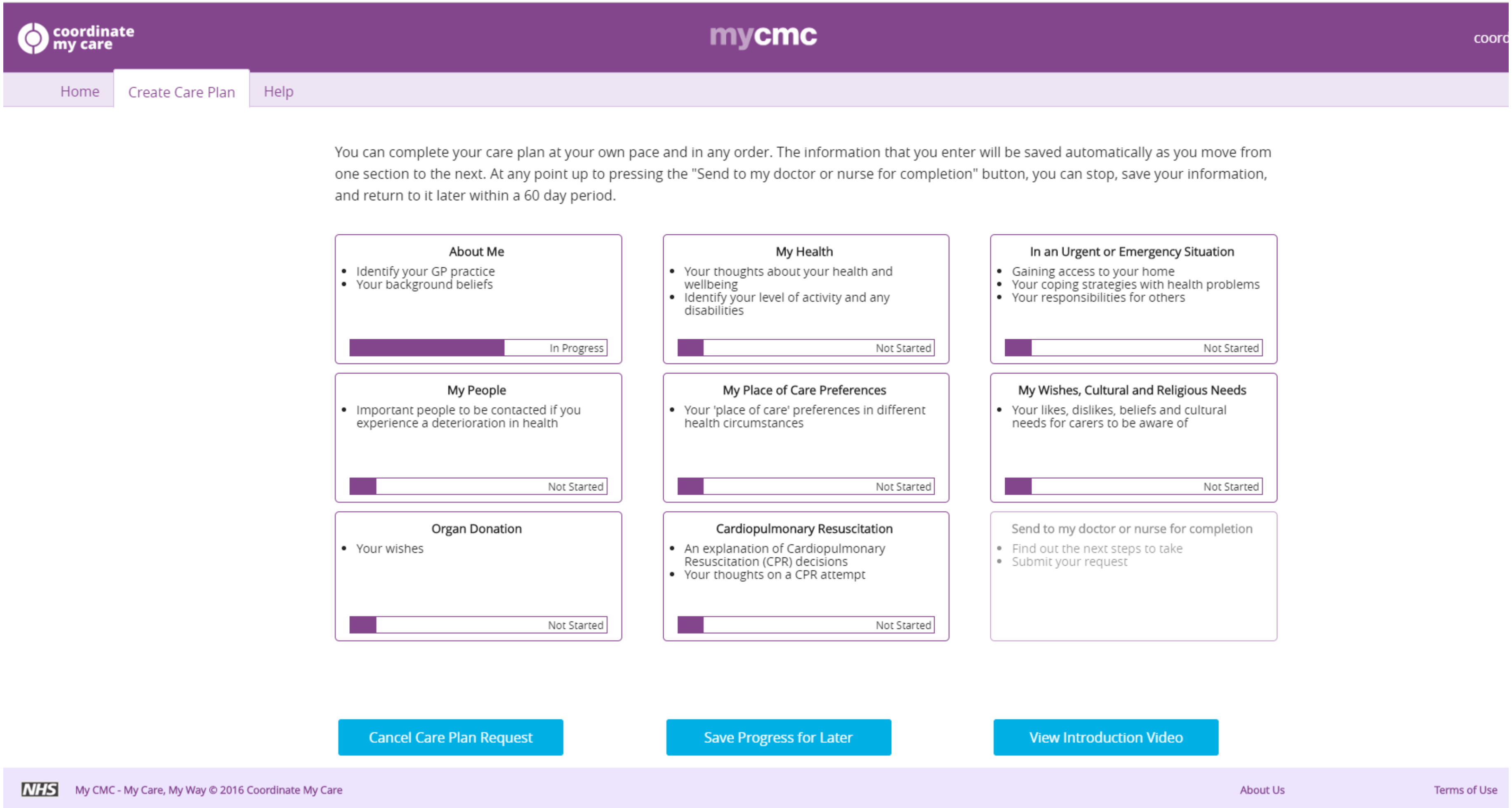
If you already have a CMC care plan and have been enrolled in myCMC by your doctor or nurse, you can view your plan here:

User name: Please enter your username
Password: Please enter your password

NHS My CMC - My Care, My Way © 2016 Coordinate My Care

Step 3

Patient fills in online questionnaire



You can complete your care plan at your own pace and in any order. The information that you enter will be saved automatically as you move from one section to the next. At any point up to pressing the "Send to my doctor or nurse for completion" button, you can stop, save your information, and return to it later within a 60 day period.

About Me
- Identify your GP practice
- Your background beliefs

In Progress

My Health
- Your thoughts about your health and wellbeing
- Identify your level of activity and any disabilities

Not Started

In an Urgent or Emergency Situation
- Gaining access to your home
- Your coping strategies with health problems
- Your responsibilities for others

Not Started

My People
- Important people to be contacted if you experience a deterioration in health

Not Started

My Place of Care Preferences
- Your 'place of care' preferences in different health circumstances

Not Started

My Wishes, Cultural and Religious Needs
- Your likes, dislikes, beliefs and cultural needs for carers to be aware of

Not Started

Organ Donation
- Your wishes

Not Started

Cardiopulmonary Resuscitation
- An explanation of Cardiopulmonary Resuscitation (CPR) decisions
- Your thoughts on a CPR attempt

Not Started

Send to my doctor or nurse for completion
- Find out the next steps to take
- Submit your request

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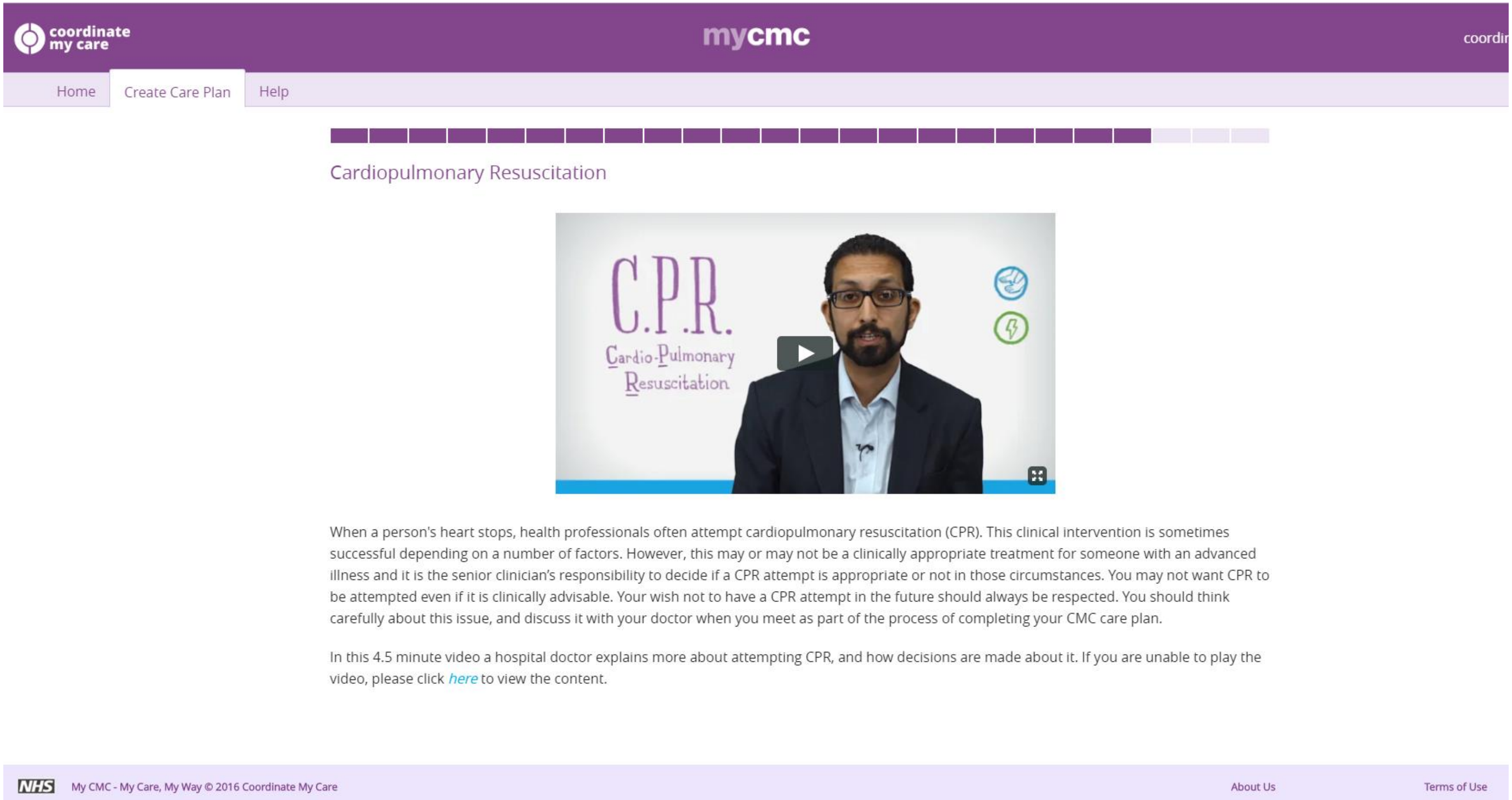
About Us

Terms of Use

Step 4

Patient listens to videos explaining resuscitation and fills in their preference (CPR is a medical decision but it's helpful for GPs to know what their patient is thinking)



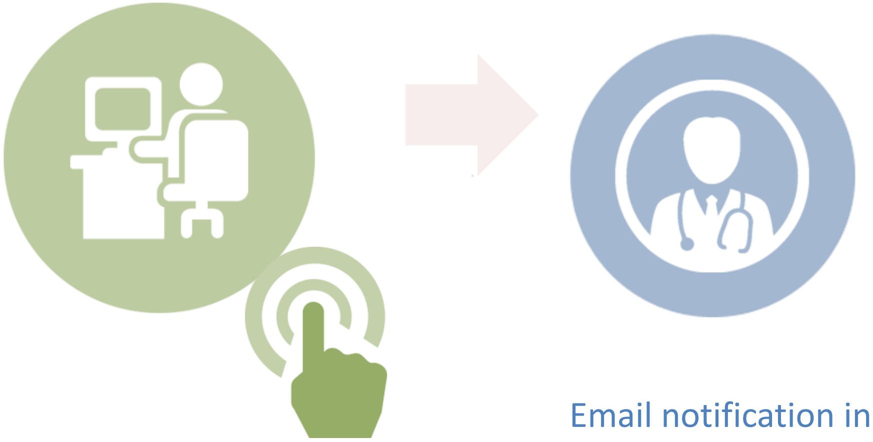
Cardiopulmonary Resuscitation

When a person's heart stops, health professionals often attempt cardiopulmonary resuscitation (CPR). This clinical intervention is sometimes successful depending on a number of factors. However, this may or may not be a clinically appropriate treatment for someone with an advanced illness and it is the senior clinician's responsibility to decide if a CPR attempt is appropriate or not in those circumstances. You may not want CPR to be attempted even if it is clinically advisable. Your wish not to have a CPR attempt in the future should always be respected. You should think carefully about this issue, and discuss it with your doctor when you meet as part of the process of completing your CMC care plan.

In this 4.5 minute video a hospital doctor explains more about attempting CPR, and how decisions are made about it. If you are unable to play the video, please click *here* to view the content.

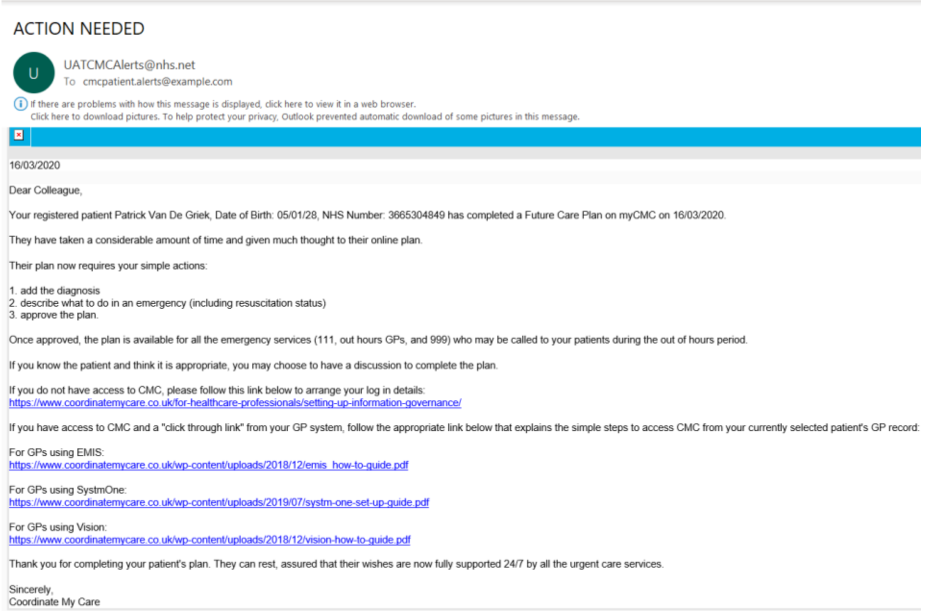
Step 5

Patient completes myCMC questionnaire and presses submit – **myCMC** sends an automated alert to GP practice email address (see below) to notify GP to finalised the draft care plan for the patient



submit

Email notification in GP practice email tray



ACTION NEEDED

UATCMCAlerts@nhs.net
To cmcpatient.alerts@example.com

If there are problems with how this message is displayed, click here to view it in a web browser.
Click here to download pictures. To help protect your privacy, Outlook prevented automatic download of some pictures in this message.

16/03/2020

Dear Colleague,

Your registered patient Patrick Van De Griek, Date of Birth: 05/01/28, NHS Number: 3665304849 has completed a Future Care Plan on myCMC on 16/03/2020.

They have taken a considerable amount of time and given much thought to their online plan.

Their plan now requires your simple actions:

1. add the diagnosis
2. describe what to do in an emergency (including resuscitation status)
3. approve the plan.

Once approved, the plan is available for all the emergency services (111, out hours GPs, and 999) who may be called to your patients during the out of hours period.

If you know the patient and think it is appropriate, you may choose to have a discussion to complete the plan.

If you do not have access to CMC, please follow this link below to arrange your log in details:
https://www.coordinatemycare.co.uk/for-healthcare-professionals/setting-up-information-governance/

If you have access to CMC and a "click through link" from your GP system, follow the appropriate link below that explains the simple steps to access CMC from your currently selected patient's GP record:

For GPs using EMIS:
https://www.coordinatemycare.co.uk/wp-content/uploads/2018/12/emis_how-to-guide.pdf

For GPs using SystmOne:
https://www.coordinatemycare.co.uk/wp-content/uploads/2019/07/systm-one-set-up-guide.pdf

For GPs using Vision:
https://www.coordinatemycare.co.uk/wp-content/uploads/2018/12/vision-how-to-guide.pdf

Thank you for completing your patient's plan. They can rest, assured that their wishes are now fully supported 24/7 by all the urgent care services.

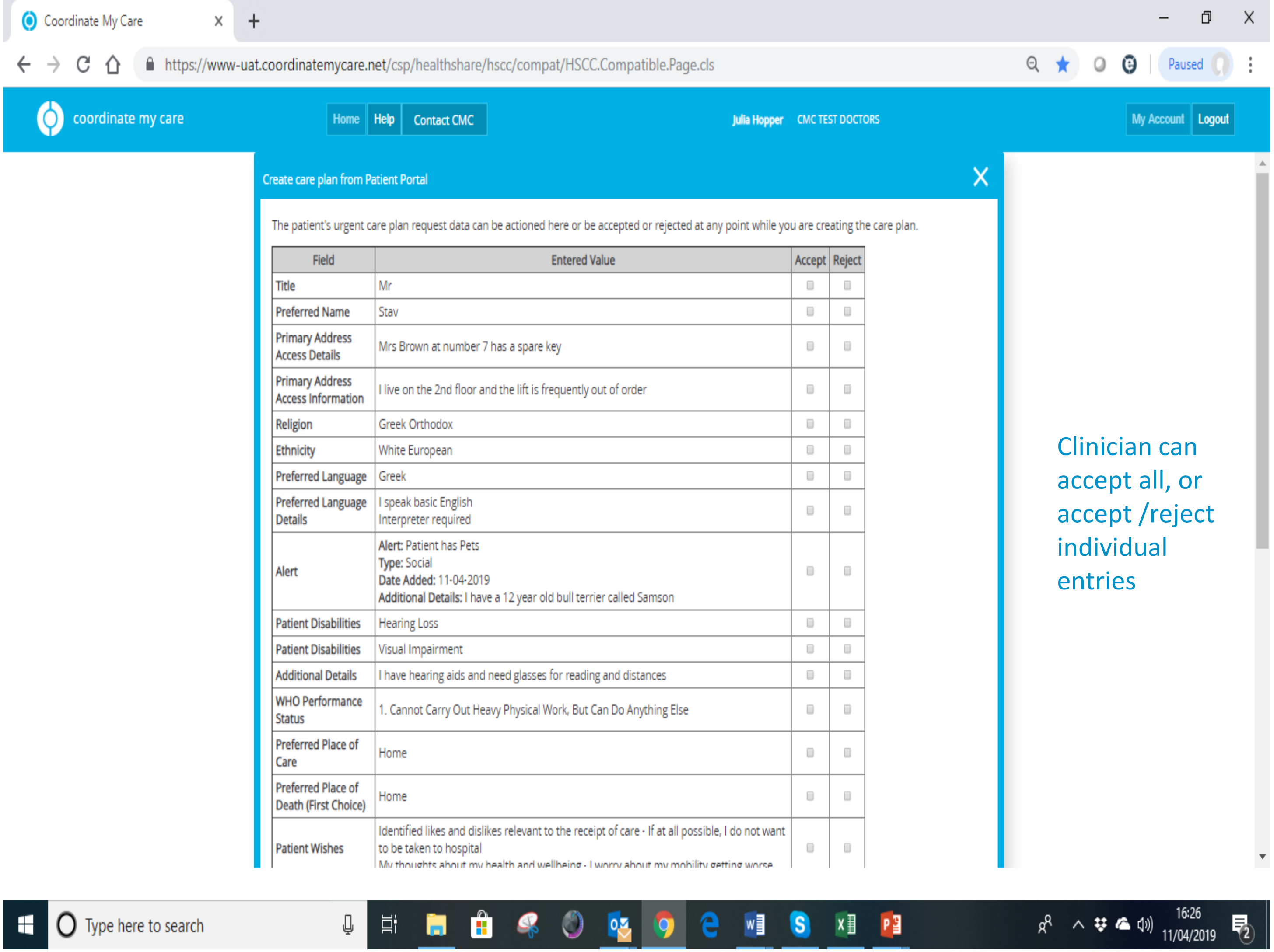
Sincerely,
Coordinate My Care

Step 6

Patient makes appointment with GP or Practice Nurse alone or with family/friend

Step 7

GP opens patient's EPR (EMIS, Vision or TPP), clicks into CMC and sees summary of patient's myCMC plan



Create care plan from Patient Portal

The patient's urgent care plan request data can be actioned here or be accepted or rejected at any point while you are creating the care plan.

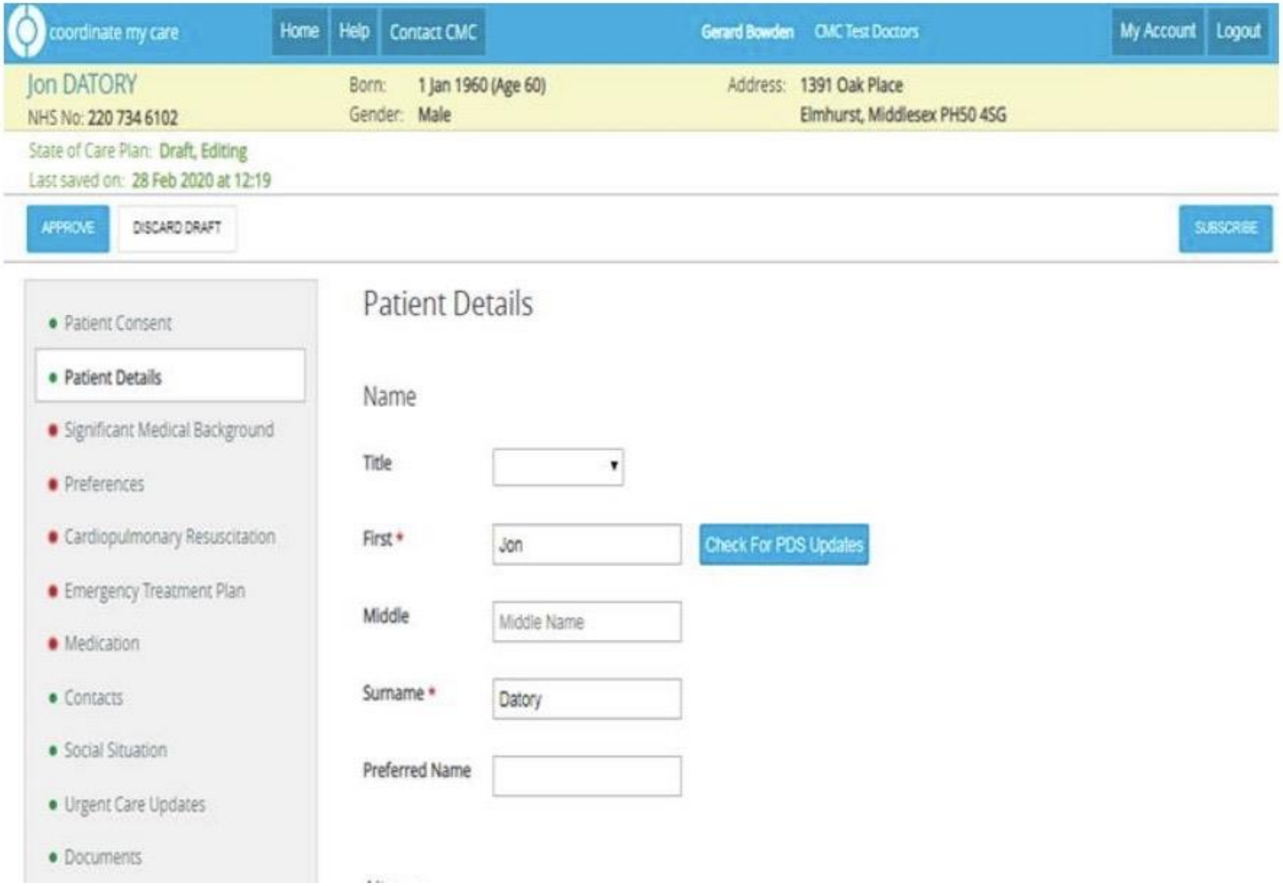
Field	Entered Value	Accept	Reject
Title	Mr	☐	☐
Preferred Name	Stav	☐	☐
Primary Address Access Details	Mrs Brown at number 7 has a spare key	☐	☐
Primary Address Access Information	I live on the 2nd floor and the lift is frequently out of order	☐	☐
Religion	Greek Orthodox	☐	☐
Ethnicity	White European	☐	☐
Preferred Language	Greek	☐	☐
Preferred Language Details	I speak basic English Interpreter required	☐	☐
Alert	**Alert:** Patient has Pets **Type:** Social **Date Added:** 11-04-2019 **Additional Details:** I have a 12 year old bull terrier called Samson	☐	☐
Patient Disabilities	Hearing Loss	☐	☐
Patient Disabilities	Visual Impairment	☐	☐
Additional Details	I have hearing aids and need glasses for reading and distances	☐	☐
WHO Performance Status	1. Cannot Carry Out Heavy Physical Work, But Can Do Anything Else	☐	☐
Preferred Place of Care	Home	☐	☐
Preferred Place of Death (First Choice)	Home	☐	☐
Patient Wishes	Identified likes and dislikes relevant to the receipt of care - If at all possible, I do not want to be taken to hospital My thoughts about my health and wellbeing - I worry about my mobility getting worse	☐	☐

