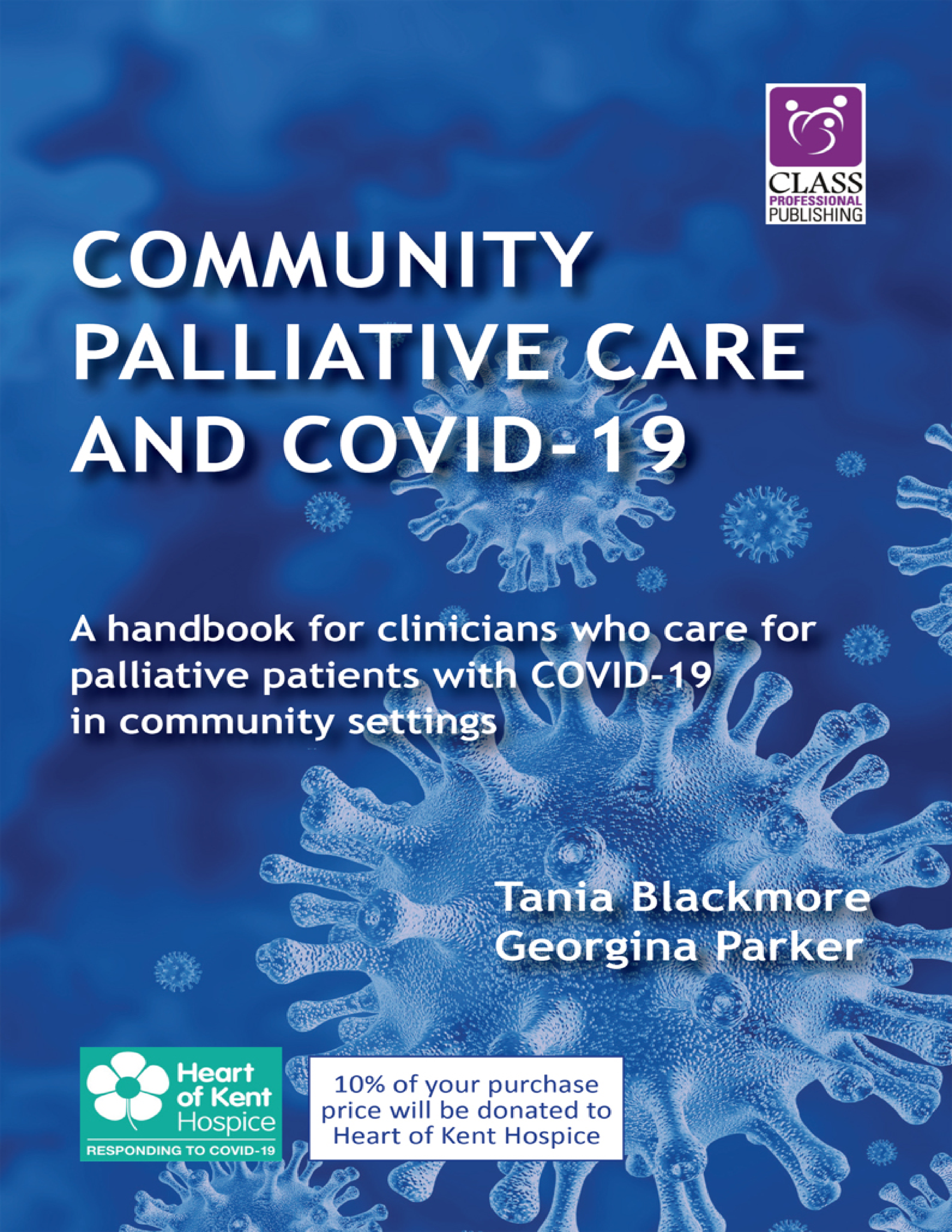

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COMMUNITY PALLIATIVE CARE AND COVID-19

A handbook for clinicians who care for palliative patients with COVID-19 in community settings

Tania Blackmore
Georgina Parker

Heart of Kent Hospice
RESPONDING TO COVID-19

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Community Palliative Care and COVID-19

Tania Blackmore
and
Georgina Parker

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Disclaimer

The details in this book are presented for information purposes only and any guidance, although accurate at the time of publication, may be subject to change. Healthcare professionals should always follow local procedures and be aware of their own scope of practice.

Acknowledgements

This book is dedicated to all those who have lost their lives to COVID-19: our thoughts are with them, their families and their loved ones. We also dedicate this book to the frontline workers who continue through the pandemic with professionalism, compassion and resilience.

Special thanks to the frontline healthcare professionals who have contributed case studies: Ashley, Harriet, OJ, Jacquie, Becca and Sophie.

The authors and contributors have pledged all royalties to Heart of Kent Hospice.

Tania Blackmore and Georgina Parker

Heart of Kent Hospice

Heart of Kent Hospice has been providing exceptional care to people living with a terminal illness in Maidstone, Aylesford, Tonbridge, Malling, and surrounding areas since 1991. The Hospice has built an excellent reputation within the local community for both the quality and compassion of the care provided. This was endorsed by the Care Quality Commission who, following an inspection in February 2017, awarded the Hospice an overall rating of 'Outstanding'.

Following the outbreak of COVID-19, the Hospice's priority was to protect their patients, their visitors, colleagues and volunteers from the spread of infection; and to ensure that care continued across all its services.

To date the Hospice has cared for over 15,700 patients and their families, while at the same time improving, expanding and adapting their services to meet the growing needs of the local community. As a local charity, independent of the NHS, the Hospice's services cost £4 million a year to run, with over £3 million raised through the generosity of their local community.

Heart of Kent Hospice is extremely grateful to the authors, who have agreed to donate their royalties from the sales of this book to support the Hospice in continuing to provide its outstanding services.

Introduction

What is Palliative Care?

The World Health Organization (WHO) defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems (physical, psychosocial and spiritual).