Clinician can accept all, or accept /reject individual entries

Step 8

All accepted entries auto-populate directly into the patient’s CMC plan

Clinician fills in mandatory fields; Medical background, CPR and emergency treatment plan. (Medications will auto-populate from GP system by the Autumn 2020)



Jon DATORY
NHS No: 220 734 6102
Born: 1 Jan 1960 (Age 60)
Gender: Male
Address: 1391 Oak Place
Elmhurst, Middlesex PH50 4SG
State of Care Plan: Draft, Editing
Last saved on: 28 Feb 2020 at 12:19

Patient Details

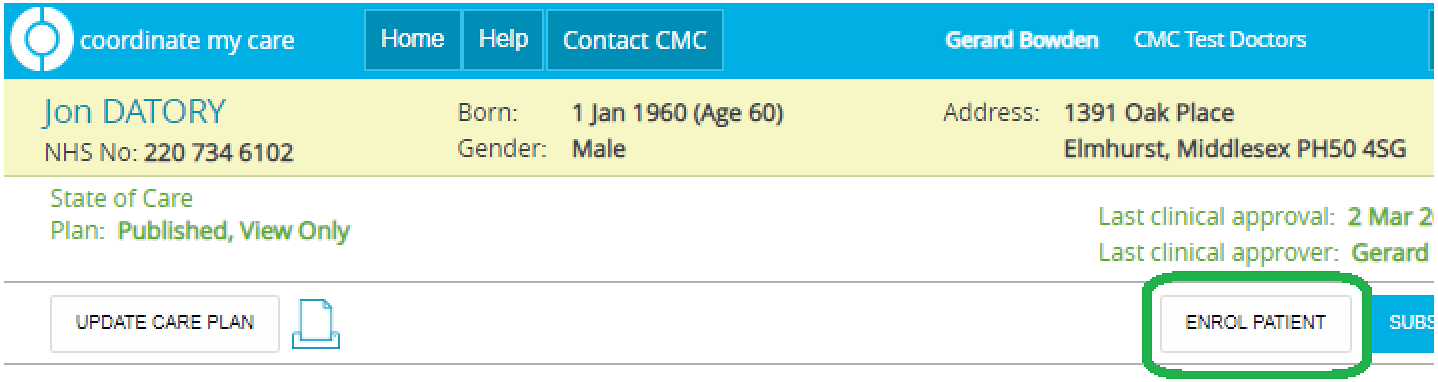
Name

Title
First * Jon
Middle Middle Name
Surname * Datory
Preferred Name

Step 9

GP enrols the patient to view their care plan – 30 seconds

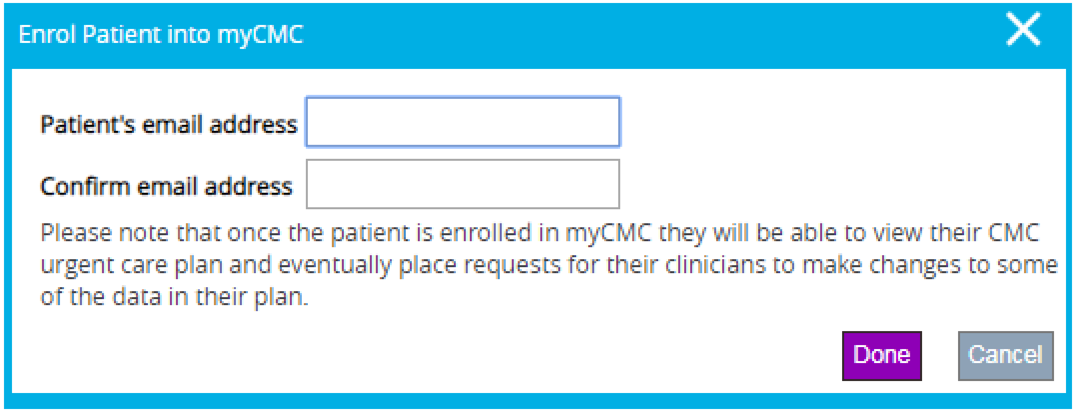
Once enrolled the patient can view their own care plan on their smart phone or other personal device.



Jon DATORY
NHS No: 220 734 6102
Born: 1 Jan 1960 (Age 60)
Gender: Male
Address: 1391 Oak Place
Elmhurst, Middlesex PH50 4SG

State of Care
Plan: Published, View Only

Last clinical approval: 2 Mar 2
Last clinical approver: Gerard



Patient's email address

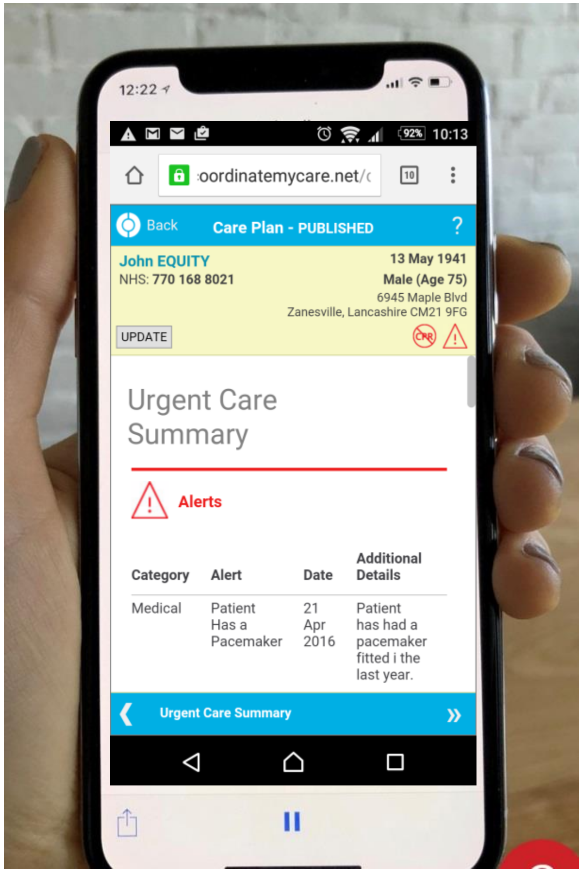
Confirm email address

Please note that once the patient is enrolled in myCMC they will be able to view their CMC urgent care plan and eventually place requests for their clinicians to make changes to some of the data in their plan.

Step 10

Patient views same urgent care plan on smartphone as seen by all urgent care services e.g. paramedic in the ambulance vehicle

Patient


12:22

10:13 92%

oordinatemycare.net/c

Back Care Plan - PUBLISHED ?

John EQUITY 13 May 1941
NHS: **770 168 8021** **Male (Age 75)**
6945 Maple Blvd
Zanesville, Lancashire CM21 9FG

UPDATE

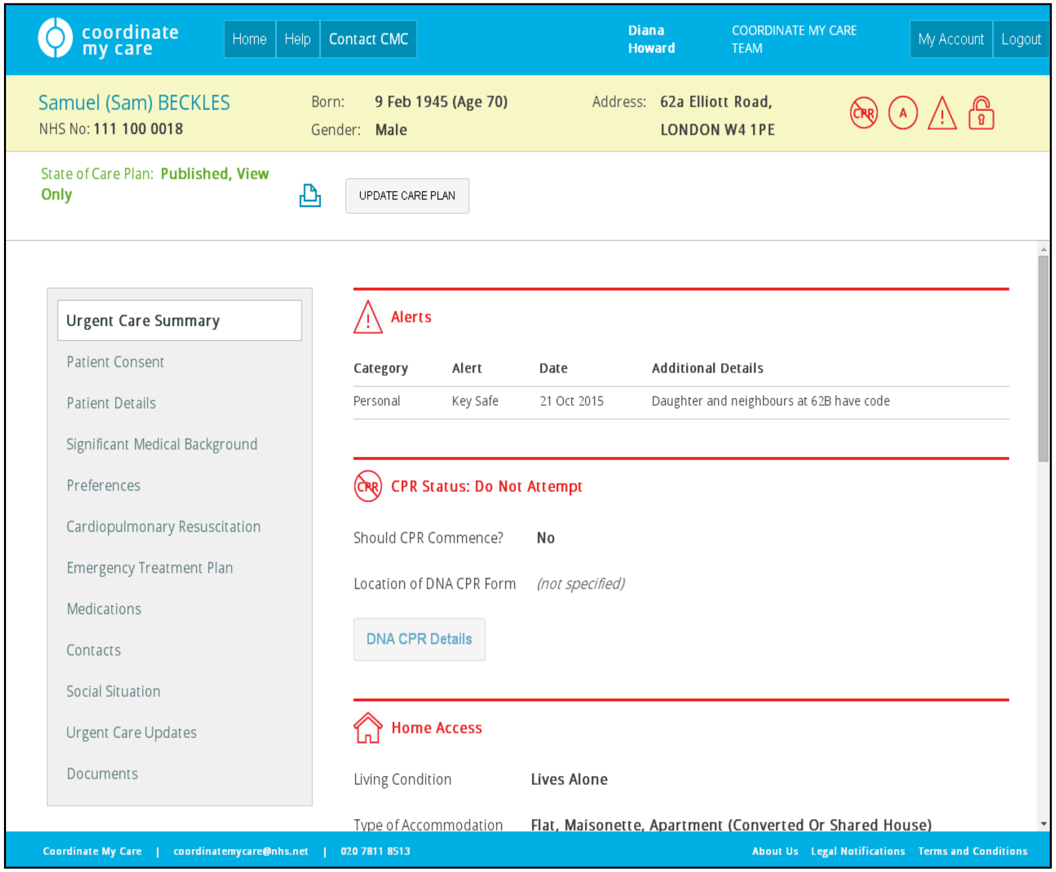
Urgent Care Summary

Alerts

Category	Alert	Date	Additional Details
Medical	Patient Has a Pacemaker	21 Apr 2016	Patient has had a pacemaker fitted i the last year.

❮ Urgent Care Summary »

111, 999, OOH GPs, GPs, EDs



Diana Howard COORDINATE MY CARE TEAM

Samuel (Sam) BECKLES
NHS No: **111 100 0018**
Born: **9 Feb 1945 (Age 70)**
Gender: **Male**
Address: **62a Elliott Road, LONDON W4 1PE**

State of Care Plan: **Published, View Only**

UPDATE CARE PLAN

Alerts

Category	Alert	Date	Additional Details
Personal	Key Safe	21 Oct 2015	Daughter and neighbours at 62B have code

CPR Status: Do Not Attempt

Should CPR Commence? **No**

Location of DNA CPR Form *(not specified)*

DNA CPR Details

Home Access

Living Condition **Lives Alone**

Type of Accommodation **Flat, Maisonette, Apartment (Converted Or Shared House)**

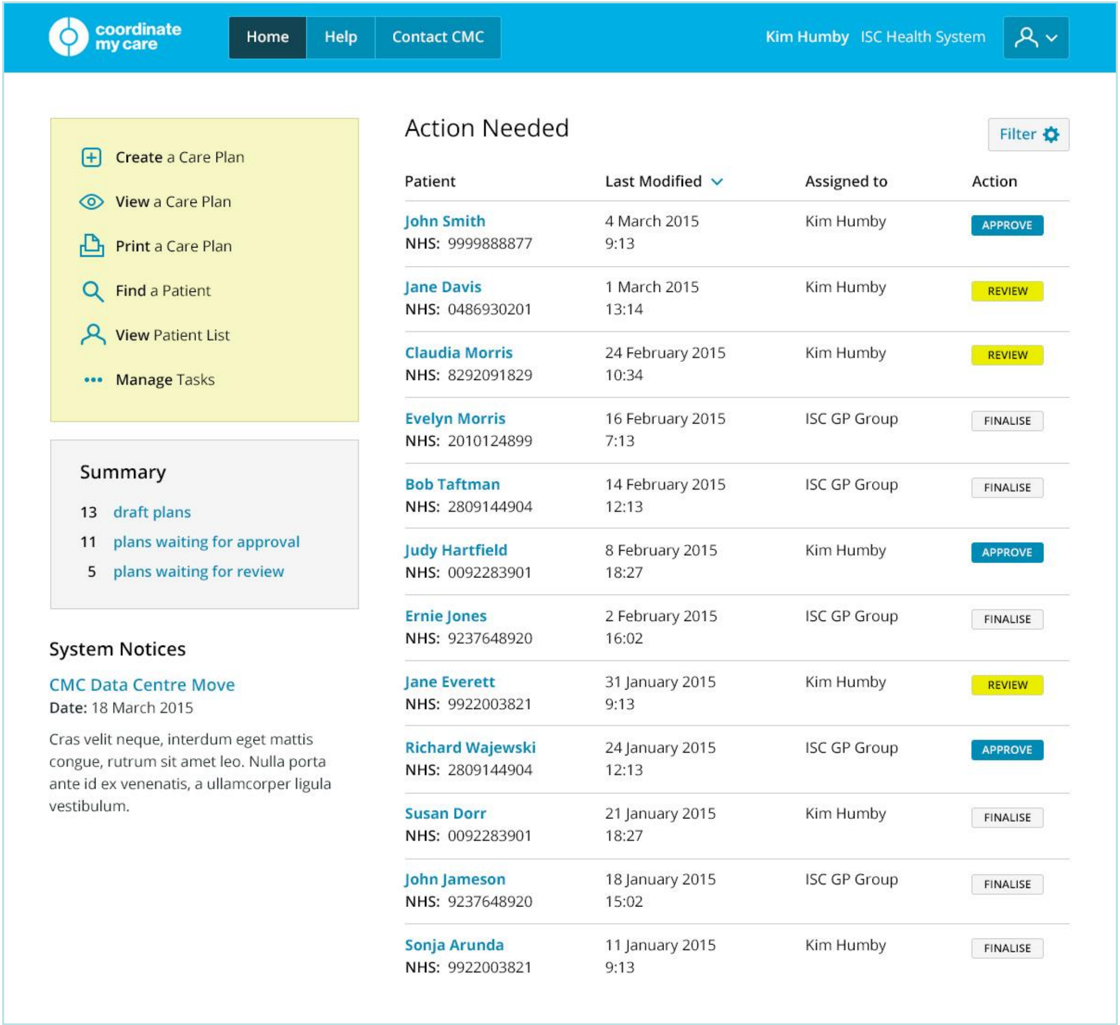
Coordinate My Care | coordinatemycare@nhs.net | 020 7811 8513 About Us Legal Notifications Terms and Conditions

Step 11

Everyone is joined up – CMC is a single version of the truth

Step 11

GP can use the CMC list to review all the plans at MDT e.g. at end of life care, heart failure, COPD meetings



Action Needed

Patient	Last Modified	Assigned to	Action
John Smith NHS: 9999888877	4 March 2015 9:13	Kim Humby	APPROVE
Jane Davis NHS: 0486930201	1 March 2015 13:14	Kim Humby	REVIEW
Claudia Morris NHS: 8292091829	24 February 2015 10:34	Kim Humby	REVIEW
Evelyn Morris NHS: 2010124899	16 February 2015 7:13	ISC GP Group	FINALISE
Bob Taftman NHS: 2809144904	14 February 2015 12:13	ISC GP Group	FINALISE
Judy Hartfield NHS: 0092283901	8 February 2015 18:27	Kim Humby	APPROVE
Ernie Jones NHS: 9237648920	2 February 2015 16:02	ISC GP Group	FINALISE
Jane Everett NHS: 9922003821	31 January 2015 9:13	Kim Humby	REVIEW
Richard Wajewski NHS: 2809144904	24 January 2015 12:13	ISC GP Group	APPROVE
Susan Dorr NHS: 0092283901	21 January 2015 18:27	Kim Humby	FINALISE
John Jameson NHS: 9237648920	18 January 2015 15:02	ISC GP Group	FINALISE
Sonja Arunda NHS: 9922003821	11 January 2015 9:13	Kim Humby	FINALISE

Summary

13 draft plans
11 plans waiting for approval
5 plans waiting for review

System Notices

CMC Data Centre Move
Date: 18 March 2015

Cras velit neque, interdum eget mattis congue, rutrum sit amet leo. Nulla porta ante id ex venenatis, a ullamcorper ligula vestibulum.

Advantages of CMC

PATIENTS

- Have a voice
- Take time to watch videos and understand concepts such as resuscitation
- Start difficult 'conversation' with their families/carers as they create their plans in their own homes
- Supported 24/7 even when GP surgery is closed
- Are not strangers to the urgent care services

DOCTORS/NURSES

- Do not have to start the conversations, patients arrive at consultation prepared
- Patients have done the hard work before coming to the consultation so takes less time to complete the plan
- Patients are identified systematically so do not have to be randomly identified in a 10 minute consultation
- Avoid unnecessary admissions for their patients and delivers better care

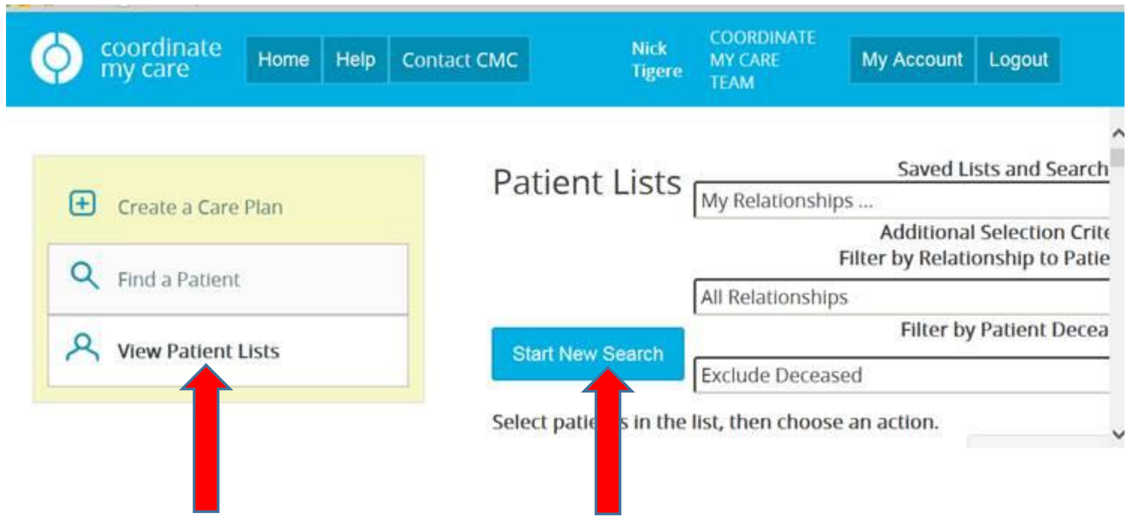
FOR FURTHER INFORMATION:

Coordinate My Care helpdesk 0207 811 8513

www.coordinatemycare.co.uk

Create a practice list to determine which patients have a CMC plan

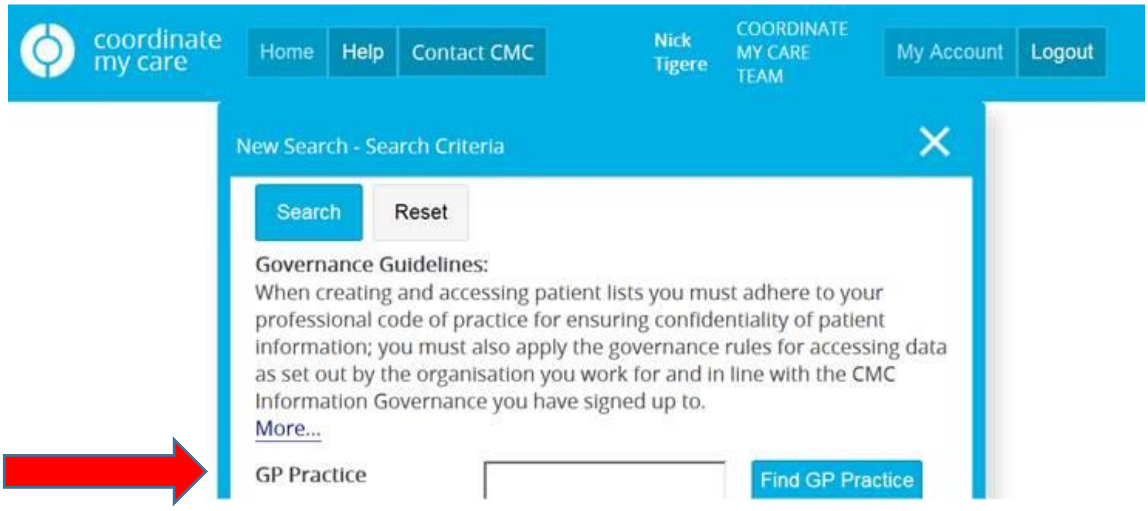
1. **Log in to CMC (via a secure N3 Portal). This cannot be done if logging in from general web browser.**



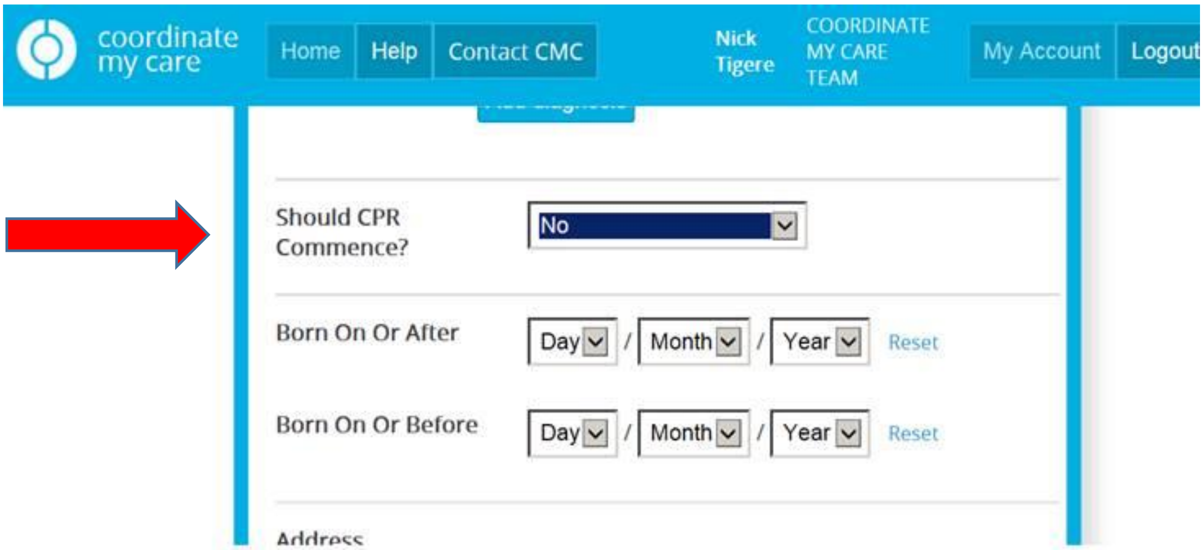
2. Click on view patient list. **3. Click on start new search**

4. Apply the relevant filters to the search. The following filters are recommended:

- GP Practice
- Should CPR commence?
- Filter by patient deceased (Exclude deceased)
- Care plan status. (Published/Draft)



Governance Guidelines:
When creating and accessing patient lists you must adhere to your professional code of practice for ensuring confidentiality of patient information; you must also apply the governance rules for accessing data as set out by the organisation you work for and in line with the CMC Information Governance you have signed up to.

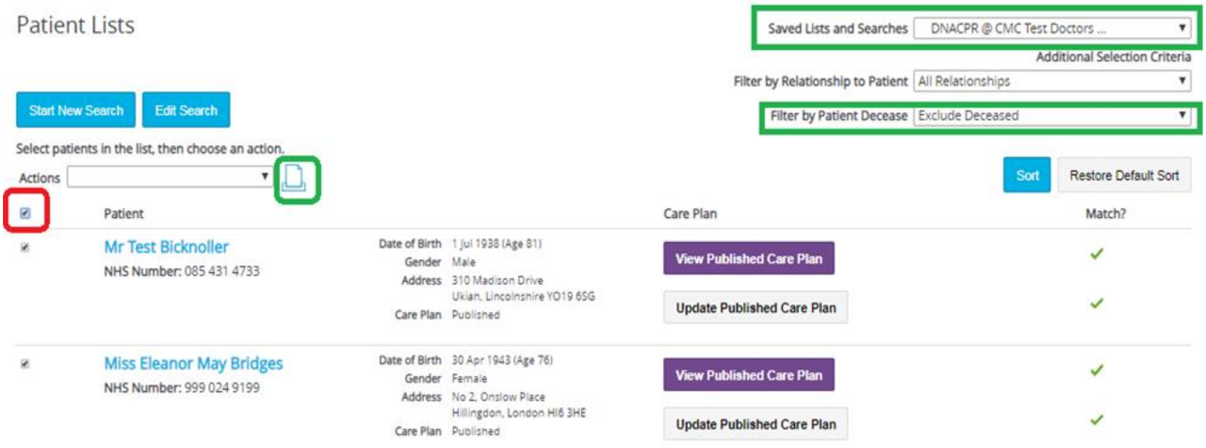


Should CPR Commence? No

Born On Or After Day / Month / Year

Born On Or Before Day / Month / Year

5. Click “Search”, which will generate a list:



Patient Lists

Saved Lists and Searches: DNACPR @ CMC Test Doctors ...

Additional Selection Criteria

Filter by Relationship to Patient: All Relationships

Filter by Patient Decease: Exclude Deceased

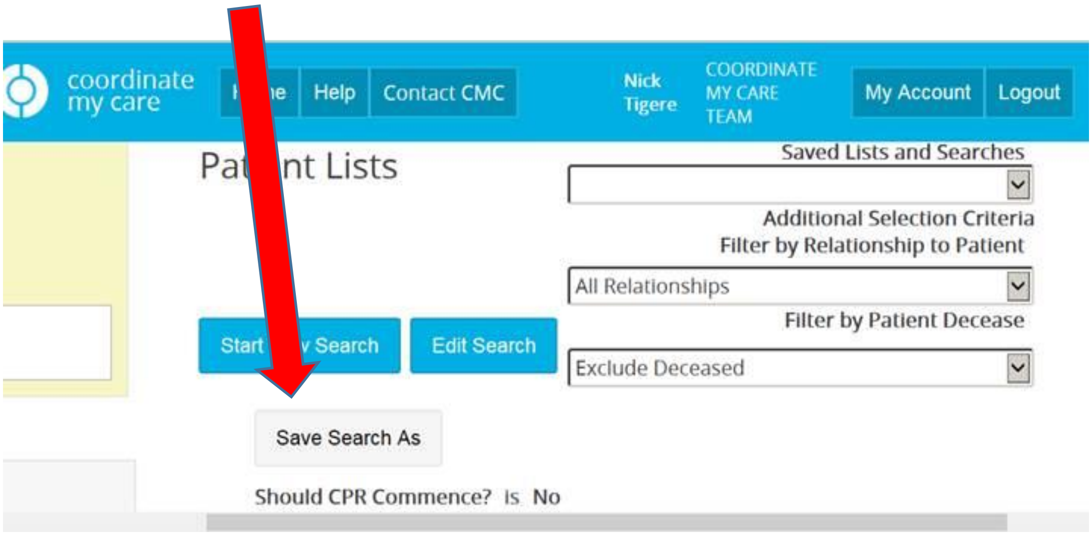
Select patients in the list, then choose an action.

Actions

☑	Patient		Care Plan	Match?
☑	Mr Test Bicknoller NHS Number: 085 431 4733	Date of Birth 1 Jul 1938 (Age 81) Gender Male Address 310 Madison Drive Ukian, Lincolnshire YO19 6SG Care Plan Published	View Published Care Plan Update Published Care Plan	✓ ✓
☑	Miss Eleanor May Bridges NHS Number: 999 024 9199	Date of Birth 30 Apr 1943 (Age 76) Gender Female Address No 2, Onslow Place Hillingdon, London HI6 3HE Care Plan Published	View Published Care Plan Update Published Care Plan	✓ ✓

Non-real data

6. Save the Search:



Saved Lists and Searches

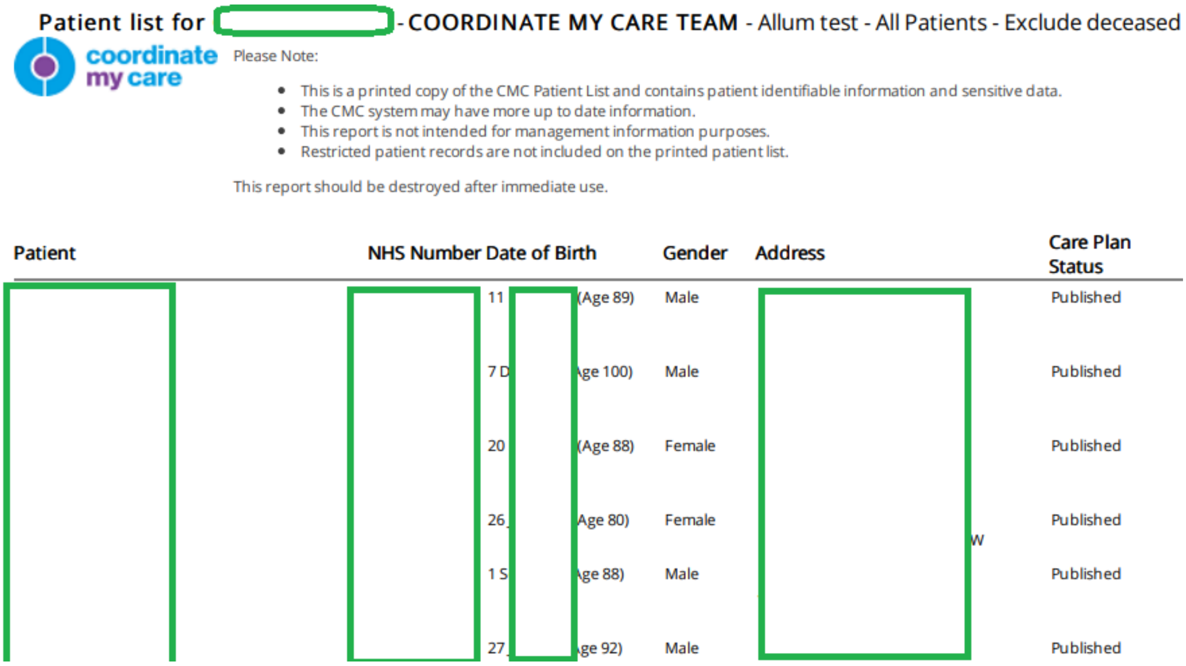
Additional Selection Criteria

Filter by Relationship to Patient: All Relationships

Filter by Patient Decease: Exclude Deceased

Should CPR Commence? is No

6. If required, download the search, which will generate a PDF:


Patient list for [redacted] **- COORDINATE MY CARE TEAM** - Allum test - All Patients - Exclude deceased

Please Note:

- This is a printed copy of the CMC Patient List and contains patient identifiable information and sensitive data.
- The CMC system may have more up to date information.
- This report is not intended for management information purposes.
- Restricted patient records are not included on the printed patient list.

This report should be destroyed after immediate use.

Patient	NHS Number	Date of Birth	Gender	Address	Care Plan Status
[redacted]	[redacted]	[redacted] (Age 89)	Male	[redacted]	Published
[redacted]	[redacted]	[redacted] Age 100)	Male	[redacted]	Published
[redacted]	[redacted]	[redacted] (Age 88)	Female	[redacted]	Published
[redacted]	[redacted]	[redacted] Age 80)	Female	[redacted]	Published
[redacted]	[redacted]	[redacted] Age 88)	Male	[redacted]	Published
[redacted]	[redacted]	[redacted] Age 92)	Male	[redacted]	Published

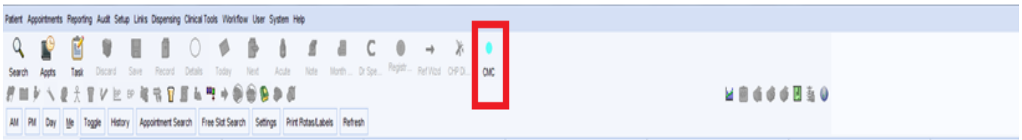
GP Practice Guide to Configure TPP SystmOne to launch the CMC System

The Coordinate My Care (CMC) system can now be launched from the TPP SystmOne in the context of the currently selected patient record using standard TPP functionality.

SystmOne users, who are also CMC users will therefore be able to create, view and update CMC urgent care plans for their patients from within SystmOne. Approved urgent care plans are viewable immediately by all urgent care services including 111, the out of hours GP services and the London Ambulance Service.

How this works:

- GP Practices and individual SystmOne users who customise their own Home pages can configure SystmOne to create a link to the CMC system.
- The TPP name and icon that you select to represent the CMC system will then appear in the SystmOne toolbar:



- When accessing a patient record in SystmOne, a user can click on the CMC icon to launch the CMC system automatically in the context of the selected patient, without having to search for or select the patient in CMC.
- Note that the TPP functionality does not support "single sign on", therefore users will still need to have a valid CMC system user account and will need to login to CMC.
- Subject to CMC user role access rights: if the SystmOne patient already has a CMC care plan, the user can view and update it; if the patient does not already have a care plan, the user can create one.

The TPP SystmOne standard functionality can be configured at your practice now. This document is a guide for GP practices and users about how to complete this configuration to enable a CMC system icon to appear in your SystmOne toolbar, which will enable you to launch the CMC system for the currently selected patient. The process should only take few minutes to complete.

Configuring SystmOne to Launch CMC

Where all users in a GP Practice have the same SystmOne Home page, this configuration needs to be done only once for all SystmOne users at the practice.

Where individual users at a GP Practice customise their Home pages, a configuration step needs to be carried out by each user.

This guide describes both the GP Practice level configuration steps and the individual user level configuration steps below.

GP Practice Level Configuration

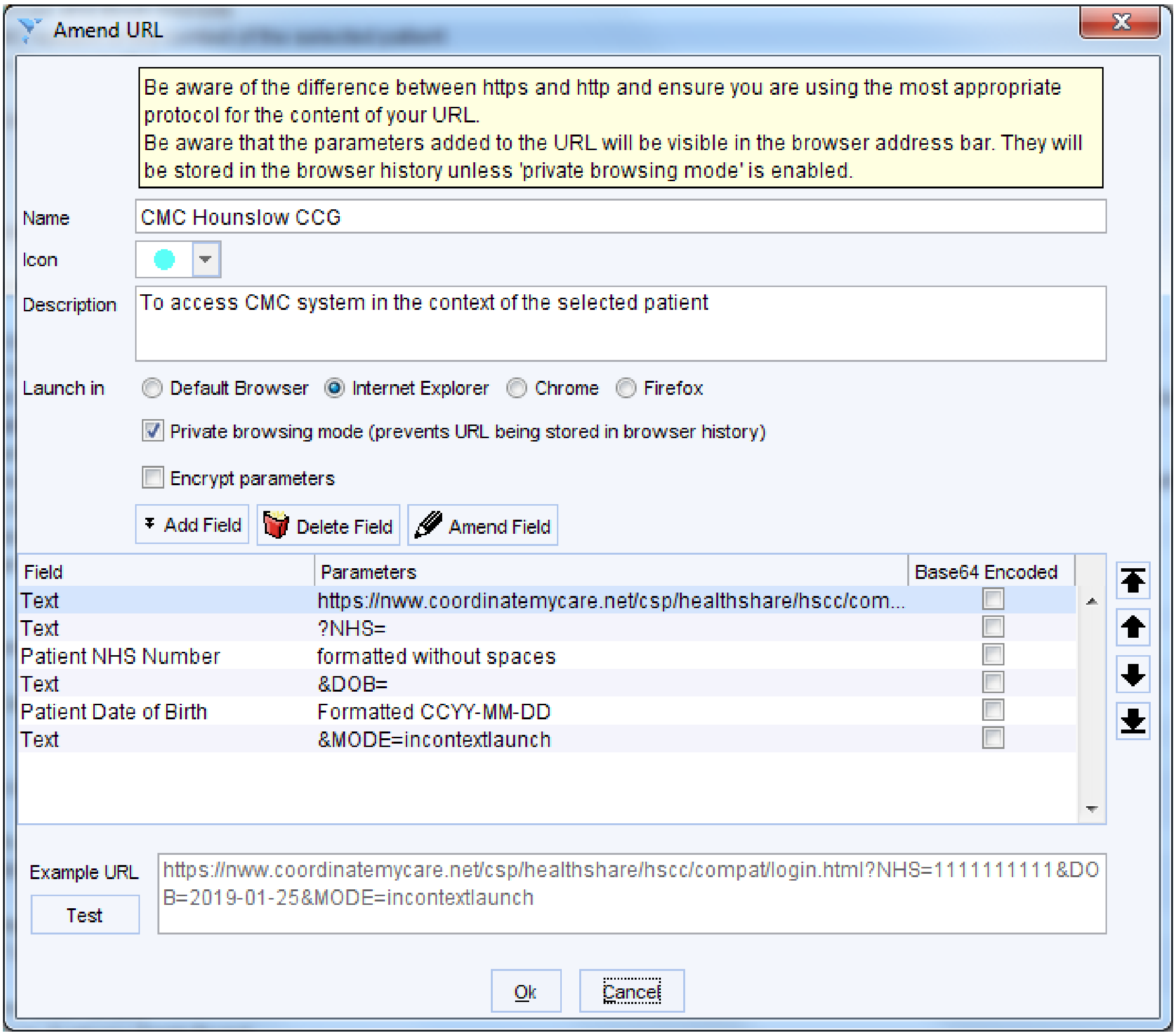
These instructions are provided from the TPP document "URL & Program Maintenance – User Guide v1.0"

To access the configuration screen within SystmOne, go to Setup > Users & Policy > URL & Program Maintenance.

SystmOne is preloaded with a number of links, which are ready for use and simply need to be added to the toolbar to be accessed.

To create the new link to the CMC system click the New URL button in the top left of the URL & Program Maintenance screen and choose the option to link to a URL.

The system will display the screen below.



Be aware of the difference between https and http and ensure you are using the most appropriate protocol for the content of your URL.
Be aware that the parameters added to the URL will be visible in the browser address bar. They will be stored in the browser history unless 'private browsing mode' is enabled.

Name: CMC Hounslow CCG

Icon: ●

Description: To access CMC system in the context of the selected patient

Launch in: ○ Default Browser ● Internet Explorer ○ Chrome ○ Firefox

☑ Private browsing mode (prevents URL being stored in browser history)

☐ Encrypt parameters

Field	Parameters	Base64 Encoded
Text	https://nww.coordinatemycare.net/csp/healthshare/hscc/com...	☐
Text	?NHS=	☐
Patient NHS Number	formatted without spaces	☐
Text	&DOB=	☐
Patient Date of Birth	Formatted CCYY-MM-DD	☐
Text	&MODE=incontextlaunch	☐

Example URL: https://nww.coordinatemycare.net/csp/healthshare/hscc/compat/login.html?NHS=1111111111&DOB=2019-01-25&MODE=incontextlaunch

To create the link to the CMC system, complete the Create URL screen as follows:

Key note:
Please make sure you read the yellow information box before continuing.

Name: enter “CMC”

Icon: select a suitable icon from the dropdown list to appear for the CMC system link in the toolbar. We recommend the pale blue circle as it resembles the colour of the CMC logo, however you may have your own preference.

Description: To launch the CMC system in the context of the currently selected patient record

Launch in: select your preferred browser, e.g. click the Internet Explorer button

Private browsing mode: set this to Yes by checking the tick box

Encrypt Parameters: set this to No by leaving the tick box unchecked

Use the Add Field button to add the following data Field types and Parameter values, as specified in the table below.

Key Note:
Please make sure you do not record any unintended space characters in the Parameters as this will result in the link not working.

In all cases leave the Base64 Encoded and Encrypted tick boxes unchecked.

Field	Parameters	Base64 Encoded	Encrypted
Text	https://nww-uat.coordinatemycare.net/csp/healthshare/hscc/compat/login.html	N	N
Text	?NHS=	N	N
Patient NHS Number	Formatted without spaces	N	N
Text	&DOB=	N	N
Patient Date of Birth	Formatted as YYYY-MM-DD	N	N
Text	&MODE=incontextlaunch	N	N

Click the Ok button to save the link to the CMC system.

This should generate the following URL:

https://nww.coordinatemycare.net/csp/healthshare/hscc/compat/login.html?NHS=1234567890&DOB=1950-12-31&MODE=incontextlaunch

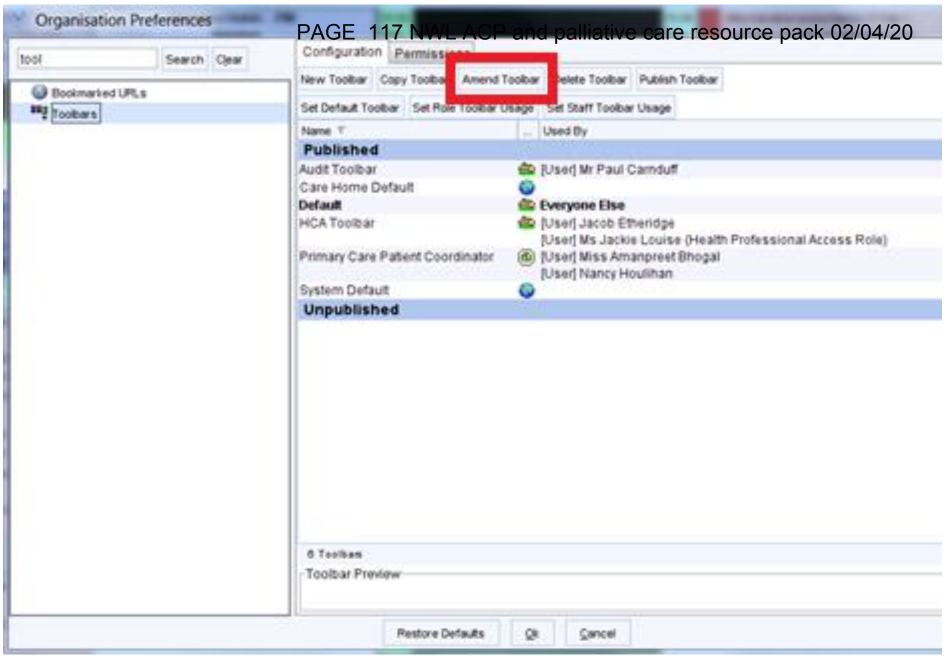
Configuring Users' Toolbars

If users in your GP Practice do not have customised Home pages, the GP practice SystmOne administrator (e.g. the Practice Manager) can complete the following simple configuration steps to get the CMC System icon to appear in the SystmOne toolbar for all users in the practice.

However, if your GP practice users do have customised Home pages, then they will each need to complete the following simple configuration steps to get the CMC system icon to appear in their Home page.

Step 1

Go to: Setup > Organisation preferences> search tool>select Toolbars >Select the toolbar to add the new CMC system icon> select Amend Toolbar>



Name	Used By
Published	
Audit Toolbar	[User] Mr Paul Carnduff
Care Home Default	
Default	**Everyone Else**
HCA Toolbar	[User] Jacob Etheridge [User] Ms Jackie Louise (Health Professional Access Role)
Primary Care Patient Coordinator	[User] Miss Amanpreet Bhogal [User] Nancy Houlihan
System Default	
Unpublished	

6 Toolbars

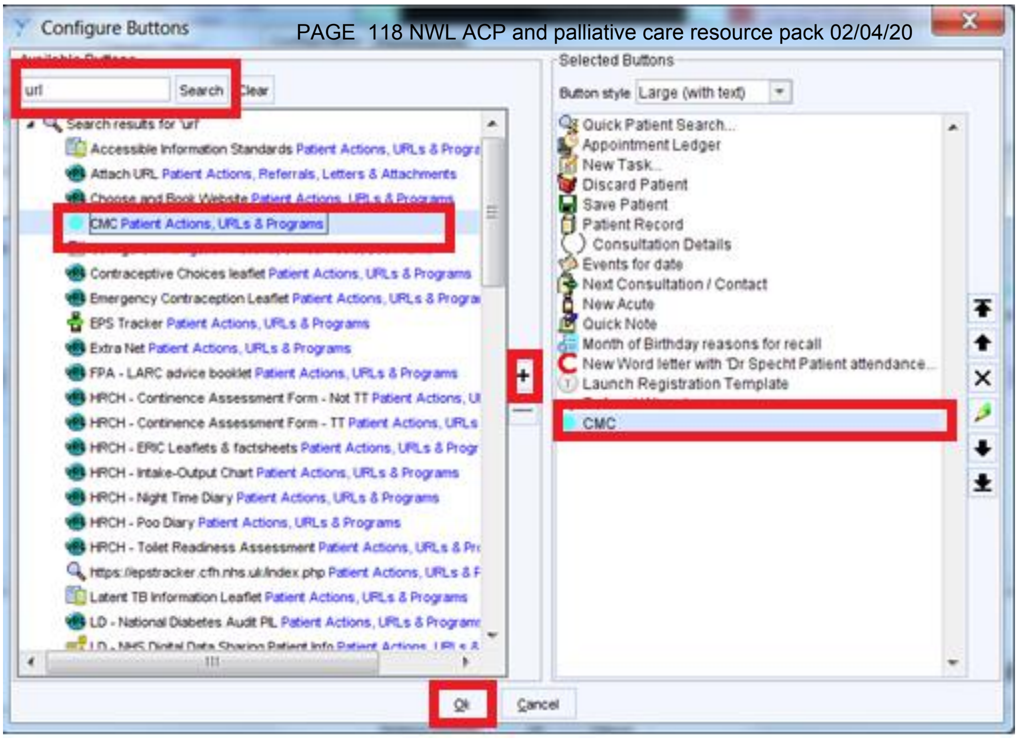
Step 2

Click Amend Button Set

Toolbar name: Default

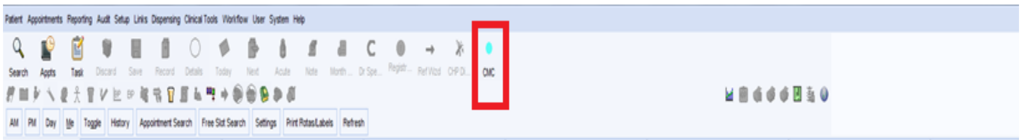
Step 3

Search URL > double click the CMC system icon or highlight and click + to move the CMC system icon into the toolbar



Click the Ok button.

The CMC system icon will now display in your toolbar, as shown below.



If you have any queries on configuring the link from TPP SystmOne to the CMC system, please do not hesitate to get in touch with the CMC Helpdesk on 0207 811 8513 or coordinatemycare@nhs.net

For any technical queries relating to TPP SystmOne and this feature specifically please contact the TPP Helpdesk on **0113 205 0095**.

We would also welcome your ongoing feedback on how useful you find this feature and any improvements to this or the wider CMC system that would support your work.

Many thanks for your support,
Coordinate My Care

How to Guide

Accessing CMC using EMIS Web

The Coordinate My Care (CMC) service is now accessible via EMIS using an ‘in-context link’. What this means for CMC users is within EMIS you will be able to create, edit and approve a CMC urgent care plan for your patients which will immediately be viewable by all the urgent care services including 111, the out of hours GP services and the London Ambulance Service.

How this works:

- In the same place where EMIS Web users access the summary care record (SCR) you will now find a CMC tab
- If you are accessing a patient record in EMIS, you will automatically be able to see if the patient has a CMC urgent care plan
- You can access your patients CMC urgent care plan within EMIS without having to search for the patient again or log in to CMC separately
- You will also be able to create a new CMC urgent care plan for a patient who is already registered in EMIS

If you are not a current user of the CMC service, please see the accompanying resource ‘CMC – A Complete Guide’ to learn more about how you can get CMC log in details and access to the system.