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;

- will enhance quality of life and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

(WHO, 2018)

The Impact of Coronavirus

Coronavirus disease, or COVID-19, is caused by a virus called the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). It was first seen in Wuhan, China in December 2019. By 11 March 2020, the World Health Organization declared a pandemic, with estimations of a global mortality rate of 3.4% with a greater mortality rate estimated in the elderly and those with underlying health conditions (Costantini, Sleeman, Peruselli and Higginson, 2020). The whole population is at risk of contracting COVID-19, but those who are older or frail, have co-morbidities and palliative diagnoses are more likely to suffer the fatal consequences of the virus (Kunz and Minder, 2020). Chinese epidemiological data suggests that the two correlating factors associated with severe disease in COVID-19 are older age and existing underlying health conditions, which are both predominant characteristics of patients with palliative needs (Bowman et al., 2020).

Specialist palliative care services are ideally placed to play a unique role in providing care to patients with palliative needs in the community who acquire COVID-19. According to Ferguson and Barham (2020), palliative care services are skilled in:

1. working within an interdisciplinary team

2. patient advocacy
3. education of generalist clinicians
4. chronic illness
5. frailty
6. co-morbidities
7. and lastly – and some would say the most important skill – the ability to place humanity in the field of medical science and intervention.

(Ferguson and Barham, 2020)

The challenges of providing palliative care within the context of COVID-19 fall into three domains of care:

1. management of patients' symptoms
2. advance care planning
3. support of families and friends of families of patient who have a palliative prognosis.

(Arya et al., 2020)

This handbook will discuss the care of community palliative care patients who have already stated that if they contract COVID-19, their preferred place of care is at home (including their care home) and also if their condition deteriorates that their preferred place of death is home or the hospice.

Advance Care Planning

Why is Advance Care Planning Important?

This handbook is about putting patients' wishes first and involving their loved ones in their care and Advance Care Planning (ACP). Advance Care Planning involves clinicians speaking to patients and their loved ones and documenting a patient's wishes if their condition were to deteriorate, this is particularly pertinent at a time of a global pandemic.

Although health systems work to keep the general population from getting COVID-19 and to treat those who do contract it, there must be in addition to this an urgent requirement to increase ACP for older adults and other vulnerable groups of the population so that unwanted hospitalisations do not occur (Block, Smith and Sudore, 2020).

Some palliative care patients will already have ACPs, but now these patients will also need to be informed of the risk they may face because of COVID-19 infection (Borasio et al., 2020).

Discussing the appropriate ceiling of care with palliative care patients who may contract COVID-19 is imperative so that these patients have control over where they want their lives to end at a time when they may not have control over many other things that they are experiencing.

Treatment Escalation Plans

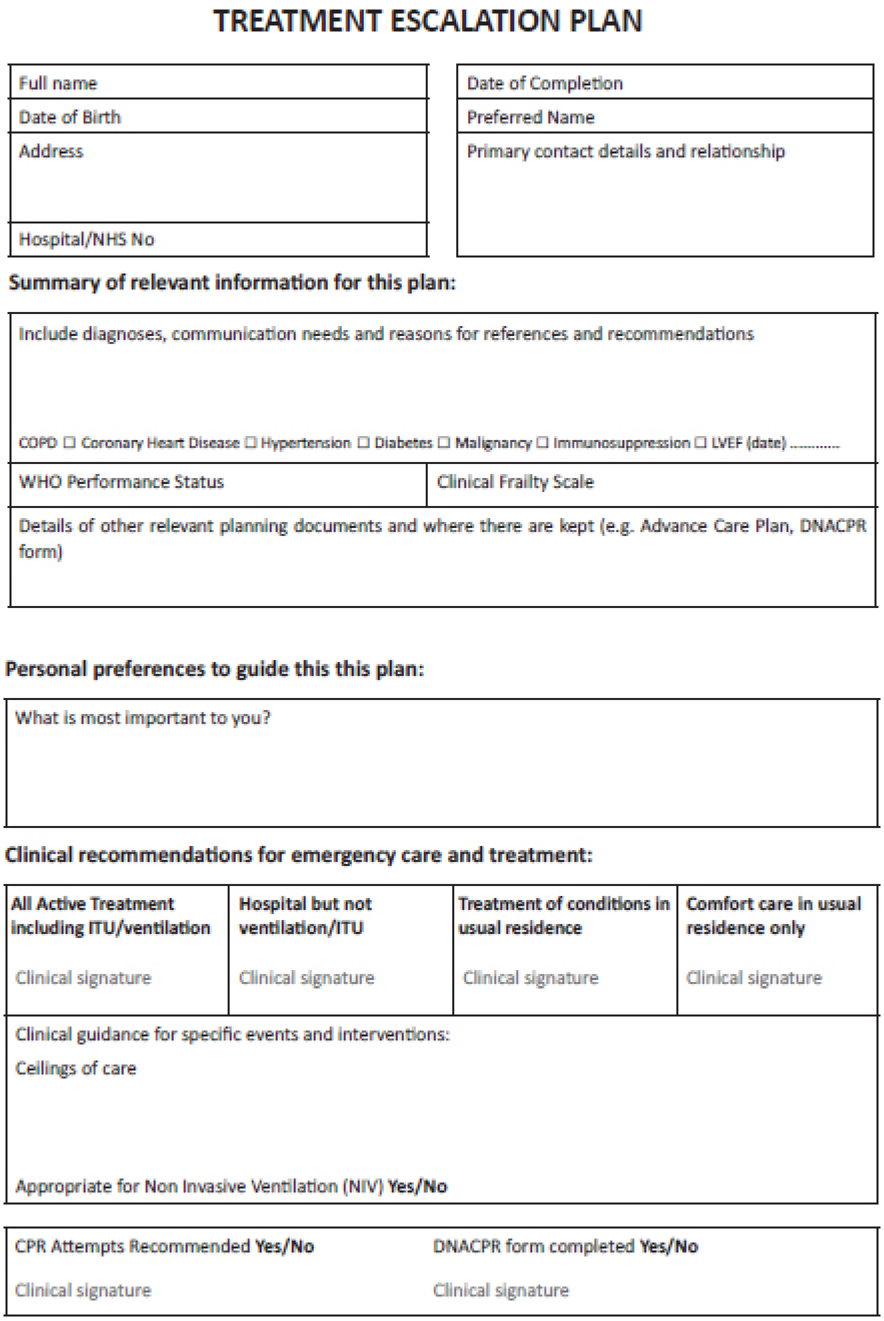
A form of advance care planning known as a Treatment Escalation Plan (TEP) is seen by some clinicians as mandatory to fulfilling the wishes of palliative care patients with COVID-19 at the end of life (McIntosh, 2020). TEPs state the ceiling of care with particular regard to life-sustaining interventions, such as cardiopulmonary resuscitation (CPR), and are considered to be more detailed than the one-dimensional approach of the forms known as DNAR – Do Not Attempt Resuscitation (Sayma et al., 2018). TEPs are also known as ceiling of treatment plans in some health sectors.