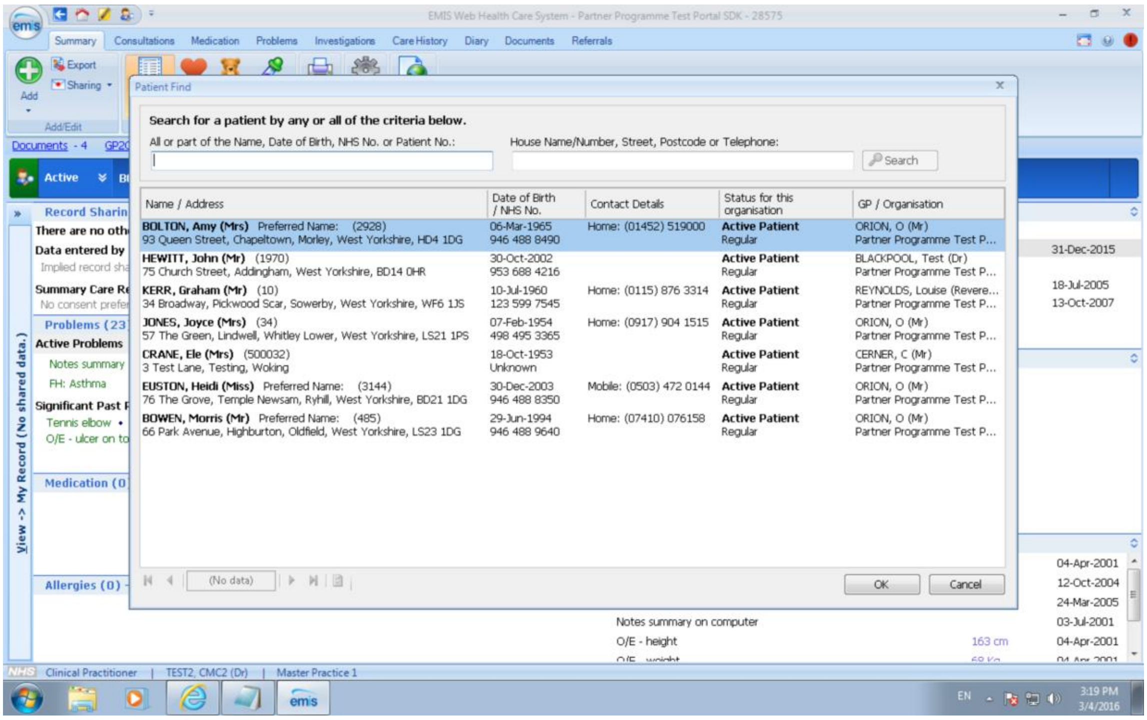
The following How to Guide is to help you benefit from this new interoperability function between EMIS Web and CMC and illustrate the screens, icons and alerts you will see as you use this new functionality.

The EMIS/CMC in-context link will be activated in a phased roll out from mid-March 2016. All EMIS practices will have this functionality available by the end of May 2016.

You will be notified by your practice manager as to when your organisation will have the functionality available and he/she will also be involved in activating the function at the practice level.

STEP 1

In EMIS you will see, view, and select your patients as normal.



Search for a patient by any or all of the criteria below.

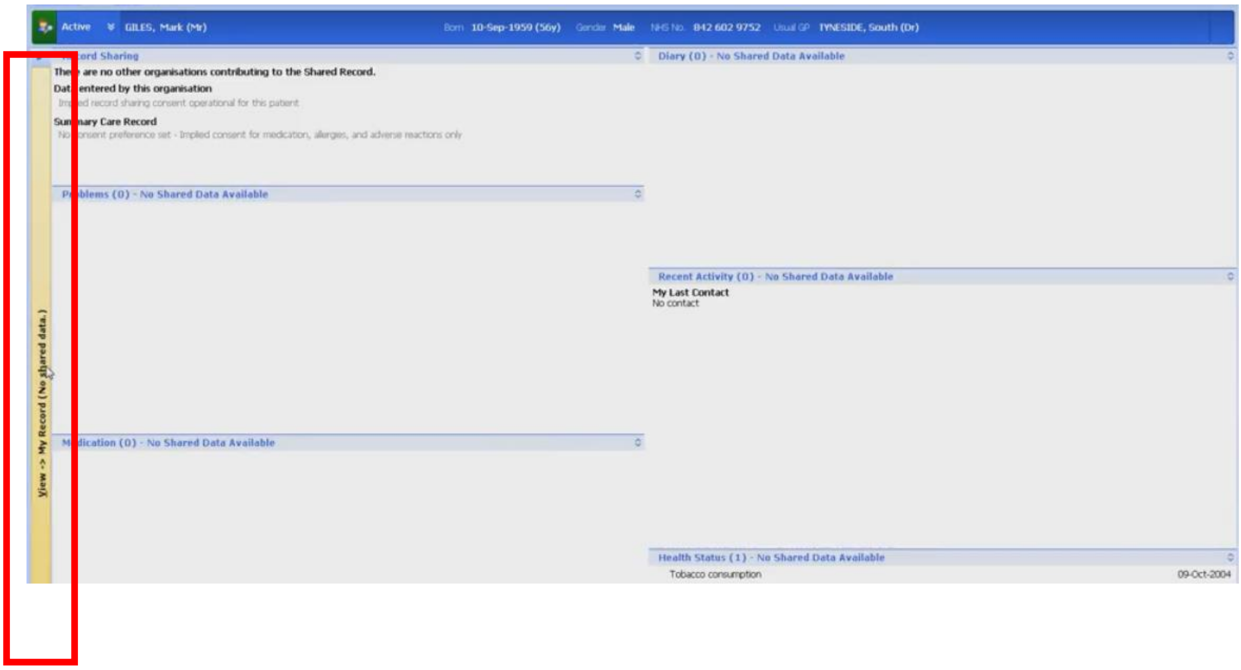
All or part of the Name, Date of Birth, NHS No. or Patient No.:

House Name/Number, Street, Postcode or Telephone:

Name / Address	Date of Birth / NHS No.	Contact Details	Status for this organisation	GP / Organisation
BOLTON, Amy (Mrs) Preferred Name: (2928) 93 Queen Street, Chapeltown, Morley, West Yorkshire, HD4 1DG	06-Mar-1965 946 488 8490	Home: (01452) 519000	**Active Patient** Regular	ORION, O (Mr) Partner Programme Test P...
HEWITT, John (Mr) (1970) 75 Church Street, Addingham, West Yorkshire, BD14 0HR	30-Oct-2002 953 688 4216		**Active Patient** Regular	BLACKPOOL, Test (Dr) Partner Programme Test P...
KERR, Graham (Mr) (10) 34 Broadway, Pickwood Scar, Sowerby, West Yorkshire, WF6 1JS	10-Jul-1960 123 599 7545	Home: (0115) 876 3314	**Active Patient** Regular	REYNOLDS, Louise (Revere... Partner Programme Test P...
JONES, Joyce (Mrs) (34) 57 The Green, Lindwell, Whitley Lower, West Yorkshire, LS21 1PS	07-Feb-1954 498 495 3365	Home: (0917) 904 1515	**Active Patient** Regular	ORION, O (Mr) Partner Programme Test P...
CRANE, Ele (Mrs) (500032) 3 Test Lane, Testing, Woking	18-Oct-1953 Unknown		**Active Patient** Regular	CERNER, C (Mr) Partner Programme Test P...
EUSTON, Heidi (Miss) Preferred Name: (3144) 76 The Grove, Temple Newsam, Ryhill, West Yorkshire, BD21 1DG	30-Dec-2003 946 488 8350	Mobile: (0503) 472 0144	**Active Patient** Regular	ORION, O (Mr) Partner Programme Test P...
BOWEN, Morris (Mr) Preferred Name: (485) 66 Park Avenue, Highburton, Oldfield, West Yorkshire, LS23 1DG	29-Jun-1994 946 488 9640	Home: (07410) 076158	**Active Patient** Regular	ORION, O (Mr) Partner Programme Test P...

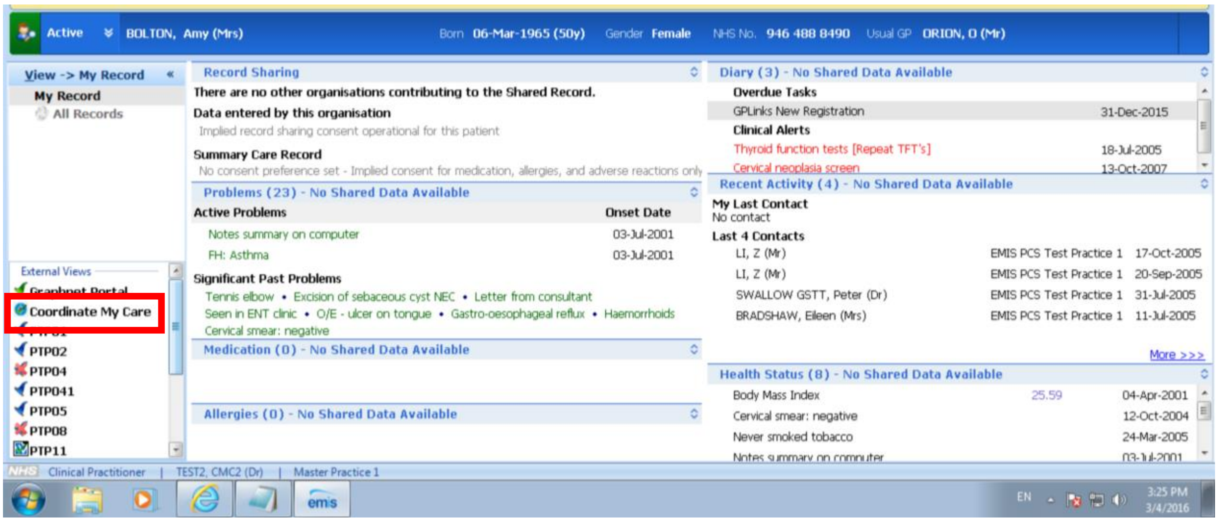
STEP 2

When you are in the selected patient’s record in EMIS, the bar along the left hand side of your screen (the external views list) must be expanded in order to view the CMC status and see if the patient has a care plan in place.



When expanded, the view will appear as below. If your patient has a care plan the CMC icon will show a tick or if there is not a care plan the CMC icon will show a cross.

<u>A patient with a CMC plan</u>



BOLTON, Amy (Mrs) Born **06-Mar-1965 (50y)** Gender **Female** NHS No. **946 488 8490** Usual GP **ORION, O (Mr)**

Record Sharing

There are no other organisations contributing to the Shared Record.

Data entered by this organisation

Implied record sharing consent operational for this patient

Summary Care Record

No consent preference set - Implied consent for medication, allergies, and adverse reactions only

Problems (23) - No Shared Data Available

Active Problems	Onset Date
Notes summary on computer	03-Jul-2001
FH: Asthma	03-Jul-2001

Significant Past Problems

Tennis elbow • Excision of sebaceous cyst NEC • Letter from consultant
Seen in ENT clinic • O/E - ulcer on tongue • Gastro-oesophageal reflux • Haemorrhoids
Cervical smear: negative

Medication (0) - No Shared Data Available

Allergies (0) - No Shared Data Available

Diary (3) - No Shared Data Available

Overdue Tasks	
GPLinks New Registration	31-Dec-2015
Clinical Alerts	
Thyroid function tests [Repeat TFT's]	18-Jul-2005
Cervical neoplasia screen	13-Oct-2007

Recent Activity (4) - No Shared Data Available

My Last Contact
No contact

Last 4 Contacts

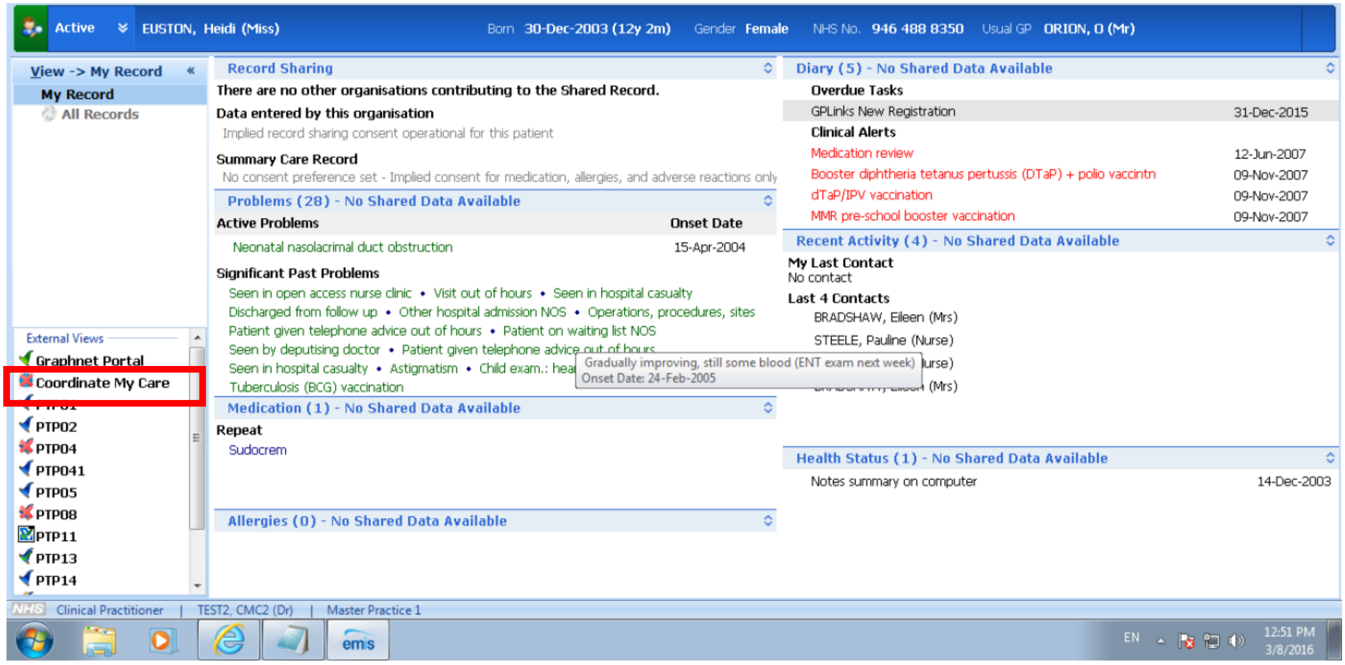
LI, Z (Mr)	EMIS PCS Test Practice 1	17-Oct-2005
LI, Z (Mr)	EMIS PCS Test Practice 1	20-Sep-2005
SWALLOW GSTT, Peter (Dr)	EMIS PCS Test Practice 1	31-Jul-2005
BRADSHAW, Eileen (Mrs)	EMIS PCS Test Practice 1	11-Jul-2005

More >>>

Health Status (8) - No Shared Data Available

Body Mass Index	25.59	04-Apr-2001
Cervical smear: negative		12-Oct-2004
Never smoked tobacco		24-Mar-2005
Notes summary on computer		03-Jul-2001

A patient without a CMC urgent care plan



EUSTON, Heidi (Miss) Born 30-Dec-2003 (12y 2m) Gender Female NHS No. 946 488 8350 Usual GP ORION, O (Mr)

Record Sharing

There are no other organisations contributing to the Shared Record.

Data entered by this organisation

Implied record sharing consent operational for this patient

Summary Care Record

No consent preference set - Implied consent for medication, allergies, and adverse reactions only

Problems (28) - No Shared Data Available

Active Problems	Onset Date
Neonatal nasolacrimal duct obstruction	15-Apr-2004

Significant Past Problems

Seen in open access nurse clinic • Visit out of hours • Seen in hospital casualty • Discharged from follow up • Other hospital admission NOS • Operations, procedures, sites • Patient given telephone advice out of hours • Patient on waiting list NOS • Seen by deputising doctor • Patient given telephone advice out of hours • Seen in hospital casualty • Astigmatism • Child exam.: hea Tuberculosis (BCG) vaccination

Gradually improving, still some blood (ENT exam next week)
Onset Date: 24-Feb-2005

Medication (1) - No Shared Data Available

Repeat

Sudocrem

Allergies (0) - No Shared Data Available

Diary (5) - No Shared Data Available

Overdue Tasks	
GPLinks New Registration	31-Dec-2015
Clinical Alerts	
Medication review	12-Jun-2007
Booster diphtheria tetanus pertussis (DTaP) + polio vaccintn	09-Nov-2007
dTaP/IPV vaccination	09-Nov-2007
MMR pre-school booster vaccination	09-Nov-2007

Recent Activity (4) - No Shared Data Available

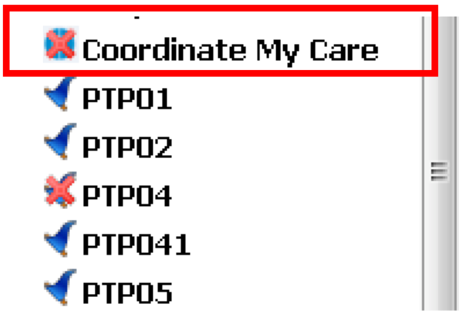
My Last Contact
No contact

Last 4 Contacts
BRADSHAW, Eileen (Mrs)
STEELE, Pauline (Nurse)
urse)
(Mrs)

Health Status (1) - No Shared Data Available

Notes summary on computer	14-Dec-2003

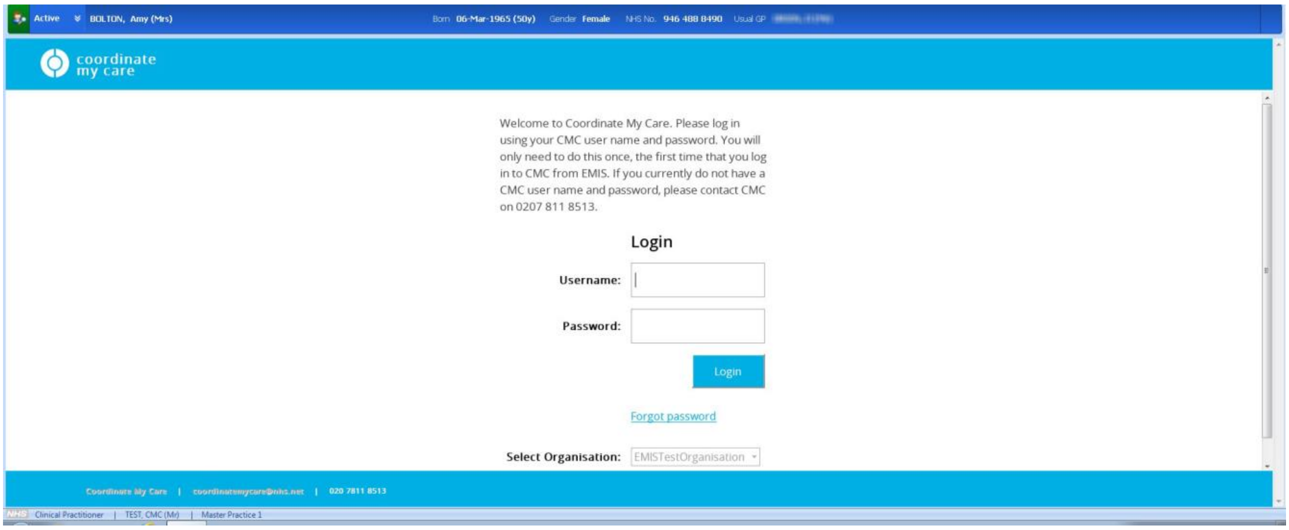
Clinical Practitioner | TEST2, CMC2 (Dr) | Master Practice 1



STEP 3

When you click on the CMC icon you will be taken to the CMC log in screen. You will only have to log in to CMC using your CMC user ID and password once. After this, you will have automatic access because the system will recognise you as a returning user.

Note: If you use EMIS Web from more than one organisation (e.g. if you work with more than one GP surgery), then you will need to provide your CMC username and password the first time you access the system from each organisation.



BOLTON, Amy (Mrs) Born 06-Mar-1965 (50y) Gender Female NHS No. 946 488 8490 Usual GP [redacted]

Welcome to Coordinate My Care. Please log in using your CMC user name and password. You will only need to do this once, the first time that you log in to CMC from EMIS. If you currently do not have a CMC user name and password, please contact CMC on 0207 811 8513.

Login

Username:

Password:

Select Organisation: EMISTestOrganisation

Coordinate My Care | coordinatemycare@nhs.net | 020 7811 8513

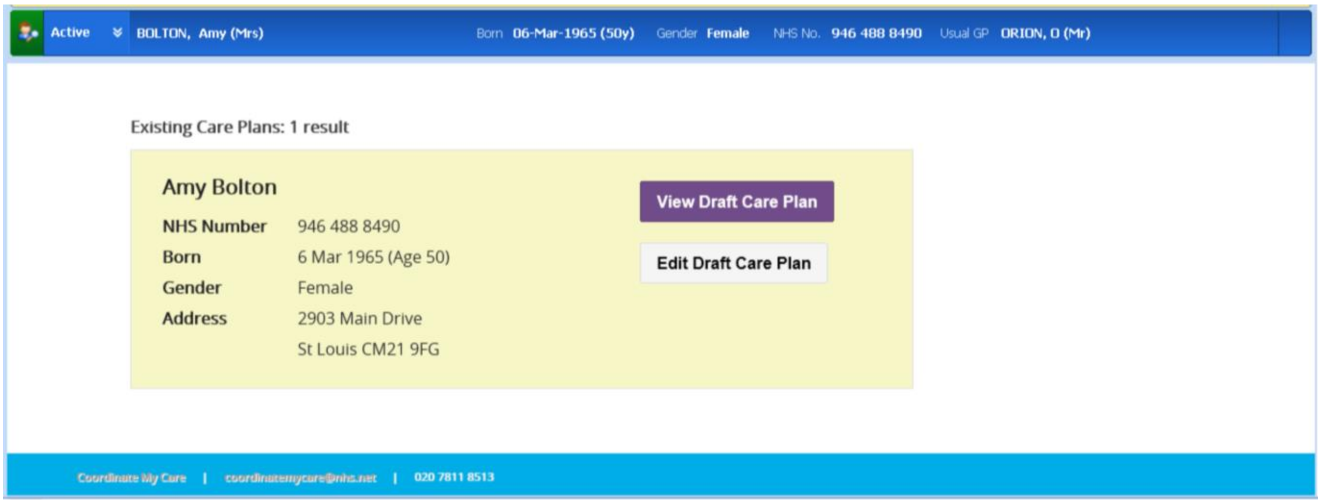
NHS Clinical Practitioner | TEST, CMC (Mr) | Master Practice 1

Please note if you are not a current user of the CMC service you will not be able to go further than this step without taking the steps described in ‘CMC – A Complete Guide’.

STEP 4

When the CMC system is accessed from an EMIS Web patient record, a CMC search is automatically performed using the patient's NHS number and date of birth. If a care plan exists for the patient, you will have the option of viewing or editing it. In the example below the patient has a draft care plan, not yet published or available to urgent care.

a) *Viewing and editing a draft urgent care plan*



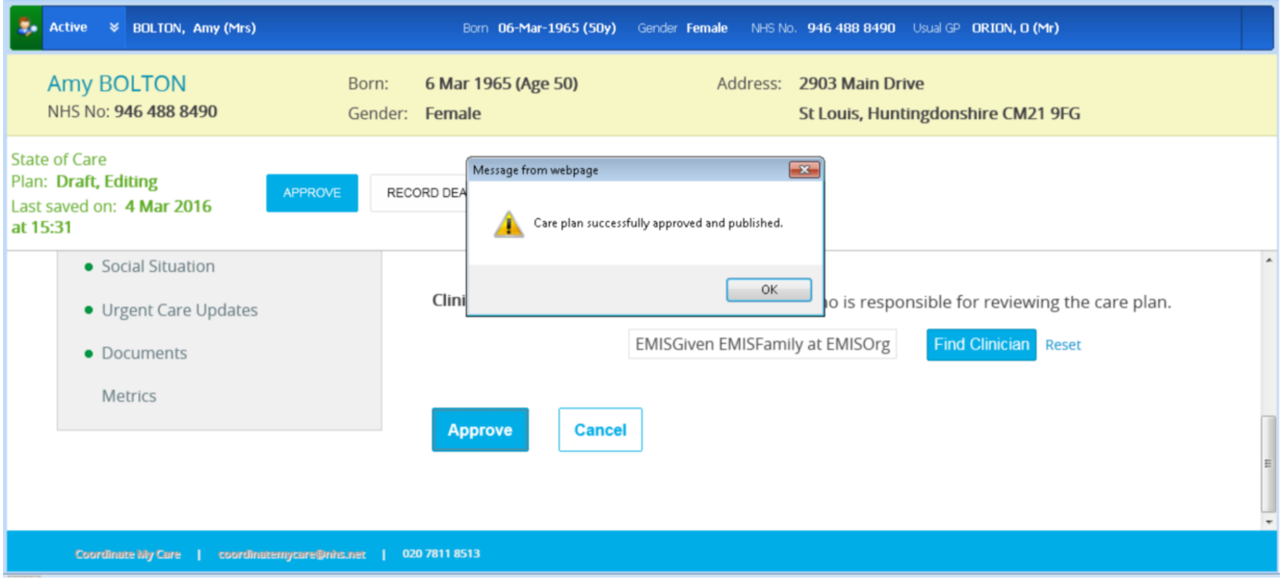
Active BOLTON, Amy (Mrs) Born 06-Mar-1965 (50y) Gender Female NHS No. 946 488 8490 Usual GP ORION, O (Mr)

Existing Care Plans: 1 result

Amy Bolton

NHS Number	946 488 8490
Born	6 Mar 1965 (Age 50)
Gender	Female
Address	2903 Main Drive St Louis CM21 9FG

From here you can edit and approve a care plan:



Active BOLTON, Amy (Mrs) Born 06-Mar-1965 (50y) Gender Female NHS No. 946 488 8490 Usual GP ORION, O (Mr)

Amy BOLTON
NHS No: 946 488 8490
Born: 6 Mar 1965 (Age 50)
Gender: Female
Address: 2903 Main Drive
St Louis, Huntingdonshire CM21 9FG

State of Care Plan: Draft, Editing
Last saved on: 4 Mar 2016 at 15:31

Message from webpage

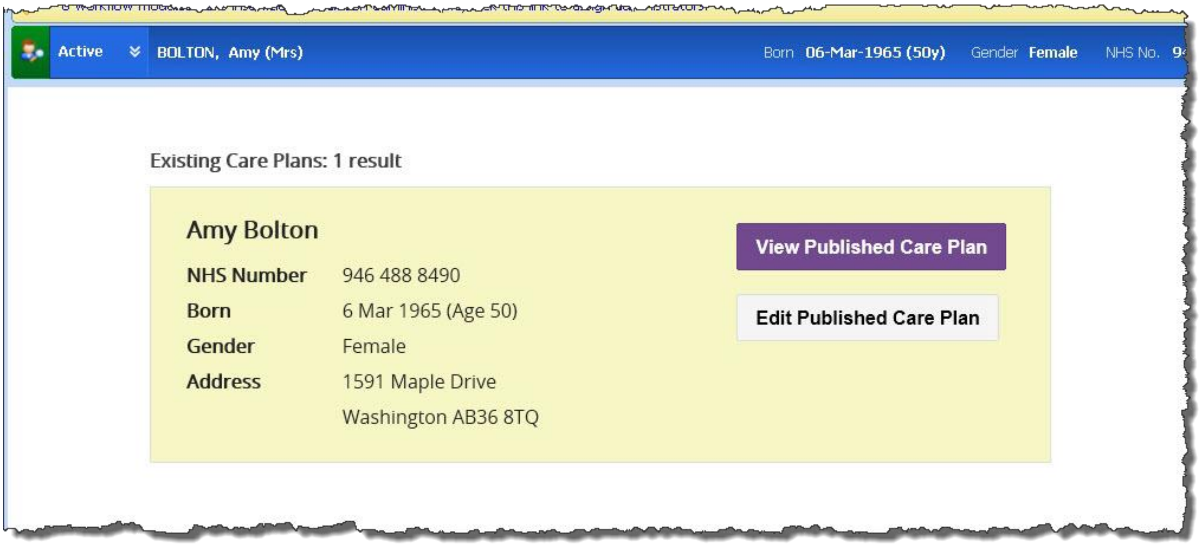
Care plan successfully approved and published.

Clini…o is responsible for reviewing the care plan.

EMISGiven EMISFamily at EMISOrg

b) *Viewing and editing a published urgent care plan*

In some cases an urgent care plan may have already been finalised and approved in which case you can view the 'published care plan'. In the example below the patient has a published care plan, which you can view and / or edit.

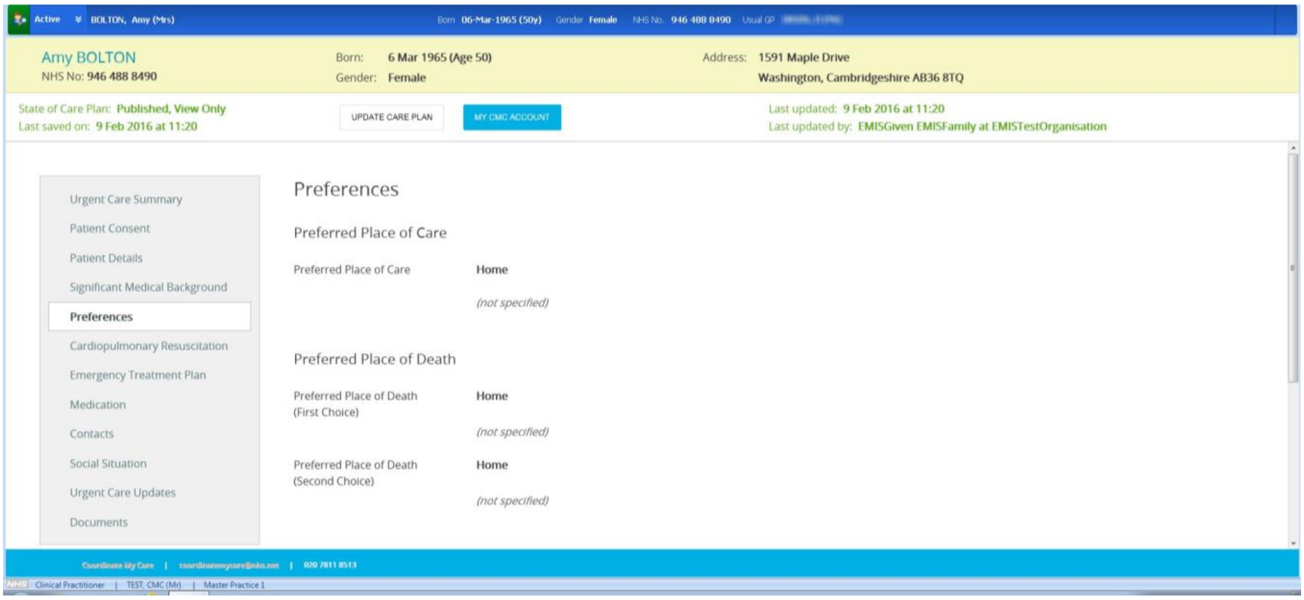


BOLTON, Amy (Mrs) Born 06-Mar-1965 (50y) Gender Female NHS No. 9

Existing Care Plans: 1 result

Amy Bolton

NHS Number	946 488 8490
Born	6 Mar 1965 (Age 50)
Gender	Female
Address	1591 Maple Drive Washington AB36 8TQ



BOLTON, Amy (Mrs) Born 06-Mar-1965 (50y) Gender Female NHS No. 946 488 8490 Usual GP [redacted]

Amy BOLTON
NHS No: 946 488 8490
Born: 6 Mar 1965 (Age 50)
Gender: Female
Address: 1591 Maple Drive
Washington, Cambridgeshire AB36 8TQ

State of Care Plan: Published, View Only
Last saved on: 9 Feb 2016 at 11:20
Last updated: 9 Feb 2016 at 11:20
Last updated by: EMISGiven EMISFamily at EMISTestOrganisation

Preferences

Preferred Place of Care

Preferred Place of Care	Home *(not specified)*

Preferred Place of Death

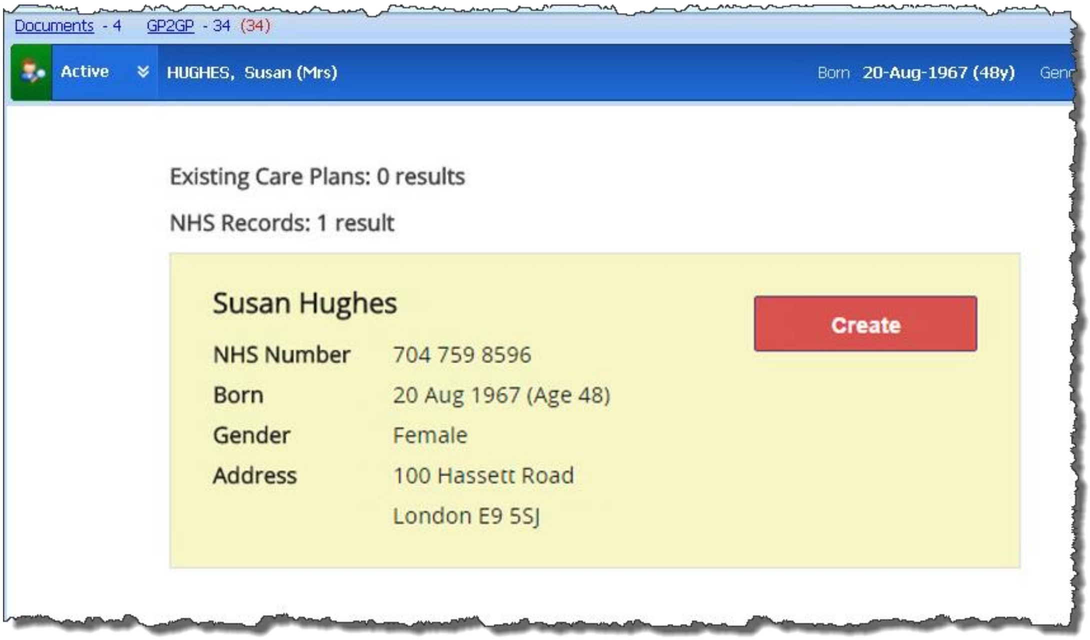
Preferred Place of Death (First Choice)	Home *(not specified)*
Preferred Place of Death (Second Choice)	Home *(not specified)*

Full functionality for updating and approving a care plan is available when a CMC care plan is opened in EMIS Web. This includes the ability to record a patient's death or withdraw consent.

Please note you that when accessing the CMC system from within EMIS Web you are restricted to the CMC plan for the specific patient who you have selected. Wider access to the CMC system outside of that patient, (for example accessing your patient lists), can only be accessed by logging in to the CMC system directly and using your usual user ID and password.

c) *Creating a new urgent care plan*

If you click on the CMC cross icon (which shows that the patient does not currently have an urgent care plan) then your patient's details will be sourced through the personal demographics service (PDS) and Spine and you will be able to start creating a new urgent care plan for your patient.



Existing Care Plans: 0 results

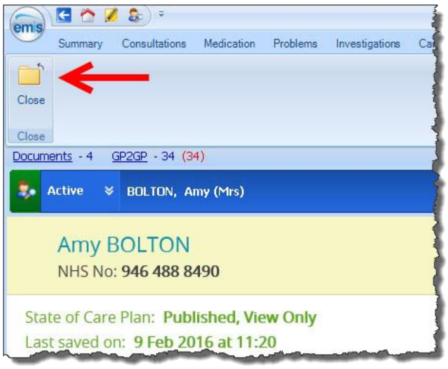
NHS Records: 1 result

Susan Hughes

NHS Number	704 759 8596
Born	20 Aug 1967 (Age 48)
Gender	Female
Address	100 Hassett Road London E9 5SJ

Step 5

When you are finished working with a care plan, use the Close icon in the top right corner of the screen to return to EMIS Web.



Amy BOLTON

NHS No: 946 488 8490

State of Care Plan: Published, View Only

Last saved on: 9 Feb 2016 at 11:20

If you have any queries on CMC please do not hesitate to contact the Helpdesk on 0207 811 8513 or coordinatemycare@nhs.net.

For any technical queries relating to EMIS please contact the EMIS helpdesk on 0845 1222 333.

We would also welcome your ongoing feedback on how useful you find this function and any improvements to this or the wider CMC system that would support your work.

Many thanks for your support,
Coordinate My Care

Section 5
Information for patients and carers

Central and
North West London
NHS Foundation Trust

Supporting excellent care in the last days of life at home

Information for people at home, their family, friends and others who are important to them, as well as community healthcare professionals

Wellbeing for life

About this booklet

This booklet explains more about how we care for somebody when we believe they are approaching, or are at, the end of their life. It has been written especially for those who wish to be at home at this time. We understand that this is a difficult time and hope that this leaflet will help answer some of the questions many people have.

The booklet gives the person and those important to them advice about what to expect and what happens when someone is deteriorating and dying. It also gives practical advice about things the person, those important to them and the healthcare team may want to consider to ensure there is the right care and support at home. Some parts of the leaflet may be more relevant than others for each person, and we have indicated this in the contents page. However some people may find it helpful to read all the sections.

At the back of the booklet is space to write down any questions or notes you may wish to make.

Additional local inserts for this booklet include useful contact details for your local area as well as documents and guidance that the healthcare team can use to help plan the right care. Please ask if you would like more information.

If you don’t feel ready to read this information just yet, you can come back to it at any time.

Tell us, we’re listening

Our staff want to know how they are doing. Tell us what you think at: **www.cnwl.nhs.uk/feedback** and then we’ll know what to do.

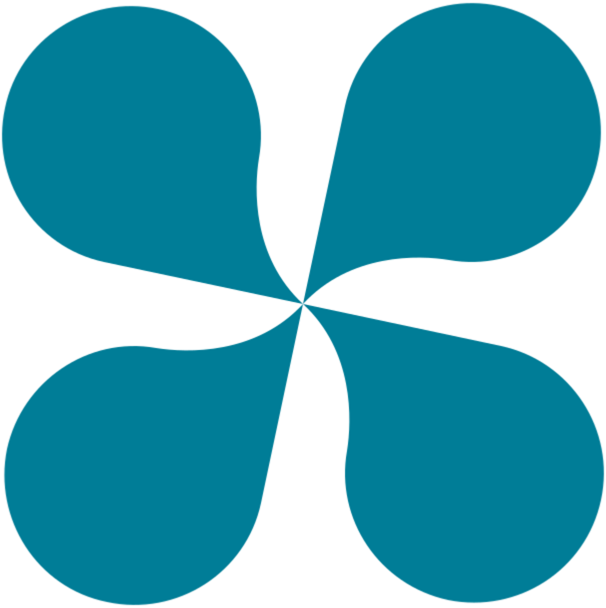
Contents

⬛ Useful information for everyone

🟩 Information most useful for healthcare professionals

Inserts:

- Useful contact details for healthcare teams and services in your area.
- Individualised Care Plan and Medication Prescribing Advice for healthcare professionals. This is for the healthcare team to document what they have discussed with a person and/or those important to them.
- A chart which can be used to easily record common symptoms over time. This can be used by patients, those important to them and healthcare professionals



The ambition

> “I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)”

National Palliative and End of Life Care Partnership (2015). Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020.

Standards of care everyone can expect at the end of life

When someone is approaching the end of their life, they can expect care that is compassionate and sensitive to their needs and preferences. Clear communication between the person, those important to them and healthcare staff is especially important. Healthcare staff will respond to changes in the person’s condition with care to relieve symptoms and distress. Each person will have an individualised plan for care in the last days of life.

Who might be involved in care at home in the last days and weeks of life?

There can be lots of different healthcare professionals visiting someone at home. Although they all have different roles and skills, they work together to make sure people and those important to them receive the right care and physical, emotional and spiritual support. This section explains the different roles and what to expect from each of them.

Any professional who comes to your home home may ask ‘What do I need to know about you to give the best care possible?’ or similar questions to help them decide what to offer you.

GP

While someone is at home, the GP has overall responsibility for care. They can help if someone is concerned about any aspect of the care, for example,

- Worried about changes in symptoms. They will discuss what treatments might help control symptoms.
- Want to talk through what may happen as a person becomes less well and discuss if someone has specific wishes regarding their care.
- They can arrange for a patient to be seen by a district nurse or for Specialist Care from a Palliative Care Team. They can refer a person or their carer to be seen at home.

Community and District nurses

Community and District nurses work closely with GPs. They offer home visits and assess a person’s nursing needs. They can help with:

- Monitoring and treating any symptoms.

- Supporting people and those important to them.
- Giving injections, changing dressings, giving advice and support on pressure area care and toilet problems, such as incontinence and constipation. They can organise the supply of appropriate equipment to help with pressure care or incontinence.
- Showing relatives or carers how to move and care for a person safely if they wish to be involved in doing this.
- Teaching someone or their carers about the safest way to take medication.
- Arranging for a carer or healthcare assistant to help with things such as washing and personal care.
- Co-ordinating care. They can contact other health or social care professionals to help if needed. District nurses often work with Palliative Care Teams to help support patients and those important to them so that they can stay at home.
- District nurses are usually a senior community nurse with specialist training and may have additional roles to those above such as prescribing dressings, and sometimes medications, as well as physical assessment skills.

Trained Carers

Carers are employed to help with all aspects of personal care, for example washing, dressing, toileting and help with preparing food or drinks. They are a valuable source of support. Carers are not trained nurses so cannot give medication. Funding for carers is either provided via social services, the NHS or privately. For the majority of patients at end of life, care can be funded by the NHS. The GP, district nurse or community palliative care team can give more information about this.

Community Specialist Palliative Care Team

Specialist palliative care teams have expertise in supporting someone at this time of life. They can give direct advice to a person or their family or any healthcare professional concerning:

- Advice on managing symptoms such as pain and nausea or any source of distress.
- Advice to a person or their family/friends to help manage a health condition that might be changing quickly.
- Support to a person or their family/friends to cope with their illness, including children and young people.

The team includes specialist palliative care nurses and doctors and they are often, but not always, linked to local hospices. Many palliative care teams also have, or work closely with, a social worker, a counsellor, an occupational therapist, a physiotherapist and a spiritual care coordinator or chaplain.

Palliative care teams are experienced in assessing and treating symptoms. They can also provide social, psychological and spiritual support for patients and those important to them. The specialist palliative care team can give more information about the services your local team provides when they visit.

Social workers

Social workers can provide information about any aspect of social support you and your family require. Specialised social workers can also provide counselling and emotional support for patients and those important to them. They can also help with applying for benefits a person or those important to them may be able to claim. Speak to the GP, district nurse or palliative care nurse to be referred to a social worker.

Physiotherapists and Occupational Therapists (OTs)

Physios and OTs can help someone maintain their independence as much as possible. They visit a person at home and can assess how they move and suggest equipment or changes to how the home environment is set up to make things easier or safer. After their assessment, they will arrange to get the equipment needed. They can also give information and support about pain relief, breathing problems, fatigue and anxiety. They can help support someone to move around as much as they are able. They can do home visits to assess how a person moves.

Local spiritual or religious support services

Local spiritual or religious leaders can offer spiritual care and support at this time. Even if a person doesn't have a spiritual or religious faith, they may still find it helpful to talk to someone about how they are thinking or feeling.

Voluntary organisations and charities

Voluntary organisations and charities offer various kinds of help, including information, loans of equipment, grants and transport. Some organisations have volunteers who can provide short periods of respite care to give carers a break during the day time. Additionally in some areas either trained carers or Marie Curie can provide free occasional additional general nursing care and support overnight in the home, usually for eight to nine hours.

The district nurse, social worker, palliative care team or GP can provide details for which organisations are available in your local area and how to contact them.

What to expect when someone is dying

If someone is approaching the end of their life there is often a period of time lasting weeks to months when they are slowly deteriorating. This is commonly experienced as finding it harder to do everyday things, such as getting washed and dressed in the morning, finding it harder to walk around, feeling tired all the time and having a smaller appetite. It is quite common for people to fluctuate and have good and bad periods. It can be difficult to say with certainty if a person is starting to die, or may improve a little.

This is a time for the person and those important to them to meet with their GP or nurses who care for them at home. They will review to see if there is anything that can be treated or changed to help the situation. They can also talk to the person about their wishes for the future if improvement is not possible. If they would wish to be at home for end of life care they can help plan practically to do this.

This period of decline over weeks and months is followed by a time, perhaps a few days, when dying becomes more likely. This booklet explains in more detail about what to expect in these last days of life.

What happens when someone is in the last days of life?

This time is entirely unique to each person. It is not always possible to:

- Know for sure that a person is in the last days of life.
- Predict exactly when a person will die.
- Know exactly what changes the person will experience when they are dying.

There are certain bodily changes telling us a person is close to death. These signs can come and go over a period of days, and not all of them will happen in everyone. If these signs go away it does not usually mean the person is recovering.

Some of these changes may be distressing for the person or those caring for them, but we hope the information in the following pages reassures that many of these changes or signs are not unusual and that there are many things both those people important to a person and their healthcare team can do to help.

If you are a carer and if any of these signs make you feel distressed or overwhelmed, do take a period of time for a break and leave the bedside, as it’s important to think about your own feelings as well as those of the person you are caring for.

Changes in the last days of life

The person’s appetite is likely to be reduced

Sign that a person may be dying	They may no longer wish to eat or drink anything. This could be because they find the effort of eating or drinking too much. But it may also be because they have little or no need or desire for food or drink. Eventually the person will stop eating or drinking, and will not be able to swallow tablets.
Is this worrying?	If a person stops eating or drinking because of their reduced appetite, this may be hard to accept, but is an ordinary part of the dying process. If they stop drinking their mouth may look dry, but this does not always mean they are dehydrated. It is normal for all dying people eventually to stop eating and drinking.
Is there anything carers can do to help?	If the person is conscious and they want something to eat or drink, you can offer sips, provided they can still swallow. You can give comfort to a person with a dry mouth by: • Offering a drink through a straw (or from a teaspoon or syringe). • Moistening the mouth with a damp sponge (special kinds of sponges are available for this purpose (the person may bite down on it at first but keep holding it and they will let go)). • Placing ice chips in the mouth. • Applying lip balm. • Using a baby toothbrush to gently clean the front of their mouth.
What can nurse or doctor do to help?	Good mouthcare is most important. The nurse or doctor may consider subcutaneous fluids (fluids given via a needle under the skin) for symptom relief, but this needs to be weighed up against side effects such as the risk of secretions and oedema (swelling). The nurse or doctor will be able to talk further about the benefits and risks of giving artificial fluids at end of life.

The person’s breathing may change

Sign that a person may be dying	As a person’s body becomes less active in the final stages of life they need less oxygen, and their breathing may become shallower. There may be long pauses between the breaths. Sometimes the person’s breathing may also make a noise. This is likely to be because they are not able to reabsorb or swallow the normal fluids in their chest or throat, which can cause a rattling sound. In the very last moments of life, the person’s breathing pattern may change. Breaths become much slower and quieter before they stop altogether.
Is this worrying?	A change in the breathing pattern is a normal part of the dying process. The rattling sound can be upsetting to hear, but it does not seem to cause any distress to the dying person. It can be a bit like snoring - which affects those who hear it more than the person who is making the sound. The person does not normally need extra oxygen at this time stage.
Is there anything carers can do to help?	If the person is anxious, sitting with them so that they know you are there may help to reduce their anxiety. Breathlessness can be frightening - a small fan and an open window can help. If the breathing is very noisy, it may be helpful to change the person’s position so that they are on their side. You can ask to be shown the best way of moving someone.
What can the nurse or doctor do to help?	The doctor or nurse may also suggest medication which may help to reduce the fluids in their chest or throat. This is not always needed, and does not always make a difference.

Tables adapted from:

The National Council for Palliative Care (2015). What to expect when someone important to you is dying. A guide for carers, families and friends of dying people.