For patients who have the mental capacity to make decisions about their management, the TEP can just be used to guide the conversation when deciding on the best course of action to take in an emergency. For patients who lack capacity to make decisions about their management in an emergency situation, the TEP can be used to guide decision making that is done on their behalf by an appointed decision-maker (Lasting Power of Attorney for Health and Welfare or Court Appointed Deputy) or by senior clinicians in their best interests. Patients may have gone as far as signing an Advanced Decision to Refuse Treatment. It is important to establish whether one of these documents or plans is already in place as part of the assessment of a palliative care patient who has COVID-19.

TEPs can take many forms depending on the area of the UK in which a patient lives (Courtney, 2020) and they have also been recently modifed to incorporate decisions if a patient contracts COVID-19. Figure 2.1 offers an example of a Treatment Escalation Plan, but, of course, a clinician should be guided by their local Trust TEP and guidance.

TEPS provide a way of recording clinical discussions with patients and loved ones on the subject of treatment options, such as mechanical ventilation. Discussion of whether ventilation is appropriate or not for patients is essential, as there will be an increased amount of vulnerable patients presenting with acute respiratory failure and pneumonia during the COVID-19 pandemic (Arya et al., 2020). This book is not intended to be an ethical debate about who should receive ventilation and who should not; instead it offers guidance for clinicians whose patients are palliative, with multiple co-morbidities, who have decided that if they contract COVID-19, they wish to be treated at home and should their condition deteriorate they would prefer to die at home and avoid hospital admission. It has been said that the tragedy of the pandemic would perhaps be compounded if patients with palliative needs were admitted to hospital, triaged and designated as appropriate for life-sustaining treatment such as ventilation, and for these patients not to be provided with adequate symptom control, dying at the wrong time, in the wrong place whilst possibly getting the wrong care (Arya et al., 2020), perhaps because a clinician in the community sector had felt uncomfortable having an in-depth conversation about ceilings of care and treatment with their palliative community patients.

Establishing ceilings and goals of care has always been an aim in palliative care, but although this is obviously heightened in a global pandemic, the principles remain the same for all clinicians when completing a TEP.



TREATMENT ESCALATION PLAN

Full name	Date of Completion
Date of Birth	Preferred Name
Address	Primary contact details and relationship
Hospital/NHS No	

Summary of relevant information for this plan:

Include diagnoses, communication needs and reasons for references and recommendations COPD ☐ Coronary Heart Disease ☐ Hypertension ☐ Diabetes ☐ Malignancy ☐ Immunosuppression ☐ LVEF (date)	
WHO Performance Status	Clinical Frailty Scale
Details of other relevant planning documents and where there are kept (e.g. Advance Care Plan, DNACPR form)	

Personal preferences to guide this this plan:

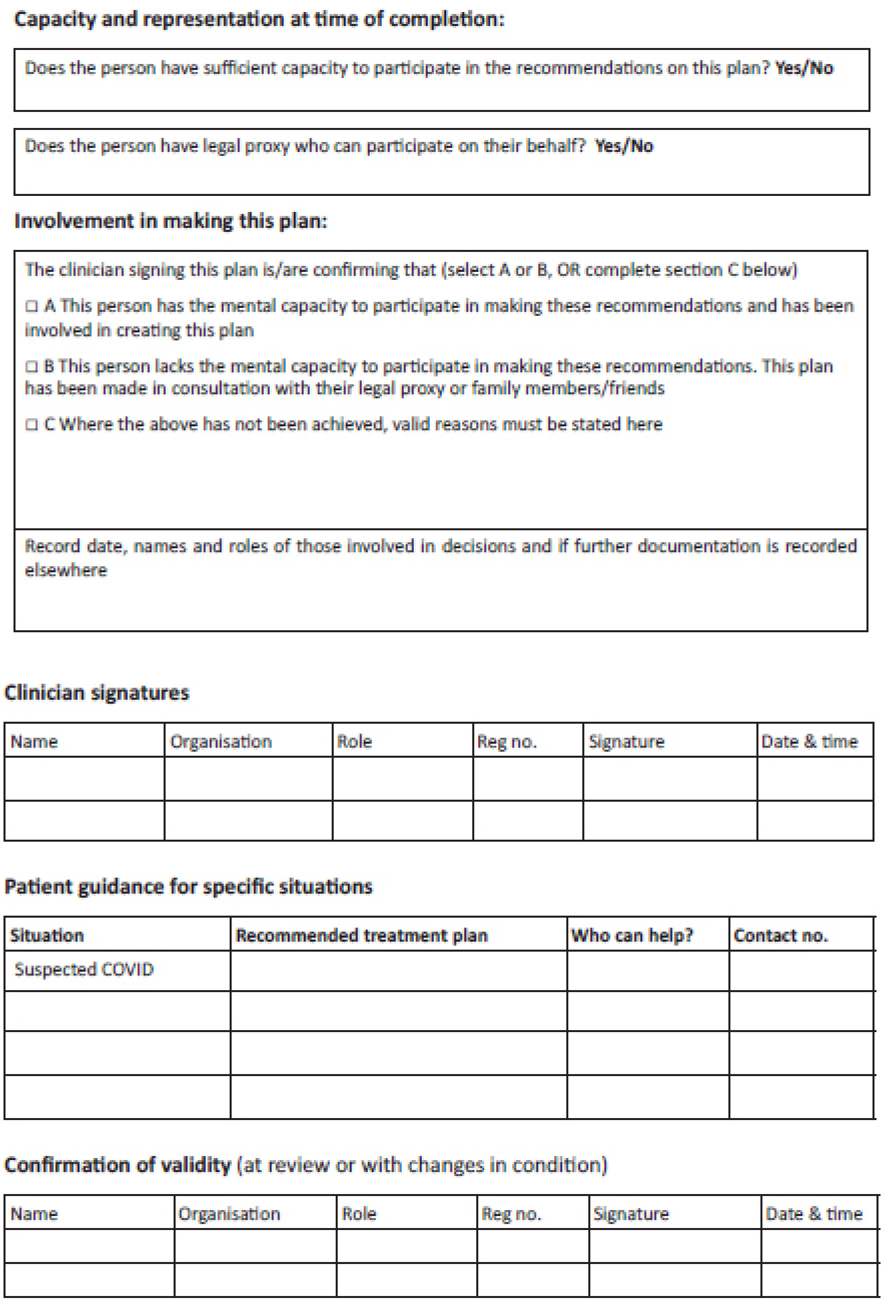
What is most important to you?