The person may become much sleepier

Sign that a person may be dying	The person is likely to spend more time sleeping, and will often be drowsy even when they are awake. They may also drift in and out consciousness. Some people become completely unconscious for a period of time before they die – this could be short, or as long as several days.
Is this worrying?	It is normal for a dying person to sleep more. They may generally become less interested in what is going on around them, and have less energy to take part, but this does not necessarily mean they are no longer hearing or understanding what is said to them.
Is there anything carers can do to help?	It is important to remember that, even when the person is or appears to be sleeping or resting, they may still be able to hear. Do not feel that you need to stop communicating with the person. Some carers might want to carry on speaking quietly and calmly to the person. They could also try letting the person know their loved one is there in other ways. For instance; holding their hand, reading to them, or playing their favourite music.
What can the nurse or doctor do to help?	The nurse or doctor will review to make sure there are no reversible causes of the drowsiness, for example medications can sometimes cause excess drowsiness, or they may consider blood tests to look for any causes. However, often there are no reversible causes of drowsiness and they will reassure a person and those important to them that it is part of the normal process in someone who is dying.

The person's skin may feel cold and change colour

Sign that a person may be dying	The person's hands, feet, ears and nose may feel cold to touch (this is due to reduced circulation). Occasionally a person's hand or other parts of the body may swell a little. Their skin may become mottled and uneven in colour. In light skin this often shows as blue and patchy, in dark skin as grey or ashen and in yellowish skin tones it can show as a grey to green colour.
Is this worrying?	These changes are all normal parts of the dying process. If the person's hands swell please be assured this is not usually painful or uncomfortable.
Is there anything carers can do to help?	It may be comforting to put loose gloves or socks on the person. You do not need to warm them up - but doing so may help carers to feel more comfortable. Gentle massage may help. If you ask, the nurse or doctor can show you how to do this.
What can the nurse or doctor do to help?	The nurse or doctor can reassure carers that these changes are a normal part of the dying process. They can help show carers how to do gentle massage.

The person may become more restless or agitated

Sign that a person may be dying	This may happen in the last few days of life, though the person may become more peaceful again before they die. Sometimes they may appear confused and may not recognise familiar faces. They may hallucinate, and see or hear people or things that are not actually there.
Is this worrying?	Restlessness and agitation can be caused by many things. It may be manageable by quiet reassurance and the comfort of people who are important to the person, though it may still be distressing for them to see. Agitation could also be caused by physical problems, like constipation or difficulty passing urine –ask the doctor or nurse caring for the person if you are concerned about this. Sometimes the person may not recognise those important to them. This may be distressing, but it is not a sign that they feel differently about them. More likely, it is that the person is unable to distinguish clearly between what is real and what is not - especially if they are a bit sleepy and drifting in and out of consciousness, rather like what can happen when we are half-awake or half-asleep.
Is there anything carers can do to help?	Simply sitting with the person may often help to calm them down. Keeping things as normal as possible may also help comfort them. Carers can help by: • Speaking clearly and audibly to the person. • Telling/reminding them who each person is. • Keeping their surrounding calm with minimal changes in noise level. • Trying not to correct them if they say something wrong or insist on them getting things accurate, as this may be upsetting for carers and the person.
What can the nurse or doctor do to help?	The nurse or doctor can check if there is any reversible cause for the agitation, such as constipation or difficulty passing urine. They may be able to offer medication to help settle the person's anxiety.

The person may lose control of their bowels or bladder

Sign that a person may be dying	This happens because the muscles in these areas relax and don't work as they did. They may also have fewer bowel movements as they eat less, and their urine may get darker as they drink less.
Is this worrying?	This may be distressing to see, and you may worry that the person may feel embarrassed.
Is there anything carers can do to help?	Carers can ask a nurse to help by showing them how to • Keep the person clean and comfortable and additional help with care as you need. • Protect the bed.
What can the nurse or doctor do to help?	The community nurse can help organize incontinence pads and, if not already in place and needed, funded carers to help with personal care. They may also consider a catheter (a long thin tube put into the person's bladder to drain urine to make them feel more comfortable)

The person's eyes are closed

Sign that a person may be dying	It is important to know that in these final stages, the person may close their eyes often. At some point they may not open them again. Their eyes may often be half-open, which can be distressing to see.
Is this worrying?	This is part of the normal process when someone is dying. The person may still be able to hear, even if they are not opening their eyes.
Is there anything carers can do to help?	As they may still be able to hear, take the opportunity to say things that are important to you both.
What can the nurse or doctor do to help?	Even if the person's eyes are closed and they don't appear to respond, the nurse or doctor will always tell the person who they are when they arrive and let them know if they are going to examine or move them. They may still be able to hear, so the nurse or doctor will explain what they are doing when they are caring for the person to reassure them.

Conversations to expect

If changes like the ones described are noticed by the healthcare team, they will offer a conversation with the person if they are able, or, if they agree, with those important to them.

Conversations may involve some of the following:

- The reason why the doctor or nurse thinks a person is dying and an estimate of prognosis (this is very difficult to say with certainty).
- An explanation of what to expect in the last few days.
- Check if the person did any advance care planning before, such as if they have a preferred place of care at end of life, or any legal documents about wishes relating to their care (for example, Advance Decision to Refuse Treatment or Lasting Power of Attorney).
- An explanation of how symptoms such as pain or breathlessness will be managed if they occur. As it can be difficult to swallow tablets alternative ways of giving medication, for example injections under the skin can be done. The doctor or nurse will make sure these medications are available in the home just in case they are needed.
- A discussion about cardiopulmonary resuscitation (CPR)
- Check if the person has an implantable cardiac defibrillator (ICD) and if so a discussion about deactivating the device.
- The healthcare professional may ask about religious or spiritual wishes, beliefs and needs. They can contact an appropriate spiritual advisor, for example a chaplain or imam if you would find this supportive.
- The healthcare professional may ask questions about the person's psychological wellbeing, for example if they are feeling very anxious or distressed, to work out how they can help best.

- The healthcare professional will ask who the person wants to be involved in their care, and also how involved those important to the person wish to be in care. They will offer support to those important to the person. They will also ask if there are any children or young adults who are close to the person who may need extra support at this time. They will suggest informing schools/ universities so that they can help support the child or young adult.
- Digital legacies are increasingly important for people who have social media or other on-line accounts with photos or information that those important to them may not be able to access after their death. More information and advice about how to manage digital legacies can be found at **http://digitallegacyassociation.org/for-the-public/**

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Things the healthcare team should consider in the last days of life:

- A medical review. This is to consider if there any reversible causes of deterioration and, if so, whether it is appropriate to treat them. Physical and psychological symptoms may also be assessed and an overall check of any sources of concern for the household.
- The healthcare professionals will communicate clearly and sensitively with the person and those who are important to them.
- The healthcare professionals will involve the person and those who are important to them in decisions about treatment and care.
- Liaising with other members of the community multi-disciplinary team to come to agreement about decision making at end of life and an individualised plan of care.
- The healthcare professional will agree an individualised plan of care for the patient including an assessment, a review of hydration and nutrition and a plan for managing current and common symptoms.
- The individualized plan of care and treatment escalation decisions should be documented on the forms the local team uses.
- These decisions will be regularly reviewed and revised as necessary.
- If not already discussed before, the healthcare team should discuss and complete a Do Not Attempt Cardio-Pulmonary Resuscitation form.
- Anticipatory injectable medications will be prescribed and available in the person’s home in case they are needed in a crisis.
- The healthcare professional will agree a plan with the person or those important to them for ongoing monitoring and support. They

- The healthcare team should update appropriate out of hours teams and any Electronic Patient Care record.
- The healthcare team may request or review a package of care if the person needs more help with personal care.
- They may consider referral to other services, for example specialist palliative care.
- The healthcare team should ensure ongoing district nurse support if already in place or refer if needed.
- The healthcare team should check if the person has an ICD (implantable cardiac defibrillator). If so a discussion about deactivation should be considered if it has not already been done.
- Digital legacies are increasingly important for people who have social media or other on-line accounts with photos or information that may not be accessible to those important to the person after their death.

  This link can be offered to the person and/or those important to them for further information and advice about what to do.

  http://digitallegacyassociation.org/for-the-public/

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Common medications used at end of life

In the last days of life it is often difficult for someone to swallow tablets as they are more sleepy. Some medications can be given in liquid form which can be easier to swallow. The healthcare team may go through a person's medications and stop those which they feel are no longer necessary to reduce the tablet burden.

If someone is unable to swallow at all, medications needed to keep them comfortable can be given as injections under the skin. If several injections are needed then the healthcare team may consider starting a syringe driver. This is a small battery pump that gives the medication continuously over 24hrs under the skin (subcutaneous) via a small needle. People do not find this uncomfortable. Normally all the medication can go in one pump. This means that repeat injections are less likely to be needed and the symptoms are better controlled throughout the day. The symptoms and medications will be reviewed daily and the community nurses do all the syringe driver changes.

Do not worry if the syringe driver alarms or stops working as the medications will still work for a few hours. Calling the District nurse is the best thing to do in this scenario.

Some of the medications that can be given as injections or via the syringe driver are:

- Painkillers – for example, Morphine or other drugs that act like morphine.
- Sedative drug – these help with symptoms of agitation and restlessness. An example of this is Midazolam.
- Anti-sickness medications. There are many anti-sickness medications that can be given as an injection or via the syringe driver. Different anti-sickness medications work in different people and situations, so a second or third medication may be tried if the first does not help.

- Anti-secretory medications. These help dry up secretions which cause noisy breathing at end of life.

The doctor or nurse will decide on the right medications for each patient based on their symptoms, their response to previous medications, any previous allergies or adverse reactions and how available the drugs are.

In the separate insert are a series of flowcharts, which the different nurses, doctors and other healthcare professionals coming to give care can refer to for advice on how best to manage pain and other symptoms at the end of life. The names of drugs and technical details are included - if you would like someone to discuss or explain these to you then please ask your GP, District Nurse or Palliative Care Team.

People without symptoms who have not needed these medications previously do not need to have medications regularly, but ‘just in case’ prescriptions will be available in case the medications are needed.

What to expect in the final moments

Some people find it helpful to know what to expect in the final moments. **If you don't feel ready to read this information just yet, you can come back to it at any time.**

The person's final moments

Particularly in the last few minutes, the person's face muscles may relax and they become very pale. Their jaw may drop and their eyes may become less clear. The person's breathing will eventually stop. Often the person's body will completely relax.

Sometimes it can be difficult to identify the exact moment when the person dies. There may be one or two last gasps a minute or so after what seemed the last breath.

This is always a profound moment, even when death has been expected for days. Those important to the person may suddenly feel overwhelmed with sadness; they may want to be alone, or they may want to ring family and friends. By this time they may be exhausted with the caring and the waiting, and the relief and finality of the moment can take them by surprise.

What happens after the person has died?

Once the person has died those important to them may wish to respond in a way which is appropriate to them at the time. This could be by:

- Carrying out a particular ritual or ceremony, if there is one that is important to the person who has died, and their culture or beliefs.
- Simply sitting and being with the person.

After this there are practical steps to take when ready, the first of which are on the next page.

Care After Death

After a loved one has died and those important to them are ready, the death needs to be confirmed. To do this:

- You do not need to call 999 if someone has an expected death at home but can contact the GP as below:
- **If in usual working hours** contact the GP so that they can come and confirm the death and complete a medical certificate.
- **If out of hours** then contact the out of hours GP to come and confirm the death. **Please tell them that the death was expected**, this avoids having to involve the coroner. They will not be able to do the medical certificate, but this will be completed by a GP who knew the person when the GP practice re-opens in working hours.
- In some circumstances the GP may need to speak to a Coroner before issuing a medical certificate, but they will explain this and the process at the time.

Those important to the patient may also wish to contact a funeral director to move their loved one to a funeral home.

Once the medical certificate is done the death can be registered. This must be done within five days at the local town hall in the borough the person died.

Please ask for a separate booklet that contains more detailed information and advice about what to do when someone dies. Alternatively the website **www.bereavementadvice.org** has lots of helpful and practical advice about what to do.

If you are considering taking your loved one home to their country of birth for burial please speak to a funeral director for further information about their repatriation services.

The healthcare team will continue to support those important to the person after their loved one has died and answer any concerns they have.

Care After Death

These are the things the healthcare team will need to consider when a person has died:

- Ensure those important to the person know contact details to arrange verification of death.
- Support relatives and give information about what to do after a death in a clear and sensitive way. There are useful leaflets from the Department of Work and Pensions regarding things that need to be done after a death.
- Ensure a Medical Certificate is issued (this is normally done by the GP) or the Coroner contacted if unable to issue certificate.
- Ensure all relevant agencies e.g. social care, palliative care, out of hours teams and equipment stores are informed of the death as soon as possible.
- Update care records e.g. Electronic Patient Care Record with the date, place and time of death.
- Offer follow-up bereavement support to those identified as important to the person and consider referral to bereavement counselling services as needed.
- Ensure staff who cared for the person are supported if needed.
- Consider if any lessons (including what worked well) can be gained from events leading up to the death and how the death was dealt with to help care for future patients.

Space to write down important contact details

We suggest you write down the contact details of the professionals looking after you, and also the contact details of people you would like us to contact if needed.

Role	Name	Contact number
GP:		
Out of Hours GP number:		111
District Nurse:		
District Nurse Out of Hours Contact:		
NHS Continuing Care Team:		
Care agency:		
Community Palliative Care Team:		
Out of Hours Community Palliative Care Team:		
Community Pharmacist/ Pharmacy:		
Contact details of family/ friend/carer you would like us to contact if needed:		

There is also a separate insert with the contact details for your local area.

Space for anything you wish to note down

e.g. questions to ask your nurse or doctor, or to record anything you wish your nurse or doctor to know

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e.g. questions to ask your nurse or doctor, or to record anything you wish your nurse or doctor to know

Acknowledgments

A wide consultation and review of existing resources was used to develop this booklet. We particularly acknowledge the following sources:

National Palliative and End of Life Care Partnership (2015). *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*. London: NHS England. Available at: http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf.

Leadership Alliance for the Care of Dying People (2014). *One Chance to Get it Right*. London: LACDP. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf.

The National Council for Palliative Care (2015). *What to expect when someone important to you is dying. A guide for carers, families and friends of dying people*. NCPC. Available at: Leadership Alliance for the Care of Dying People (2014). One Chance to Get it Right. London: LACDP. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf.

Marie Curie Cancer Care, 2014. What to expect in the last weeks and days. https://www.mariecurie.org.uk/help/terminal-illness/ planning-ahead/preparing/what-to-expect

This document is also available in other languages, large print, Braille, and audio format upon request. Please email **communications.cnwl@nhs.net**

هذه الوثيقة متاحة أيضاً بلغات أخرى والأحرف الطباعية الكبيرة وبطريقة برايل للمكفوفين وبصيغة سمعية عند الطلب

Arabic

این مدرک همچنین بنا به درخواست به زبانهای دیگر، در چاپ درشت و در فرمت صوتی موجود است.

Farsi

এই ডকুমেন্ট অন্য ভাষায়, বড় প্রিন্ট আকারে, ব্রেল এবং অডিও টেপ আকারেও অনুরোধ পাওয়া যায়

Bengali

Dokumentigaan waxaa xitaa lagu heli karaa luqado kale, daabacad far waa-wayn, farta indhoolaha (Braille) iyo hab dhegaysi ah markii la soo codsado.

Somali

Mediante solicitação, este documento encontra-se também disponível noutras línguas, num formato de impressão maior, em Braille e em áudio.

Portuguese

நீங்கள் கேட்டுக்கொண்டால், இந்த ஆவணம் வேறு மொழிகளிலும், பெரிய எழுத்து அச்சிலும் அல்லது ஒலிநாடா வடிவிலும் அளிக்கப்படும்.

Tamil

Este documento también está disponible y puede solicitarse en otros idiomas, letra grande, braille y formato de audio.

Spanish

Dokument ten jest na życzenie udostępniany także w innych wersjach językowych, w dużym druku, w alfabecie Braille'a lub w formacie audio.

Polish

આ દસ્તાવેજ વિનંતી કરવાથી બીજી ભાષાઓ, મોટા છાપેલા અક્ષરો અથવા ઓડિઓ રચનામાં પણ મળી રહેશે.

Gujarati

Be belge istenirse, başka dillerde, iri harflerle, Braille ile (görme engelliler için) ve ses kasetinde de temin edilebilir.

Turkish

Central and North West London NHS Foundation Trust,
Stephenson House, 75 Hampstead Road, London NW1 2PL.
Tel: 020 3214 5700 **www.cnwl.nhs.uk**

Ref: 0705_APR2017 | **April 2017**

Q&A from cancer charities – UPDATE: 18 March 2020

People living with cancer now

Q1 Do I need to do anything differently as someone who is being treated / in remission from cancer/living with a chronic cancer?

The Government is advising that people with cancer should be particularly stringent in following social distancing measures. They are:

1. Avoid contact with someone who is displaying symptoms of coronavirus (COVID-19). These symptoms include high temperature and/or new and continuous cough;
2. Avoid non-essential use of public transport, varying your travel times to avoid rush hour, when possible;
3. Work from home, where possible. Your employer should support you to do this. Please refer to employer guidance for more information;
4. Avoid large gatherings, and gatherings in smaller public spaces such as pubs, cinemas, restaurants, theatres, bars, clubs
5. Avoid gatherings with friends and family. Keep in touch using remote technology such as phone, internet, and social media.
6. Use telephone or online services to contact your GP or other essential services.

The detailed advice can be found here: https://www.gov.uk/government/publications/covid-19-guidance-on-social-distancing-and-for-vulnerable-people/guidance-on-social-distancing-for-everyone-in-the-uk-and-protecting-older-people-and-vulnerable-adults

Some people with cancer are more at risk of becoming seriously ill if they contract the COVID-19 infection:

- People having chemotherapy, or who have received chemotherapy in the last 3 months
- People having immunotherapy or other continuing antibody treatments for cancer
- People having other targeted cancer treatments which can affect the immune system, such as protein kinase inhibitors or PARP inhibitors
- People having intensive (radical) radiotherapy for lung cancer
- People who have had bone marrow or stem cell transplants in the last 6 months, or who are still taking immunosuppression drugs
- People with cancers of the blood or bone marrow such as leukaemia, lymphoma or myeloma who are at any stage of treatment

If you are in this category, next week the NHS in England will directly contact you with advice the more stringent measures you should take in order to keep yourself and others safe. For now, you should rigorously follow the social distancing advice in full.

Q3 What will happen to my cancer treatment? For example:

- **Will it be postponed?**
- **Should I still go to hospital appointments?**
- **How will my hospital decide whether I am a priority for treatment? Will there be national rules?**
- **If treatment, including stem cell transplants, are deferred and I begin to relapse will this limit my eligibility for future lines of treatment?**

- **Should I start chemotherapy treatment (particularly if it is a 2nd/3rd line for "mop up") or postpone?**
- **As a stage 4 patient will I be given life support if I have breathing difficulties due to the virus?**
- **If I get the virus and recover, will this affect my cancer treatment and outlook?**

Clinicians will always make decisions to prioritise treatment for those most in need and in consultation with patients.

Many hospitals have started to use more telephone consultations as a way of helping people to avoid long waits in clinics and for treatment. You may be called to arrange your treatments in this way, and planned treatments may need to be moved to help with running a smooth service.

Your clinical team are best placed to talk with you about the effect on your treatment and appointments. They will work with you to determine the best course of action in each individual situation. If you have any concerns or questions about your treatment, please speak to your clinical team.

Q3a. I am on chemotherapy. If I experience sweats/ cough/ shivering should I call NHS 111 or the chemotherapy care line?

You should call the chemotherapy care line.

Q3b. If I need to self-isolate for more than seven days, what will happen in relation to treatment that has to be done weekly?

Your clinical team are best placed to talk with you about the effect on your treatment and appointments. They will work with you to determine the best course of action in each individual situation.

There is guidance on staying at home if you or someone in your household think you have coronavirus: https://www.gov.uk/government/publications/covid-19-stay-at-home-guidance/stay-at-home-guidance-for-households-with-possible-coronavirus-covid-19-infection

Q4 What are the symptoms likely to be?/Will the symptoms be different because I have cancer?/What should I look out for?

The NHS outlines the common symptoms of coronavirus on its website.

Coronavirus can have serious effects on anyone who has a long-term health condition or a weakened immune system, including some people with cancer. Follow the advice on avoiding catching or spreading germs. (see Q1).

Q4a. Can you catch this virus more than once?

It is not yet known whether reinfection is possible, although many experts think it is unlikely.

Q5 What should I do if my clinician is diagnosed with coronavirus?

If your clinician is diagnosed with coronavirus and you have not seen them recently, then you are unlikely to have been exposed to coronavirus.

Health professionals are working to contact anyone who has been in close contact with people who have coronavirus. If you are concerned about the impact this will have on your treatment, contact your hospital for advice.

Q6 Should I go to work / not see friends / not see friends who've travelled from affected areas?

We recommend everyone follows the Government advice on social distancing. Please see answer to Q1.

Q7 What if I have travel planned or a holiday booked to one of the affected areas – am I more at risk if I do travel?

The Government is currently advising against all non-essential travel. If you feel your travel is essential, you should talk to your clinical team about any plans.

The Foreign Office has the most up-to-date information about how different countries are affected: www.nhs.uk/conditions/coronavirus-covid-19/advice-for-travellers/

People who have had cancer in the past

Q8 Does having had cancer treatment in the past (for example, stem cell transplants, chemotherapy, radiotherapy) in the past – even if I am now in remission – increase my risk if I get the virus?

This depends on the type of cancer and the treatment you have had. Most people make a full recovery after cancer treatment and their immune system either recovers fully or is not affected. (see Q1 response)

Family/friends/carers of people living with cancer

Q9 I have been exposed to the virus and am a carer for someone with cancer. What should I do? Who will look after the person I care for if I am unable to?

The Government is currently advising that if you have symptoms and you live with a vulnerable person, you should try to find somewhere else for them to stay for 14 days.

If you provide essential care (such as help with washing, dressing, or preparing meals), you may find this guidance on Home care provision useful.

It is also a good idea to think about what happens if you become unwell. If you need help with care but you're not sure who to contact, or if you do not have family or friends who can help, you can contact your local council who should be able to help you. Carers UK have also produced advice for those currently caring for others: https://www.carersuk.org/help-and-advice/health/looking-after-your-health/coronavirus-covid-19

Q10 I am a carer to someone with cancer. Should I be doing anything differently?

If you provide essential care (such as help with washing, dressing, or preparing meals), you may find this guidance on Home care provision useful.

Q11 Should I consider not sending my child with cancer/sibling of a child with cancer to school?

Current advice is for children to still attend school, and to follow the Public Health England advice to minimise the risk of infection by washing your hands frequently, practicing good hygiene and avoiding contact with people who are unwell www.nhs.uk/conditions/coronavirus-covid-19/.

If you have any concerns, please speak to the clinical team overseeing your child's care.

The future

Q11 Will cancer patients be a priority for the vaccine if/when it is developed?

There is currently no vaccine for this form of coronavirus. Research is being done to develop a vaccine, but this will take many months.

The best way to reduce your chance of infection is to follow the NHS advice on reducing the risk of picking up infections including thoroughly washing your hands frequently, practicing good hygiene and avoiding contact with people who are unwell: www.nhs.uk/conditions/coronavirus-covid-19/

Q12 If the pressure on the NHS grows, will my treatment be delayed?

See Q3.

Q13 Will there be problems accessing my cancer drugs?

There are currently no medicine shortages as a result of COVID-19. The country is well prepared to deal with any impacts of the coronavirus and we have stockpiles of generic drugs like paracetamol in the event of any supply issues.

The Department of Health and Social Care is working closely with industry, the NHS and others in the supply chain to ensure patients can access the medicines they need and precautions are in place to prevent future shortages.

There is no need for patients to change the way they order prescriptions or take their medicines. Patients should always follow the advice of doctors, pharmacists or other prescribers who prescribe and dispense their medicines and medical products. The NHS has tried-and-tested ways of making sure patients receive their medicines and medical products, even under difficult circumstances. If patients order extra prescriptions, or stockpile, it will put pressure on stocks, meaning that some patients may not get the medicines or medical products they need.

For people worried they have cancer

Q14. I am worried that I have symptoms of cancer. Should I still go to my GP?

It is important that you seek clinical advice if you have a worrying symptom. GP surgeries have been advised to offer online consultations and remote triage so that people do not have to attend in person unnecessarily. Please contact your GP surgery directly if you are worried about a possible cancer symptom.

Q15. I have just been referred by my GP with suspected cancer. Should I attend my diagnostic appointment?

Please discuss with the clinical team at the hospital.

In the event of any disruption, hospitals will always make decisions to prioritise tests for those most in need.

St Joseph's Hospice

CONFIDENTIALITY CLASSIFICATION	
C1 Non-confidential	
C2 Restricted int. circulation	X
C3 Restricted ext. circulation	

Carer administration of sub-cutaneous injections procedure

Procedure summary

This procedure sets down the minimum acceptable standards for all aspects of carers'* administration of as required subcutaneous medications and fulfils legal and governance requirements.

Document Detail	
Document type	Procedure
Document name	Carer administration of sub-cutaneous injections procedure
Document location	The Loop and X:\Public\Policies, procedures and guidelines\Clinical
Version	2.0
Effective from	October 2019
Review date	October 2021
Owner	Medical Consultant
Author(s)	Dr Kate Crossland – Specialty Doctor in Palliative Medicine Dr Margaret Clifford – Consultant in Palliative Medicine Jane Naismith – Nurse Consultant, Community Palliative Care Roxanne Vieira-Moreno – Community Palliative Care Team Lead
Approved by, date	Drugs and Pharmacy Committee
Superseded documents	V1
Related documents	Medication administration procedure Patient and carer self-administration procedure Risk Assessment Procedure
Keywords	Injection Injectable medication Family Carer Administration
Relevant external law, regulation, standards	1) General Medical Council *Good Practice in Prescribing and Managing medicines and devices* 2013 paras 6-13 2) General Medical Council. *Delegation and Referral* paras 3-5 2013 3) Nursing and Midwifery council. *Accountability and Delegation: what you need to know. The principles of accountability and delegation for nurses, students, healthcare assistants and assistant practitioners - a guide for the nursing team* 2011

Change History

Date	Change details, since approval	Approved by
16.10.19	Reviewed by Consultants Tara Whitburn, Hannah Robinson, Tom Osborne and Medical Director Andrew Tysoe Calnon. No changes required	D&P Chair's action 16.10.19

Policy Statement

St Joseph's Hospice aims to deliver high quality specialist palliative care which is responsive to patient need and determined in partnership with patients and their families/ carers* wherever possible. In all activity, the Hospice aims to provide services in a way that is consistent with its Mission and core values of human dignity, compassion, justice, quality and advocacy.

Management of complex symptoms can be a barrier to patients' achieving home as their preferred place of death. Although in the UK there are a variety of services available in the community these are not always able to respond in the time frame necessary to enable effective symptom management.

The aim of the procedure is to help guide healthcare professionals through the necessary steps involved in allowing a carer* to administer injectable medication.

The policies and procedures in relation to administration of medications have been developed and overseen by the Drugs and Pharmacy Committee who meet monthly and report to the Clinical Governance Committee.

Definitions:

Injections / Injectable medication – This will usually comprise medications for symptom control in the last days – weeks of life, most commonly given as subcutaneous injections. There may sometimes be circumstances, which require medications to be given by injectable routes other than subcutaneous, e.g. intravenous via a PICC line.

Carer – Any person providing care for the patient who is doing so as part of a personal rather than professional relationship. This is usually a family member or friend.[1]

Controlled drug – Some prescription medicines are controlled under the Misuse of Drugs legislation (and subsequent amendments). These medicines are called controlled medicines or controlled drugs.[2]

Competence - "The state of having the knowledge, judgement, skills, energy, experience and motivation required to respond adequately to the demands of one's [professional] responsibilities." [3]

Who this procedure applies to:

Patients: Any patients resident in the boroughs of City of London, Hackney, Tower Hamlets and Newham who are on the caseload of the community palliative care team based at St Joseph's Hospice.

Staff: All registered nurses employed by either St Joseph's Hospice, Community health / district nursing services in the above boroughs, and / or the Marie Curie night nursing service, who are involved in caring for patients on the caseload of the community palliative care team based at St Joseph's Hospice will need to adopt this procedure via their individual approval processes.

Risk Management:

1. Participation of carer(s) in administration of subcutaneous injections must be entirely voluntary. The healthcare professional assessing suitability must ensure that the carer has not been subjected to undue pressure from either the patient, another family member or a healthcare professional to take on this role. The healthcare professional must assure the carer that they can stop administering subcutaneous injections at any time if they don't feel comfortable to continue.
2. The healthcare professional must complete a risk assessment template (appendix 2) prior to any carer taking on the role of administration of subcutaneous injections.
3. The carer must complete a satisfactory competence assessment prior to administering subcutaneous injections, and a registered nurse must complete the competence assessment checklist (appendix 3).
4. Should a drug error occur, and the carer's competence is in question or carer's intentions in doubt then the carer must not continue to administer subcutaneous injections.
5. The prescriber and registered nurse must pre-agree appropriate boundaries for administration of subcutaneous injections, including which drugs are appropriate for the carer to administer, the maximum number of injections of each drug the carer should administer in a 24-hour period etc. It may be that not all subcutaneous drugs are appropriate for the carer to give.
6. Carers will be provided with a "carer's direction to administer as required subcutaneous medication" form, which includes information about sharps disposal and the steps to take in case of needlestick injuries.
7. Carers will be provided with the appropriate equipment for administration of subcutaneous injections and appropriate disposal of sharps.
8. Carers will be permitted to take on the role of administration of subcutaneous injections with the consent of a patient who has capacity. Where a patient does not have capacity, the GP / Specialist Palliative Care (SPC) Multidisciplinary Team (MDT) will make an assessment of best interests and document same. If the SPC MDT is making the best interests decision, the GP must be in agreement and the SPC Consultant will sign the relevant section of the consent form on behalf of the MDT.
   If a more timely decision is needed, the Clinical Nurse Specialist can sign the consent form following a telephone discussion with the on-call medical Consultant; the reasons for this and the telephone discussion must be documented in the patient's notes.
9. The carer's involvement in administering subcutaneous injections, and experience of same, must be taken into account when assessing bereavement risk and providing bereavement support.

Procedure:

1. **Discuss with GP / primary prescriber** whether they would be willing to allow a carer to administer injectable medication. Only proceed with the rest of the procedure if the GP / primary prescriber is in agreement.

2. **Assess the patient / carers' suitability**
   Complete the checklist in appendix 1. This may be completed by a community palliative care CNS (band 7 or above) or doctor (registrar level or above).

3. **Undertake a risk assessment**

3.1 Complete a Risk Assessment for each carer – see example in appendix 2. This should be completed by the registered nurse and signed off by the medical or nurse consultant.
3.2 If any likelihood score is greater than 1 then this is an indication of unsuitability to proceed for an individual carer; however as each carer is considered separately it does not preclude proceeding with another carer
3.3 Risk assessment should be re-evaluated following the carer's competence assessment

4. Approach the patient and carer

4.1 Where possible, discuss with the patient the possibility of their carer(s) administering subcutaneous injections. The patient may wish to specify which carers they would be willing to allow to take on this role.
4.2 Ask the carer(s) nominated by the patient if they are willing to take on administration of subcutaneous injections. Ensure that the carer understands that taking on this role is entirely voluntary and that they can choose to stop at any time if they feel uncomfortable. (Note: Professional staff must continue to assess on an ongoing basis the impact the administration role is having on the carer and patient.)
4.3 Provide copies of the information leaflet (see appendix 6) to the patient and carer and, if time allows, give them at least 24 hours to read and consider the information.
4.4 Ensure you discuss:
  - That the carer will need to be assessed for competence
  - That advice and support tailored to the individual patient and carer will be arranged
  - That it can be difficult for carers to undertake this as it places a burden on them - they do not have to do it; they can change their minds
  - That near the end of life injections may need to be given; these will not cause death but may happen near the time of death
  - That the hospice can be contacted 24/7 for advice

4.5 If the patient and carer are happy to proceed move on to assessing competence.

5. Assess the carer's competence

5.1 Use the checklist provided in appendix 3 when assessing the carer's competence. Where more than 1 carer will be administering injectable medication a separate checklist must be completed for each carer.
5.2 The competence assessment must ONLY be undertaken by a registered nurse who themselves is aware of the correct use, limitations and hazards of subcutaneous injections as part of their scope of practice.[11]
5.3 Re-assess risk assessment following carer's competence assessment.

6. Document consent

6.1 If the patient has capacity, they must give consent for their carer(s) to administer subcutaneous injections. Where a patient does not have capacity, the GP / Specialist Palliative Care MDT will make an assessment of best interests and document same. If the SPC MDT is making the best interests decision, the GP must be in agreement and the SPC Consultant will sign the relevant section of the consent form on behalf of the MDT.
6.2 The carer, patient and / or GP / Consultant must complete and sign the relevant sections of the consent form contained in appendix 4. Where there are multiple carers administering subcutaneous injections to a patient, a separate consent form must be completed for each individual carer.

7. Provide support and guidance for the carer

7.1 Provide the carer(s) with a bespoke "carer's direction to administer as required subcutaneous injections" form (see appendix 5).
This template contains information about when and how often each injectable medication can be given, the indication for each medication, and when and who to contact for guidance and support.

7.2 Advise the carer that all injectable medications they administer must be documented on the Authorisation Chart. Please note this is the same Authorisation Chart already in use in each borough and being completed by healthcare professionals administering subcutaneous medications.

7.3 Advise the carer that the Authorisation Chart must be kept with the patient and must be accessible by any healthcare professional who visits the patient.

7.4 Complete a special alert on the patient's St Joseph's Electronic Patient Record / Crosscare record that says "*Name of carer* (*relationship to patient)* is authorised to give injectable medications to this patient – see "Documents" and request that the GP, District Nurses and other relevant professionals complete equivalent alerts on their own documentation.

7.5 Carers who are administering subcutaneous injections must receive a phone call or face to face visit from a CPCT CNS or doctor at least once a week to monitor and support them.

7.6 If at any time a carer wants to stop giving subcutaneous injections, reassure them this is fine and will not affect the patient's care. Inform district nursing team and GP, remove alert from Crosscare notes, and remove "carer's direction to administer as required subcutaneous injections" form from patient's home at next visit

7.7 If a drug error occurs, the carer's competency is in question or carer's intentions are in doubt then the carer must not continue to administer subcutaneous injections. If any of these situations occur, sensitively inform patient and carer of this; then inform district nursing team and GP, remove alert from Crosscare notes, and remove "carer's direction to administer as required subcutaneous injections" form from patient's home at next visit

References

1) https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets
2) Misuse of Drugs Act 1971; Misuse of Drugs Regulations 2001
3) Ref: Integrated core career and competence framework for registered nurses (RCN)
4) General Medical Council *Good Practice in Prescribing and Managing medicines and devices* 2013 paras 6-13
5) General Medical Council. *Delegation and Referral* paras 3-5 2013
6) Nursing and Midwifery council. *Accountability and Delegation: what you need to know. The principles of accountability and delegation for nurses, students, healthcare assistants and assistant practioners- a guide for the nursing team* 2011
7) National Health Service National Prescribing Centre. *A guide to good practice in the management of controlled drugs in primary care,* 3rd edition, December 2009
8) Anderson BA and Kralik D. *Palliative care at home: Carers and medication management*. BMJ Support Palliat Care 2008; 6: 349-356.
9) Bradford and Airedale teaching PCT trust. Subcutaneous drug administration by carers (Adult palliative care) October 2006. Accessed via palliativedrugs.com
10) The Lincolnshire Policy for Informal Carer's Administration of As Required Subcutaneous Injections in Community Palliative Care
11) Standards for Competency for Registered Nurses 2013 Nursing and Midwifery Council

……………………………end …………………

Appendices

Appendix 1 – Criteria for Suitability Checklist

	Criteria suggesting suitability	Y/N
(1)	The carer(s) are over the age of 18 years.	
(2)	The patient has unpredictable symptoms where continuous medication (i.e. syringe driver) would produce undesirable side effects e.g. drowsiness.	
(3)	The patient may require a stat dose of medication in an anticipated emergency e.g. seizure, large bleed.	
(4)	The patient does not want to be dependent on health care professionals administering their medication, and may potentially like their carer(s) to administer subcutaneous injections.	
	Criteria that may prevent suitability NB these are relative, not absolute, contra-indications	
(5)	There is concern about misuse of injectable medications in the home, e.g. contact with known illegal drug users, security issues within the home etc.	
(6)	There is concern that the carer will not be able to cope either physically or emotionally with undertaking medication administration.	
(7)	The patient is on a complicated drug regime.	
(8)	There are safeguarding concerns regarding the patient and / or carer(s).	
(9)	The patient is known to be positive for HIV / viral Hepatitis.	

If you have answered "Yes" to point (1) and at least one out of points (2), (3) and (4), the patient may be considered potentially suitable to have carer(s) administer subcutaneous injections.

If you have answered "Yes" to any of points (5) to (9), a discussion should take place at the St Joseph's Hospice MDM for the relevant borough and the MDT must, after considering the issues, decide whether or not to proceed further. The MDT discussion and decision must be clearly documented in the St Joseph's EPR system, Crosscare.

(Adapted from Bradford and Airedale teaching PCT trust. Subcutaneous drug administration by carers (Adult palliative care) October 2006. Accessed via palliativedrugs.com)

Appendix 2 – Risk assessment template

Patient's Name:
NHS Number:
DOB:
Assessor's Name ……………………………………………… Title ……………………………………………………

Department : …………………………………………………… Function assessed:… ……………………….

Injectable medication given by non-professional carer…………………………………………………….

Date completed:………………………………………………

Hazard	Who might be harmed	Likelihood /5	Consequence /5	Risk Score	Control Measures	Further action
Wrong drug given	Patient (and carer emotionally)				Assessment of carer competence undertaken before carer allowed to give medication. Assessment repeated until carer feels confident. Written information (authorisation chart) in home with drug name and doses. Telephone advice available 24/7 for support.	
Wrong dose given	Patient (and carer emotionally)				Assessment of carer competence undertaken before carer allowed to give medication. Assessment repeated until carer feels	

					confident. Written information (authorisation chart) in home with drug name and doses. Telephone advice available 24/7 for support.	
Carer distress - Carer may feel burdened by needing to give injections, may feel distressed if has to give injections close to end of life	Carer				Discuss this openly with carer and patient. Provide ongoing support at appropriate level for carer. Telephone advice available 24/7.	
Add individual risks where relevant						

Signed……………………………………Designation………………………………………Date………………………

Agreed by
…………………………………………………………Designation………………………………………Date………….

(This should be a medical consultant)

Date for Review (recommend 3-monthly) …………………………………………………

Appendix 3 – Competence Assessment (Please complete a separate assessment for each carer)

To be completed by the Assessing Nurse

Name of Assessor .... Designation/role ....

Place of work .... Telephone Contact Number ....

Patient's Name ....

Address ....

DOB: .... NHS Number: ....
..
Carer's Name ....Date of assessment ....

This assessment form should be completed by the carer and assessor together for each episode of supervised practice.

		Initial	
Section A Knowledge The carer:	Y/N	Carer	Assessor
Is able to name and identify specific drug being used and main potential side effects.			
Is aware of how and who to contact in the case of queries or untoward events			
Is able to identify potential problems with injection site and their likely causes.			
Section B Observation The carer:			
Washes hands before preparing drugs and equipment required for the injection.			
Checks injection site for redness, swelling or leakage before giving the medication			
Checks drug preparation and dosage against patient's prescription			
Checks expiry date on drug preparation (if expired –discard)			
Ensures drug is stored at room temperature away from sun light.			
Draws up correct drug dosage.			
Expels air correctly from syringe.			
Removes needle from syringe and disposes of needle safely.			
EITHER:			
Attaches correct needle for subcutaneous injection.			
Inserts needle at 45-90 degrees			
OR:			
Connects syringe to giving set correctly and expels the drug.			
Flushes line with 0.3-0.5ml sterile water for injection.			

Section C Post injection The carer:			
Re-checks site for redness or leakage after injection.			
Disposes of syringe and needle safely.			
Documents that the injection has been given, recording the time, drug, dosage, signature.			
Knows when to seek help/advice and how to obtain this. For example, if symptoms are not controlled and they feel unable to give the injection			
Knows how to seek help in case of a needlestick injury.			

All stages above need to be met to meet competence.

1. Person assessing competence

……………………………… (*name of carer)* is competent to undertake a subcutaneous injection via an injection or injection line.

Signature ………………………………………… Designation …………………………………………………
Date …………………………………………………… Date Reassessment Due ………………………………

Please keep a copy of this assessment in the patient's notes

Appendix 4 – Consent Form

Section 1 (To be completed by the carer):

I, ….(carer name)……, have been fully informed about my role in administering subcutaneous injections and I am happy to participate in this role as a carer to (patient's name)….,………………………… (date of birth)…………………. (NHS number)…………………………..

Carer to please read the following statements and initial box as appropriate:

I have been given an information leaflet and given at least 24 hours to read and consider its contents before proceeding further. ☐

I have been taught the procedure and undergone an assessment of my competence to give subcutaneous injections. ☐

I am happy to proceed with administering subcutaneous injections. ☐

I know who to call for support and have their contact numbers. ☐

I have been provided with a "carer's direction to administer as required subcutaneous injections" form and need to comply with its contents. ☐

I am aware that I can relinquish this role at any time. ☐

Carer's signature: ____________________

Date /Time: ____________________

Section 2 (To be completed by the patient – where feasible):

I……….(patient name) ……….am happy for my carer………….(Carer name)………. to take on the role of giving me subcutaneous injections.

Patient's signature: ____________________

Date /Time: ____________________

Section 3 (To be completed by the GP / Palliative Care Consultant where patient lacks capacity to consent):

I………….(doctor's name)…………agree that it is appropriate and in the patient's best interests for ……….(Carer name)…………..to administer subcutaneous injections to ………(patient name, DOB, NHS number)……. who lacks capacity to consent to same.

Doctor's signature: ____________________

Date /Time: ____________________

Section 4 (To be completed by witness, must be a healthcare professional):

I……………(name / role)…………….have witnessed the above carer and / or patient completing and signing this form.

Witness signature: ________________________

Date /Time: ________________________

Appendix 5

Carer's direction to administer as required subcutaneous injections

This document should remain with the patient.

Surname:		**Forename:**	
Date of Birth:		**NHS No:**	
STJH No:		**Origin of chart:**	St Joseph's Hospice - Hackney

Allergies and adverse drug reactions:

Signed by healthcare professional:

Name: Designation:

Signature: Date:

Drug	Indication for use	Dose	Route	Frequency	Any other comments
	Pain				
	Nausea/vomiting				
	Agitation/restlessness				
	Respiratory/noisy secertions				
	Breathlessness				
	(other)				

GUIDANCE FOR PRESCRIBER:

- Check St. Joseph'e Hospice risk assessment tool has been completed and signed for each carer administering subcutaneous injections.
- Check each carer's competence in administering subcutaneous injections has been assessed, using the St. Joseph's competence asessment tool.
- Doses to be as simple as possible, think about vial sizes.
- No dose ranges to be used for carer administration.
- Carers to record doses on same Authorisation Chart used by District Nurses/visiting professionals.
- Give a maximum frequency in line with recommendations below

GUIDANCE FOR CARER:

Please phone St. Joseph's on 03003030400 if:

- an hour (or sooner if you are worried) after giving the drug, the symptom has not improved
- you have given more than 3 doses of a single drug in a 24 hour period
- you have any queries or concerns at all

If you no longer wish to give subcutaneous injections, please let St Joseph's Hospice know so that we can arrange for the district nursing team to take over

Steps involved in administering injection:

1. Wash and dry your hands thoroughly.
2. Check the Authorisation Chart for time the last dose was given, making sure it is ok to give injection.
3. Check the site you are going to give the injection into for inflammation, redness, hardness or soreness.
4. Assemble equipment
   - Needle
   - Syringe
   - Drug to be given
   - Sharps bin
5. Drawing up medication
   - Check the label for medication name (does it match the drug listed on this form and the Authorisation Chart) and expiry date
   - Attach the needle to the syringe
   - Break open the vial of the drug to be given by snapping the top off
   - Draw up the drug into the syringe
   - If you have an air bubble into the syringe, push the plunger in slightly to remove the bubble, do not worry about a small bubble.
6. Administer the injection as you have been shown.
7. Dispose of the needle and syringe into the sharps bin.
8. Write on the Authorisation Chart the time, date, drug, dose, route and sign to record you have given it.
9. Wash and dry your hands thoroughly.

Needlestick injury

If you pierce or puncture your skin with a used needle, follow this first aid advice immediately:

- Encourage the wound to bleed, ideally by holding it under running water.
- Wash the wound using running water and plenty of soap.
- Don't scrub the wound while you're washing it.
- Don't suck the wound.
- Dry the wound and cover it with a waterproof plaster or dressing.
- Contact St Joseph's Hospice (03003030400) for further advice.

Appendix 6 – Information leaflet about carers giving subcutaneous injections

Information about carers giving subcutaneous injections

Introduction

As patients become more poorly they often cannot swallow oral medication or liquids. General pain relief and other symptoms can usually be managed by giving medicine using a small pump called a syringe driver. This is set up and managed by the district nurses and palliative care team.

Sometimes, an extra injection of medicine is needed to keep symptoms under control. This is similar to giving an extra dose of oral medicines when needed, just given by injection instead.

Usually, the district nurse is called out if an injection is needed. Sometimes, patients would like family members or friends (who we refer to as 'carers') to be trained to do this too. This can be helpful as it means the patient does not have to wait for the district nurse to arrive.

What are the steps involved?

If a carer would like to do this, some steps need to be followed to make sure everyone involved is happy that it is a safe thing to do.

- The doctors and nurses will assess if it might be helpful and possible. This would include thinking about what medicine might be needed, how often, and how complicated the situation is.
- The patient will be asked if they would like their carer to give injections.
- The carer will be asked if they would like to learn more about it.
- The doctor or nurse will talk to the carer about benefits and difficulties, for example
  - It can be difficult for carers as it places a burden on them – they do not have to do it; they can change their minds.
  - Near the end of life, injections may need to be given; these will not cause death but may happen near the time of death.
  - It can be a positive way for carers to help support their family members.
- The carer will have some training to show them how to give an injection- including a 'competence assessment'. They will need to show they are able to give an injection on their own and they will be able to say if they are happy to do this
- The carer will be given written information about how often they can give injections, including when to ask for help.

Frequently asked carers' questions

<u>What if I can't go ahead with giving injections?</u>

You will receive training in how to give an injection, and this can be repeated until you feel happy. The person giving the training will assess if you are safe to give an injection. If you or the person giving the training do not feel you are safe to do this, then the patient will continue to receive injections when needed by the district nurse.

<u>What if the I (or my ill relative) want to stop giving injections?</u>

If at any point you wants to stop giving injections, this is fine. You and your relative will both be given information about who to contact to say you would like to stop. The district nurse will continue to give injections when needed.

Your relative (the patient) can say at any point that they want you (their carer) to stop giving injections. The district nurse and palliative care teams will be making regular contact and checking that things are ok.

Can more than one person be trained to give injections?

Yes, this is fine. Each person will need to go through the steps above separately.

Please write down any questions you might have to talk to your doctors and nurses about:

Sub-cut injections digital resources

Sub-cut Injections - digital resource (this is a working resource currently in development)

https://subcut.helixcentre.com

When finished, the site will have the following resources:

1. Instructions for:

- Ampoule
- Blunt needle
- No needle

2. Carer diary, with instructions on how to create one from a blank sheet (if no template sheets are provided by teams)

3. Medication Guide (aka Guide for Carers)

4. Injection training pack

5. Patient and carer information

CARiAD Documents for printing

https://www.dropbox.com/s/u9tuejh6m7k7slx/EOLC%20-%20CARiAD%20Sub%20Cut%20Injections%20-%20complete%20NHS%20docs.zip?dl=0

Tip: You may, in urgency, may need to print off these documents in-house and just staple and hand out to carers. Otherwise, using the printers that CARiAD suggest.