Clinical recommendations for emergency care and treatment:

All Active Treatment including ITU/ventilation Clinical signature	**Hospital but not ventilation/ITU** Clinical signature	**Treatment of conditions in usual residence** Clinical signature	**Comfort care in usual residence only** Clinical signature
Clinical guidance for specific events and interventions: Ceilings of care Appropriate for Non Invasive Ventilation (NIV) **Yes/No**			

CPR Attempts Recommended **Yes/No** Clinical signature	DNACPR form completed **Yes/No** Clinical signature

Figure 2.1 Example of a Treatment Escalation Plan including COVID-19 care planning



Capacity and representation at time of completion:

Does the person have sufficient capacity to participate in the recommendations on this plan? **Yes/No**

Does the person have legal proxy who can participate on their behalf? **Yes/No**

Involvement in making this plan:

The clinician signing this plan is/are confirming that (select A or B, OR complete section C below)

☐ A This person has the mental capacity to participate in making these recommendations and has been involved in creating this plan

☐ B This person lacks the mental capacity to participate in making these recommendations. This plan has been made in consultation with their legal proxy or family members/friends

☐ C Where the above has not been achieved, valid reasons must be stated here

Record date, names and roles of those involved in decisions and if further documentation is recorded elsewhere

Clinician signatures

Name	Organisation	Role	Reg no.	Signature	Date & time

Patient guidance for specific situations

Situation	**Recommended treatment plan**	**Who can help?**	**Contact no.**
Suspected COVID			

Confirmation of validity (at review or with changes in condition)

Name	Organisation	Role	Reg no.	Signature	Date & time

Suggested guidance for completing a TEP is as follows:

1. Establish a therapeutic relationship with your patient.
2. Assess the patient's current medical illness, including their frailty and underlying conditions. NB – in the example TEP in Figure 2.1, please note the WHO Performance Status and the Clinical Frailty Scale are used to structure this

assessment (see pages 12–13 for more information on these clinical assessment scales).

3. Assess the patient’s personal goals and values.
4. Assess the patient’s decision-making capacity.
5. Explain the options of treatment, intervention and care to your patient in the event of them contracting COVID-19.
6. Make treatment recommendations to your patient based on your clinical knowledge and seek the patient’s consent to these recommendations.

(Adapted from Mottiar et al., 2020)

Clinical Assessment Scales

During the COVID-19 crisis, clinicians have been faced with making tough clinical decisions on ceilings of treatment and care. The National Institute for Health and Care Excellence (NICE) has recommended that all adults admitted to hospital (regardless of their COVID-19 status) have an assessment of their degree of frailty (NICE, 2020a). They recommend using the Clinical Frailty Scale as part of a holistic assessment where appropriate (NHS, 2020). People who are frail are less able to fully recover their level of function after a stressor event. The frailer they are, the less likely recovery will occur and the higher the risk of poor outcomes from a stressor such as an infection. The Clinical Frailty Scale is validated for use in the over-65s but is not generally recommended for use in patients with learning disability. It is vital that it is used appropriately and that there is an appreciation that the scale is a measure of a patient’s baseline – not how they present when unwell with an acute infection (Rockwood and Theou, 2020).

It has been argued in the research literature that intervention assessment should not be based on an age cut-off, but a wider assessment of an individual patient’s abilities to function, their prognosis, co-morbidities and individual treatment preferences (Le Couteur, Anderson and Newman, 2020). Of course, there has to be a recognition that the whole population is at risk of contracting COVID-19, but the older population often have co-morbidities, tend to be more frail and therefore have a higher risk of fatality due to the virus, despite hospital admission and intensive care (Kunz and Minder, 2020). If elderly patients with palliative needs wish to die at home and choose not to be hospitalised if they deteriorate as a result of COVID-19, then it is the role of the community palliative care team to support this wish, whether the patient's preferred place to die is in their family accommodation, or a residential or nursing home (Kunz and Minder, 2020). The use of frailty scales is further discussed by Chong, Chan, Tan and Lim (2020), who highlight the importance of not using these scales as the only rationale for whether a patient receives critical intervention if they contract COVID-19. It had been postulated that a CFS of 5 could potentially be used as a threshold for the admission of patients with COVID-19 pneumonia to ICU. However recent evidence from Australasia would suggest that CFS scores ≥5 alone are not useful for guiding the allocation of critical care resources for non-COVID-19 pneumonia and that only CFS scores ≥7 were associated with higher (adjusted) mortality (Darvall et al., 2020).

In palliative care, patients are assessed in a holistic manner, noting their wishes, underlying illness and prognosis in order to make a joint decision between clinician and patient about appropriate clinical intervention should the patient contract COVID-19. The role of hospice community palliative care clinicians during the COVID-19 pandemic is to relieve suffering, manage clinical uncertainty and support patients in making decisions about their care (Etkind et al., 2020). Although COVID-19 has impeded clinicians' conversations with patients with palliative needs because of less face-to-face consultations and social distancing, it has also triggered some ACP discussions because the threat of the virus has motivated vulnerable individuals to have meaningful conversations about their care and treatment choices (Hopkins et al., 2020).

WHO Performance Status Classification

The WHO performance status classification categorises patients as follows:

0: able to carry out all normal activity without restriction

1: restricted in strenuous activity, but ambulatory and able to carry out light work

2: ambulatory and capable of all self-care, but unable to carry out any work activities; up and about more than 50% of waking hours

3: symptomatic and in a chair or in bed for more than 50% of the day, but not bedridden

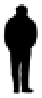
4: completely disabled; cannot carry out any self-care; totally confined to bed or chair.

(NICE, 2007)

Clinical Frailty Scale

The Clinical Frailty Scale is outlined below:

	**1**	**Very Fit**	People who are robust, active, energetic and motivated. These people commonly exercise regularly.

			They are among the fittest for their age.
	**2**	**Well**	People who have no active disease symptoms, but are less fit than those in category 1. Often, they exercise or are very active occasionally, e.g. seasonally.
	**3**	**Managing Well**	People whose medical problems are well controlled, even if occasionally symptomatic, but often are not regularly active beyond routine walking.
	**4**	**Living with Very Mild Frailty**	Previously ‘vulnerable’ this category marks early transition from complete independence. While not dependent on others for daily help, often symptoms limit activities. A common complaint is being ‘slowed up’, and/or being tired during the day.
	**5**	**Living with Mild Frailty**	People who often have more evident slowing, and need help in high order instrumental activities of daily living (finances, transportation, heavy housework). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation, medications and begins to restrict light housework.

	6	**Living with Moderate Frailty**	People who need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing, and might need minimal assistance (cueing, standby) with dressing.
	7	**Living with Severe Frailty**	Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).
	8	**Living with Very Severe Frailty**	Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.
	9	**Terminally Ill**	Approaching the end of life. This category applies to people with a life expectancy of less than 6 months, who are not otherwise living with severe frailty. (Many terminally ill people can still exercise until very close to death).

Scoring Frailty in People with Dementia

The degree of frailty corresponds to the degree of dementia. Common symptoms in **mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

In **very severe dementia** they are often bedfast. Many are virtually mute.

Source: Rockwood et al., 2005. Clinical Frailty Scale © 2005–2020 Rockwood, Version 2.0 (EN). All rights reserved. Reproduced with permission.

Conversations about Advance Care Planning

Advance care planning including TEPs has been changed in response to the COVID-19 pandemic and there has become an urgent need to complete this documentation. Priorities in the questions asked during clinician and patient discussions in advance care planning now have different priorities than they did before the pandemic (Abel, Kellehear, Millington Sanders, Taubert and Kingston, 2020; Rosa and Davidson, 2020). It has been suggested that these ACP conversations should now have three specific foci:

1. When you are well what matters most to you?
2. When you are feeling unwell, which of those would you prioritise?
3. To ensure these priorities, how do you gain support from your loved ones and carers when you are less well?

(Abel et al., 2020)

Further Reading

The resources below are useful sources of information for healthcare professionals.

- Department of Health commissioned site with professional training resources on ACP:
  http://www.advancecareplanning.org.uk
- Information on making, registration and use of LPAs, downloadable information packs and professional articles:
  http://www.direct.gov.uk
  http://www.www.justice.gov.uk
- Marie Curie Charity – Care and Support through Terminal Illness:
  https://www.mariecurie.org.uk/professionals
- The Gold Standards Framework:
  https://www.goldstandardsframework.org.uk/advance-care-planning#:~:text=Advance%20Care%20Planning%20discussions%20in%20the%20UK%20in,the%20means%20of%20leading%20a%20fuller%20life%20meanwhile

3

Care and Nursing Homes

It has been recognised that COVID-19 has caused a disproportionate amount of fatalities in nursing homes and therefore palliative care guidelines for nursing and care homes need to be readdressed internationally and globally (Gilissen et al., 2020). The Office of National Statistics recorded that deaths have doubled in UK care homes due to COVID-19 between the 19th and 24th of April 2020, and internationally data has suggested that COVID-19 deaths in nursing and residential homes are between 19% and 72% of all COVID-19 deaths (Gordon et al., 2020).

A 2020 international study of eight different countries, including the UK, found that the available documentation and guidance for residents of nursing homes and care homes who contracted coronavirus were aimed at specific clinical tasks, such as control of fever and monitoring visitors etc., but very little mention of end-of-life considerations, such as referral to specialist services (for example, community specialist teams or psychological specialists) or the spiritual care of their residents (Gillissen et al., 2020). The study recommended the urgent formulation of new international COVID-19 guidelines for nursing and care homes to include the key aspects of palliative care, holistic symptom control assessment, staff education, referral to specialist palliative services, advance care planning, communication guidance with the resident and their family, and bereavement (Gillissen et al., 2020). It also called for further research and a clinical focus specifically on testing and prognostication of COVID-19 in the elderly so that prevention, treatment and rehabilitation can be optimised in this high-risk elderly and frail group (Lithander et al., 2020).

The effect of the COVID-19 pandemic on nursing and residential homes has been disastrous for residents, their loved ones and the staff who look after these residents, and there has been a call in the UK for a closer integration of the care home sector with the NHS (Gordon et al., 2020). Future questions will have to be answered by UK health policy-makers in order to understand why nursing homes were so hard hit by the COVID-19 outbreak in 2020. Daly (2020) proposes that the following questions need to be considered to inform future practice in COVID-19 management in nursing and residential homes and to avoid unnecessary deaths and suffering:

1. Did care homes have the target of a specific policy or action plan?
2. Was testing and monitoring available to care homes?
3. Were staff and workforce measures put in place?
4. Was there additional funding available for care homes because of extra responsibilities such as PPE?

(Daly, 2020)

Further Reading

Advice for Patients

- Asthma UK and British Lung Foundation. Post-COVID HUB: https://www.post-covid.org.uk.
- Chartered Society of Physiotherapy. Covid-19: the road to recovery activity planner.

https://www.csp.org.uk/system/files/documents/2020-06/001751_covid19-the_road_to_recovery_activity_planner_v3.pdf.