What you can do to practically care for someone who is in their last days and hours of life

NHS

It is important to be aware of what to expect and how to make the experience as comfortable as possible.

Communication and environment

When approaching the end of life, people often sleep more than they are awake and may drift in and out of consciousness.

Try to imagine what the person you are caring for would want. Provide familiar sounds and sensations, a favourite blanket for example, or piece of music. Keep the environment calm by not having too many people in the room at once and avoid bright lighting. This can reduce anxiety even when someone is unconscious. Even when they cannot respond, it is important to keep talking to them as they can most probably hear right up until they die.

Feeling sick

Sometimes people can feel nauseated or sick when they are dying.

If vomiting, and unable to sit up, turn the person on their side to protect their airway. There are medicines that can be given to help relieve this.

Moving

The person will require washing at least once a day and regular turning every 2-4 hours to protect their skin from developing pressure sores.

Alternate their position from lying on their back to each side. You can use pillows or rolled up towels to support them and also to support under their arms and between and under their legs. When you are washing the person, look for signs of redness, or changes in the colour or appearance of their skin. Check the back of the head and ears, the shoulder blades and elbows and the base of the spine, hips and buttocks, ankles, heels and between the knees.

Your health team will advise you on the medications that can help with controlling symptoms experienced at the end of life.

Pain

Some people may be in pain when they are dying. If they are less conscious they may grimace or groan to show this. There are medicines that can be given to ease pain.

Always check their positioning in bed to see if this can also help. They may be too weak to move and this can cause discomfort. Consider if they have any areas that are known to hurt, for example a bad back, and remember this when positioning them.

Going to the toilet

Towards the end of life, a person may lose control of their bladder and bowel. Even though we expect someone to go to the toilet less as they eat and drink less, contact the health care team that is looking after them if they have not passed any urine for 12 hours or more as it can be uncomfortable.

Keep the person comfortable by regularly washing them and changing pads if they are wet or soiled.

Mouth care

While people rarely complain of thirst at the end of life, a dry mouth can be a problem due to breathing mostly through their mouth.

It's important to keep lips moist with a small amount of un-perfumed lip balm to prevent cracking. Regularly wet inside their mouth and around their teeth with a moistened toothbrush whether he or she is awake or has lost consciousness. Check for sore areas and white patches on the tongue, gums and inside the cheek which can be sore. If this happens tell the person's healthcare professionals as it can be treated easily.

Breathlessness and cough

Breathlessness and cough can be another cause of agitation and distress and it can make it difficult to communicate. Don't expect the person to talk and give them time and space to respond. Reassure them that the unpleasant feeling will pass.

You can offer reassurance by talking calmly and opening a window to allow fresh air in. If possible, sit the person up with pillows rather than lying flat as this can help the sensation of not being able to breathe.

Before someone dies their breathing often becomes noisy. Some people call this the 'death rattle'. Try not to be alarmed by this, it is normal. It is due to an accumulation of secretions and the muscles at the back of the throat relaxing. There are medicines that can be given to help dry up secretions if it is a problem.

Agitation or restlessness

Some people can become agitated and appear distressed when they are dying. It can be frightening to look after someone who is restless. It's important to check if the cause is reversible like having a full bladder or bowel which can be reversed by using a catheter to drain the urine or medicines to open the bowels. Your health team can assess if this is necessary.

Check if their pad is wet to see if they are passing urine or if they are opening their bowels. If it's not either of these things, there are things you can do and give to help. Try to reassure the person by talking to them calmly and sitting with them. Touch can be effective in doing this too. There are also medicines that can be given to help settle and relax someone.

Looking after yourself

Caring for a dying person can be exhausting both physically and emotionally. Take time out to eat and rest. Try to share the care with other people when possible and remember it is OK to leave the person's side to have a break.

Washing

Sometimes it may be too disruptive for the person to have a full wash. Just washing their hands and face and bottom can feel refreshing.

To give a bed bath, use two separate flannels, one for the face and top half of the body and one for the bottom half. Start at the top of the body, washing their face, arms, back, chest, and tummy. Next, wash their feet and legs. Finally, wash the area between their legs and their bottom. Rinse off soap completely to stop their skin feeling itchy. Dry their skin gently but thoroughly. Only expose the parts of the person's body that are being washed at the time – you can cover the rest of their body with a towel. This helps to keep them warm and maintains their dignity.

Eating

As the body shuts down it no longer needs food and fluid to keep it going. When a person is dying they often lose their desire to eat or drink and finally their ability to swallow. They can lose weight rapidly.

This is often difficult to accept because we often equate food with health and feeding people as an act of love. However, hunger and thirst are rarely a problem at the end of life.

Continue to offer a variety of soft foods and sips of water with a teaspoon or straw for as long as the person is conscious (but allow them to refuse it). It's important not to force food or drink onto someone who no longer wants it. Remember to sit them up when offering food and fluids to avoid choking.

When a person is no longer able to swallow some people want them to have fluids via other routes like a drip, but at the end of life this offers little, if any, benefit. The body cannot process the fluid like a healthy body can and it can be harmful to artificially feed and hydrate. Risks include infection at the insertion site or in the blood, and fluid overload resulting in swelling or even breathing problems.

Section 6

Care after death

Care immediately before and after death

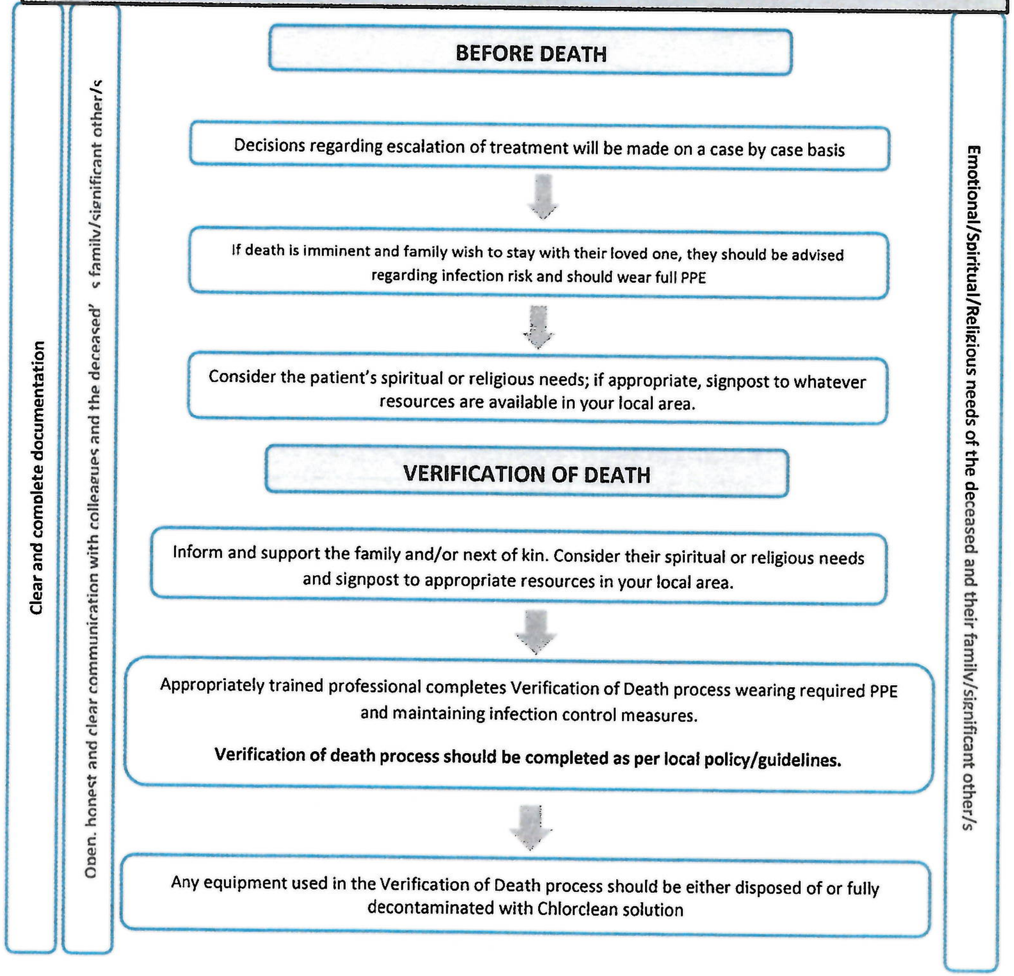
A proportion of people who have severe COVID-19 will die of the infection or complications. This guidance includes a flow chart of what needs to be done and how best to support people in this situation, throughout this period. Bereavement support will be essential particularly for those with existing 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)



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

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

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.

↓

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.

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.

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

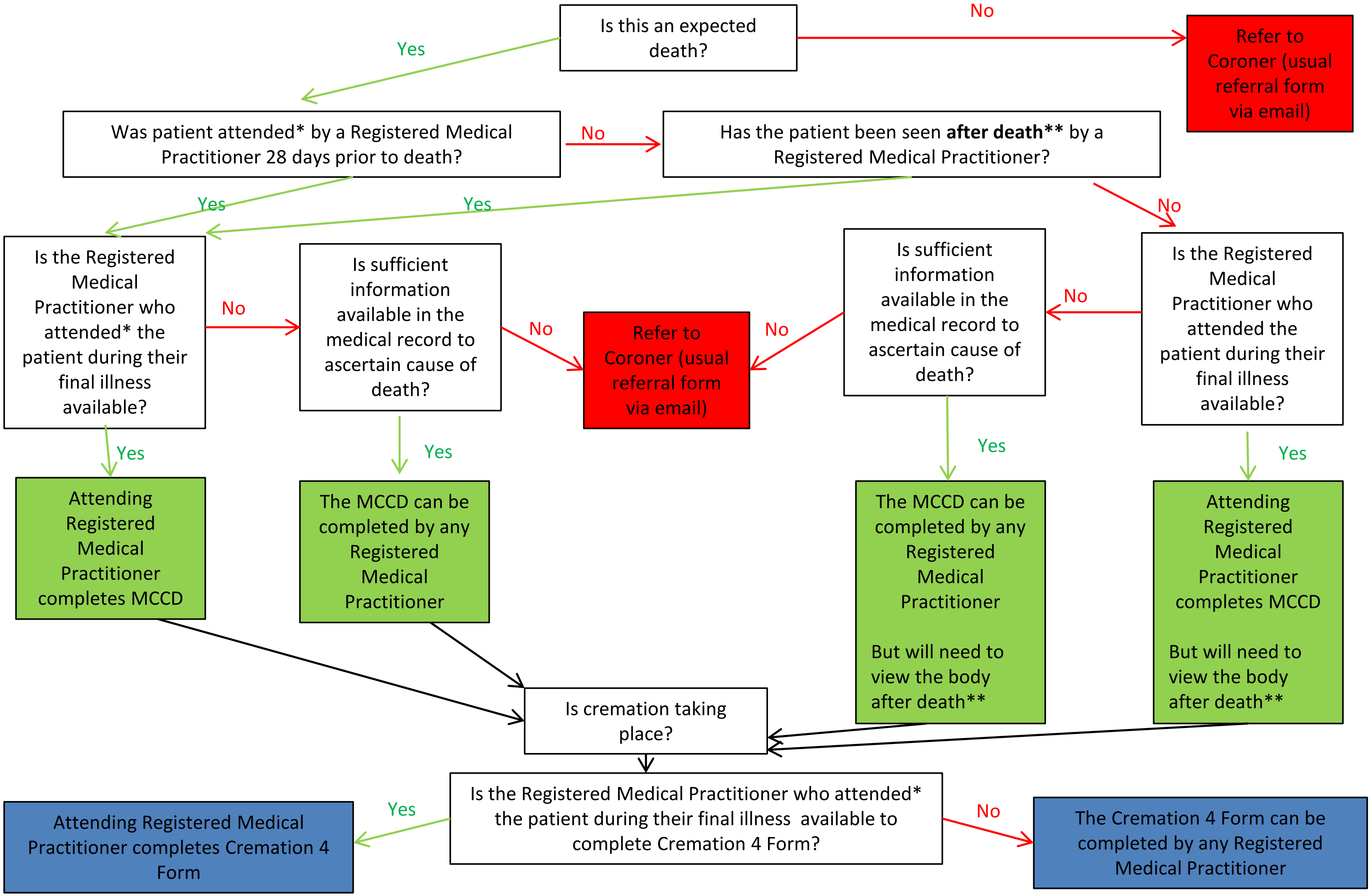
↓

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 Coronavirus Act 2020: Death certification and cremation processes



Is this an expected death?

Refer to Coroner (usual referral form via email)

Was patient attended* by a Registered Medical Practitioner 28 days prior to death?

Has the patient been seen **after death**** by a Registered Medical Practitioner?

Is the Registered Medical Practitioner who attended* the patient during their final illness available?

Is sufficient information available in the medical record to ascertain cause of death?

Refer to Coroner (usual referral form via email)

Is sufficient information available in the medical record to ascertain cause of death?

Is the Registered Medical Practitioner who attended the patient during their final illness available?

Attending Registered Medical Practitioner completes MCCD

The MCCD can be completed by any Registered Medical Practitioner

The MCCD can be completed by any Registered Medical Practitioner

But will need to view the body after death**

Attending Registered Medical Practitioner completes MCCD

But will need to view the body after death**

Is cremation taking place?

Is the Registered Medical Practitioner who attended* the patient during their final illness available to complete Cremation 4 Form?

Attending Registered Medical Practitioner completes Cremation 4 Form

The Cremation 4 Form can be completed by any Registered Medical Practitioner

*A patient is now considered to have been attended (seen) by a Registered Medical Practitioner when alive including via video consultation

** A patient is only considered seen after death if this has been done IN PERSON

HM Passport Office

General Register Office

GRO Circular No.5/2020
General Register Office
Trafalgar Road
Southport
PR8 2HH

Superintendent Registrars
Registrars of Births and Deaths
Additional Registrars
Registration Authorities
Proper Officers

27 March 2020

Dear Colleague,

Coronavirus Act 2020

Further to the e-alert of yesterday confirming that the Coronavirus Act 2020 had received Royal Assent, I can now confirm that the section of the Act enabling modifications to registration processes has also been commenced by regulation.

The provisions now in place allow the following:

<u>MCCD for registration purposes</u>

- A medical certificate can be accepted from any medical practitioner so long as they are able to state to the best of their knowledge the cause of death.
- Registrars can accept MCCDs without referral to the coroner, provided it contains an acceptable cause of death, and indicates that a medical practitioner has seen the deceased either within the 28 days prior to death, or after death (this does not need to be the certifying medical practitioner).
- While these provisions are in force, if it is indicated that a patient was seen in the 28 days prior to death by video link (such as skype) this should be accepted as

seen. This (video link) does not however meet the requirement for seen after death.
- Advice on Covid-19 as a cause of death was provided in circular 02/2020

Signing of the MCCD

- Provision for any registered medical practitioner to issue a MCCD without having personally attended the deceased, provided they are sufficiently able, from the available information, to ascertain the cause of death.
- The declaration on MCCDs will be amended as necessary by certifying doctors. This will show whether or not they have been in medical attendance and if not whether another doctor has seen the deceased after death and/or within 28 days prior to death.
- The after-death requirement will be through the existing ringed boxes on the MCCD.
- If there is no other reason for the death to be referred to the coroner, the MCCD should be accepted. If possible, registration officers should liaise with their local surgeries and hospitals to ascertain a list of possible signatories and their GMC numbers.

The registration

- Permission is granted to remove the requirement for a death or still-birth informant to attend and provide details in person and the requirement for them to sign the register where a local authority can no longer offer face to face service registrations or where this is needed by way of additional contingency.
- This will enable the information for the registration to be collected by telephone. When registering by telephone, in the signature box (space 8 of the death entry) registrars should record the full name of the informant followed by the words ‘information given by telephone’ (the same wording should be used for still-birth registrations).
- It is possible for telephone registration to be undertaken from the office or remotely and each authority should direct on practice for their area.

Remote registration

- If working remotely registrars will still require secure e-mail links in order to receive and send information.
- If without print facilities, registrars will need to register manually, although information will still be able to be captured onto RON. In such cases the RON entry should be completed after the register page has been signed by the registrar

and they have added their designation. After capturing to RON, the entry can be locked.

- The disposal form can also be completed manually and as an option, once signed off, it can be photographed and sent on to the relevant authority as an email attachment with the original being retained.

Qualified Informants

- The list of qualified informants is temporarily extended to include a funeral director (where they are acting on behalf of the family)
- Funeral directors are an addition to the existing list of qualified informants rather than a replacement, family members are still allowed (and may be preferred).
- Where a funeral director does act as informant their designation shall be recorded as “Causing the body………” and the words ‘Funeral Director’ should be recorded after their surname, in the informant surname field.

Electronic transmission of documents

- The provisions also allow for the electronic transfer of documents relating to the certification and registration process (e.g. transfer of the MCCD from the medical practitioner to the registrar and the form for burial or cremation (the Green), from the registrar to the relevant authority).
- It is not envisaged that scanned documents should be received via a third party.
- Under this arrangement these documents can be scanned or photographed and sent as an attachment, though a wet signature is still required on the original.
- For MCCDs medical practitioners should be provided with a secure (local authority) email address to send to.
- Disposal forms can be completed manually and similarly scanned or photographed for onward sending. Registrars should engage to find an email address for the relevant authority (local burial and crematorium authority); which could be a local authority shared mailbox (as long as the relevant person at the crematorium or cemetery can access it) as well as an address for returning counterfoils.
- After the emergency period, arrangements should be made to have all original forms sent to the register office to be processed in the normal manner.

Detailed guidance as to how the above modifications may be used is enclosed with this circular. Please also note that registration officers should advise their Compliance Officer, whether they intend to use some or all the modifications.

Yours faithfully

Andrew Dent

Andrew Dent
Deputy Registrar General

Email from Dr Lyndsey Williams

Dear Colleagues,

The Coronavirus Act 2020 has received Royal Assent.

Please see below the specifics of the Act enabling modifications to death registration processes commenced by regulation.

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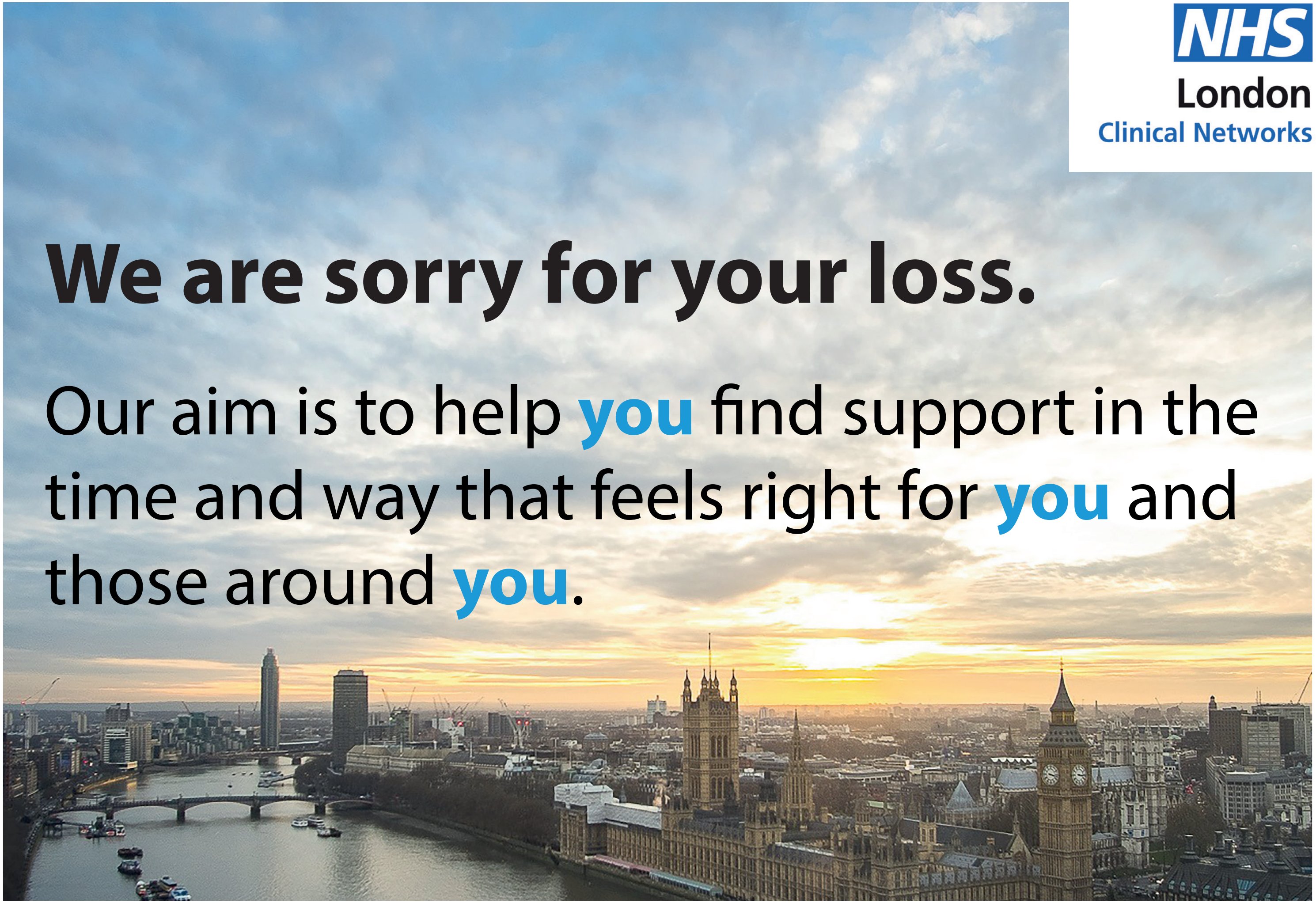
Dr Lyndsey Williams

Macmillan GP EOLC Brent CCG

Clinical Director Brent CCG



NHS
London
Clinical Networks

We are sorry for your loss.

Our aim is to help **you** find support in the time and way that feels right for **you** and those around **you**.

Support during your bereavement journey

NHS
London
Clinical Networks

We have put together a list of bereavement resources. These may be of help to you now or during your bereavement journey.

When someone in the UK dies, information about what needs to happen next can be found at: **www.gov.uk/after-a-death**

If you are bereaved and would like to speak with someone, you can call Cruse Bereavement Care for free on Tel **0808 808 1677** or visit **www.cruse.org.uk**

Child Bereavement UK offers support for families and professionals when a child dies or when a child grieves national helpline **0800 02 888 40**

At a Loss has a website with useful bereavement resources **www.ataloss.org**

Independent Age provides information and advice on a range of subjects including welfare, legal and financial Tel **0800 319 6789** or **www.independentage.org/information/personal-life/when-someone-dies**

If you are looking for local help and support, Marie Curie has information on a range of issues including practical, legal and financial. Tel **0800 090 2903** or **www.mariecurie.org.uk/help/support/support-directory/bereavement-support#coping**

Section 7
Additional resources

Additional information, resources and links

Symptom Control / Management

RCGP: Additional COVID 19 guidance available https://elearning.rcgp.org.uk/mod/page/view.php?id=10389

Bereavement

Marie Curie: https://www.mariecurie.org.uk/help/support/coronavirus

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

Care homes

British Geriatrics Society: **https://www.bgs.org.uk/resources/resource-series/coronavirus-and-older-people**

Managing the COVID-19 pandemic in care homes: **https://www.bgs.org.uk/sites/default/files/content/attachment/2020-03-25/BGS%20Managing%20the%20COVID-19%20pandemic%20in%20care%20homes_0.pdf**

Ethics

PHE - Responding to COVID-19: the ethical framework for adult social care, published 19 March 2020: **https://www.gov.uk/government/publications/covid-19-ethical-framework-for-adult-social-care/responding-to-covid-19-the-ethical-framework-for-adult-social-care**

Feedback and further queries

For any further information or for queries about this pack please contact: Nwlccgs.covid19community@nhs.net