- Facebook. Long Covid Support Group: https://www.facebook.com/groups/longcovid.
- Homerton University Hospital. ACERS: post COVID-19 patient information pack: https://www.hackneycitizen.co.uk/wp-content/uploads/Post-COVID-19-information-pack-5.pdf.
- Mental Health Foundation. How to look after your mental health during the coronavirus outbreaks. https://www.mentalhealth.org.uk/coronavirus.
- Mind. Coronavirus and your mental health: https://www.mind.org.uk/information-support/coronavirus.
- Royal College of Occupational Therapists. How to conserve your energy: practical advice for people during and after having COVID-19: https://www.rcot.co.uk/conserving-energy.

Social and Financial Support

- Advisory Conciliation and Arbitration Service (ACAS). Coronavirus (COVID-19): advice for employers and employees: https://www.acas.org.uk/coronavirus.
- Carers UK. Coronavirus guidance: https://www.carersuk.org/helpand-advice/coronavirus-covid-19/coronavirus-covid-19.
- Citizens Advice Bureau. Helping people through the COVID-19 pandemic: https://www.citizensadvice.org.uk/cymraeg/aboutus/policy/policy-research-topics/welfare-policy-research-surveysand-consultation-responses/welfare-policy-research/helping-peoplethrough-the-covid-19-pandemic.

- Social Care Institute for Excellence. Supporting people who are isolated or at risk during the COVID-19 crisis: https://www.scie.org.uk/care-providers/coronavirus-covid-19/support-for-isolated.

(Adapted from Greenhalgh et al., 2020)

4

Communication

The Impact of COVID-19

COVID-19 has affected our clinical practice in a plethora of ways, and perhaps especially the way in which we communicate in healthcare from clinician to clinician, clinician to patient, and clinician to patient's loved ones and carers. Clinicians are increasingly required to embrace technology and remote ways of communication and, even when communicating face-to-face, have to deal with the barrier of personal protective equipment (PPE) impeding communication. A recent study has suggested we need to address the differences that we, as clinicians, are experiencing in our interactions in practice and share these with each other in order to address the following key points (Rubinelli et al., 2020):

1. **Risk communication and uncertainty**
   When a new infectious disease spreads, there is uncertainty and scientific guidance often changes, which can lead to a lack of trust in healthcare systems from the public.

2. **Goals of care**
   There is an increasing need for clinicians to have conversations with patients, loved ones and carers about goals of care as the number of deaths from COVID-19

increases. These conversations in non-COVID-19 times are ideally had after the clinician has built up a rapport with the patient and their family, whereas during a pandemic clinicians are forced to have these conversations remotely whilst wearing PPE.

3. **Shared decision making**
   The emphasis may change from patient-centred care to a focus on the clinical resources that are available, such as beds and ventilators.

4. **Breaking bad news**
   Clinicians who have not had training or experience in having difficult conversations may be forced to engage in these in the context of COVID-19. Even experienced clinicians who are confident in having difficult clinical conversations are likely to be required to deal with issues that they may never have experienced before, such as quarantine and explaining social isolation rules to families when a patient is dying.

5. **Grief, loss and isolation**
   The effects of COVID-19 are long-lasting and will affect all aspects of society, including loss of the loved one, loss of social contact and loss of income.

6. **Core communication skills**
   Healthcare professionals require mechanisms and communication tools based on evidence-based research to elicit effective communication during a crisis.

7. **Healthcare care provider wellness and stress**
   The amount of overwhelming stress that healthcare professionals can experience during a pandemic can impact negatively on their ability to communicate clinically. It is therefore important to put in place strategies that support them.

(Adapted from Rubinelli et al., 2020)

Communication with Patients and Loved Ones

Clinicians employ many methods of communication with patients and their families and loved ones, including both verbal and non-verbal interaction. However, during the pandemic, methods of communication have been greatly restricted due to remote working, PPE and social distancing. It has been claimed that patients and their families are suffering emotionally in a unique way due to the changes in communication that have occurred. Clinical communication is hindered as, in certain areas of clinical practice, clinicians can no longer look directly in the patient's eyes, embrace them, touch their hands or be physically close to them (Annachiara et al., 2020). If conveying support via video calling, telephone, or even an email, practitioners are obliged to heighten the use of their voice, pause or inflect (Annachiara et al., 2020).

According to Back, Tulsky and Arnold (2020a), it's not too late for us, as clinicians, to learn the skills we need, and we should look at past techniques and communication tools to guide us through the COVID-19 pandemic. One tool suggested by Back, Tulsky and Arnold (2020a) is a talking map (as shown in Table 4.1) to be used in conversations concerning COVID-19.

You can see that the tool in Table 4.1 also encompasses hospital patients, but it is still a useful guide on how to initiate conversations with community patients.

Communicating with patients and families is about establishing a connection with others and the acronyms in Table 4.2 can help you remember the rules of effective communication in all areas of clinical practice, especially when dealing with distressed, angry and vulnerable patients in the COVID-19 pandemic.

Table 4.1 Talking maps for communication during the COVID-19 pandemic

CALMER: A Talking Map for COVID-Related Proactive Planning		
CALMER	**What to say**	**What to do**
Check in	Take a deep breath (yourself) ‘How are you doing with all this?’	Take their emotional temperature
Ask about COVID	‘What have you been thinking about COVID and your situations?’	Just listen
Lay out issues	‘Here is something I want us to be prepared for.’ ‘You mentioned COVID. I agree.’ ‘Is there anything you want us to know if you have COVID/if your COVID gets really bad?’	Use the most appropriate phrases
Motivate them to	‘If things took a turn for the worse, what you say	Make a recommendation

choose a proxy and talk about what matters	now can help your family/loved ones.’ ‘Who is your backup person – who helps us make decisions if you can’t speak? Who else?’ ‘We’re in an extraordinary situation. Given that, what matters to you? About any part of your life? About your healthcare?’	– if they would be able to hear it: ‘Based on what I’ve heard, I’d recommend [this]. What do you think?’
Expect emotion	‘This can be hard to think about.’	Watch for this – acknowledge at any point
Record the discussion	‘I’ll write what you said in the chart. It’s really helpful, thank you’	Any documentation – even brief – will help your colleagues and your patient

SHARE: A Talking Map for Explaining Resource Allocation

This talking map is used only when an institution has declared use of crisis standards of care, or a surge state. When the crisis standards or surge are not applicable, this map should no longer be used.

SHARE	What to say
Show the guideline	‘Here’s what our institution/system/region is doing for patients with this condition.’ (Start with the part directly relevant to that person).
Headline what it means for the patient’s care	‘So, for you, what this means is that we care for you on the floor and do everything we can to help you feel better and fight this illness. What we won’t do is transfer you to the ICU or do CPR if your heart stops.’ (Note that you talk about what you WILL do first, then what you won’t do.)
Affirm the care you will provide	‘We will be doing [the care plan], and we hope you will recover.’
Respond to emotion	‘I can see how it feels unfair.’
Emphasise that the same rules apply to everyone	‘We are using the same rules with every other patient in this hospital/system/institution. We are not singling you out.’

Source: Back, Tulsky and Arnold, 2020a.

Table 4.2 Connect – tips for effective communication

Connect	**Action**	**Further comments**
C – Calm – keep calm	Do not shout back	If you shout back, the individual will mirror your response; keep calm and they will hopefully be calmed as a result
O – Open	Be open to listen to concerns	Even if you do not think their concerns are rational or justified, listen and try to understand
N – Now – talk now	Do not let things escalate. Deal with distress straight away	Do not dismiss fear and anxiety; acknowledge and respond as soon as possible
N – Negotiate	Say you are going to listen and try to understand	Tell the individual what you must do as a clinician, but also that you are prepared to help them and that is your main intention
E – Express	Do not	Let individuals tell you their

	interrupt, reassure but do not dismiss their concerns	story and their journey as you may be the first person they have had the courage to tell this to
C – Close the conversation	Summarise their concerns to them in their own words	Bullet point their concerns to show you have listened
T –Time	Give a time to talk again or signpost them to another agency to talk	If you are going to speak again, give a time that you will be available to talk again or refer to another agency or profession that is better placed to discuss their concerns

Patients, families and loved ones rely on clinicians to give an accurate prognosis of disease trajectories but, as COVID-19 is still a new and rapidly evolving virus, this is not always easy to do (Gibbon et al., 2020). The uncertainty for clinicians during the COVID-19 pandemic understandably has an impact on their communication abilities and the effects listed below have been noted in particular:

1. **Anchoring bias**
   The concept whereby clinicians are exceptionally pessimistic about the outcome for COVID-19 patients

(community clinicians have reported that some palliative patients, despite having COVID-19 and co-morbidities, have made a good recovery from COVID-19 or have only experienced mild symptoms).

2. **Availability bias**
   The concept whereby clinicians have had to constrain the options available to patients based on resources/restrictions such as limited equipment or social isolation guidelines.
3. **False consensus bias**
   The concept whereby clinicians, because they themselves are under stress, assume that their patients have the same belief system as themselves, i.e. they ignore the specific cultural beliefs and individual values of their patients within the stressful context of the COVID-19 pandemic (Gibbon et al., 2020).

What this tells us is that during the COVID-19 pandemic, we as clinicians must make an exceptional effort to understand the fear and anxieties of our patients, their families and loved ones in order to have effective clinical interactions. The global nature of COVID-19 means that the risks of this virus for the community and society are both physiological and psychological, so making small changes to the way we communicate can make a positive change to patients, their families and ourselves (Jonathan et al., 2020).

Telemedicine Communication

During COVID-19, most hospices turned to remote telephone or video consultations for their communication with palliative care patients in order to reduce the exposure of vulnerable patients to possible infection. Research has shown that overall, palliative care patients who receive care through telephone consultations are satisfied with their consultation and that in times of increased workload, telemedicine allows clinicians to assess more patients because it saves travel time (Calton, Abedini and Fratkin, 2020).

The following techniques are recommended for clinicians during telemedicine consultations:

1. Choose a quiet and private space.
2. Use a laptop/desktop rather than a phone.
3. Look at the camera in attempt to make virtual eye contact.
4. Reassure the patient that there are no other people in the room in order to maintain confidentiality.
5. Pay attention to the patient's body language and gestures.
6. Don't be afraid to acknowledge the context of COVID-19 by saying something such as 'these are strange times we are living in, everyone is a bit unsettled at the moment; I know I am' (Carlton et al., 2020).

Clinicians can try to overcome the obvious barriers in telemedicine, but, equally, the frustrations and anxieties we feel as clinicians in delivering care to our patients and loved ones without using our usual methods of expressing compassion, such as real eye contact, the touch of a hand or an embrace, should also be acknowledged (Annachiara et al., 2020).

5

Personal Protective Equipment

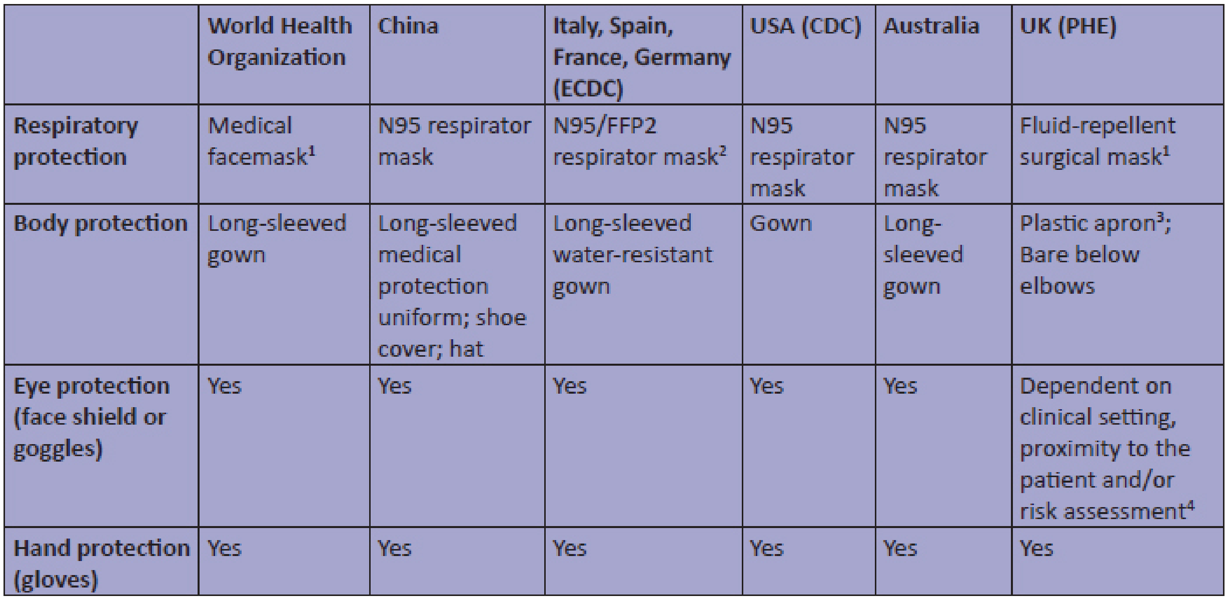
Guidance on Wearing PPE

Clinicians need to wear facial masks during face-to-face interactions with patients in the community, in line with the ethical principles of the clinical practice of beneficence and non-maleficence, caution over convenience, and to avoid harm to our patients and the wider society (Thomas et al., 2020). We must, as healthcare professionals, also wear PPE to protect ourselves and colleagues. Many infections during the global outbreak of COVID-19 have been recorded in healthcare workers, and a study evaluating the national PPE guidance for NHS healthcare workers during the early stages of the outbreak (Thomas et al., 2020) maintained that PPE equipment for secondary care settings was sub-optimal. See Table 5.1 for a summary of international guidance on wearing PPE, although as with all guidance, recommendations and standards for PPE are constantly evolving.

Communicating Effectively Whilst Wearing PPE

Because of the widespread use of medical masks and other protective equipment by community-based clinicians, communication by facial expressions has been greatly impeded. It has been suggested that clinicians need to embrace the following ABC mnemonic to ensure that their interactions are still positive whilst wearing masks:

Table 5.1 Global PPE guidance for healthcare workers



	World Health Organization	China	Italy, Spain, France, Germany (ECDC)	USA (CDC)	Australia	UK (PHE)
Respiratory protection	Medical facemask[1]	N95 respirator mask	N95/FFP2 respirator mask[2]	N95 respirator mask	N95 respirator mask	Fluid-repellent surgical mask[1]
Body protection	Long-sleeved gown	Long-sleeved medical protection uniform; shoe cover; hat	Long-sleeved water-resistant gown	Gown	Long-sleeved gown	Plastic apron[3]; Bare below elbows
Eye protection (face shield or goggles)	Yes	Yes	Yes	Yes	Yes	Dependent on clinical setting, proximity to the patient and/or risk assessment[4]
Hand protection (gloves)	Yes	Yes	Yes	Yes	Yes	Yes

Source: Thomas et al., 2020

A – Attend mindfully

Become more aware of our gestures and the tone of our voices.

B – Behave calmly

Approach patients from the front, give them time to process what you are saying, drop down to their eye level and give them your full attention.

C – Communicate clearly

Use short simple sentence structures, underline words with gestures, pause after statements and questions, and use a much quieter approach than usual.

(Schlögl and Jones, 2020)

PPE Portraits

A small pilot study during the Ebola crisis in Africa showed that when healthcare workers placed photos of themselves on their PPE, known as PPE portraits, this improved the mental welfare of their patients and the clinicians were perceived as more compassionate by their patients (Brown-Johnson et al., 2020). We often see evidence of personal identification on healthcare workers' PPE to compensate for the lack of facial gestures and human individuality reduced by the wearing of PPE.

Moving Forwards

Further research into the optimal use of PPE to protect both clinicians and patients is required internationally as we gain further insights into this global pandemic (Thomas et al., 2020) and greater training is also needed for clinicians on communication skills while wearing PPE to reduce the negative impact on patient-to-clinician communication (Schlögl and Jones, 2020).

Step 1 Portrait Creation

- Plain background
- Diffuse light (not direct sunlight)
- Look directly into the camera lens
- Close cropped around head – crop the top of the head if needed, but not the bottom of the face

- Prompt – 'What is the smile you wish your parents could see?'
- Using phone, stand back and use the zoom function to avert wide-angle distortions

Step 2 Organisation and Printing

- Save portrait files in an easy to retrieve manner (lastname-firstname)
- Consider a shared drive so others can assist with printing
- Print pictures four to an 8x11 page (ideally the same provider for four)
- Labels (matte, not glossy) or paper and scissors can be used
- Label organisation and integration into donning process is key to consistent and easy use

Step 3 Affix Portrait

- Affix portrait to chest at heart level – you are offering warmth and care 'from the heart'
- If PPE will be used again, turn down a corner of the sticker to make it easy to take the portrait off
- Dispose of the portrait when done wearing PPE

Figure 5.1 PPE portraits
Source: Brown-Johnson et al., 2020.

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[1] Respirator masks are only recommended if performing selected aerosol generating procedures or also in the UK if working in higher risk acute areas.

[2] In the absence of FFP2/3 respirator masks, healthcare workers should use masks with the highest available filter level. Respirator masks can be used for up to 4 hours for multiple patients without removing them, unless the respirator is damaged, soiled or contaminated, for example, a symptomatic suspected case coughing on them.

[3] Disposable fluid-resistent gowns or coveralls to be only worn if performing selected AGPs or working in higher risk acute care areas or in operating theatre/labour ward

areas with possible or confirmed cases.

[4] Eye/face protection should be worn if working in a higher risk acute care area/labour ward/operating theatre with possible or confirmed cases or when performing selcted AGPs or if in close proximity to a possible or confirmed case in an acute assessment/inpatient/maternity/radiology area. In other instances eye/face protection should be worn if following an anticipated/likely risk of contamination to the eyes from splashes, droplets of blood or bodily fluids.

6

Patient Management and Symptom Control

The ethics of managing patients during medical emergencies is that everyone matters equally, but this does not mean that everyone should be treated the same (Department of Health and Social Care, 2017). The World Health Organization (WHO) has stated that 'responses [to emergencies and crises] that do not include palliative care are medically deficient and ethically indefensible' (WHO, 2018). Quality palliative care is therefore vital at this time and its delivery is a shared responsibility across sectors and providers, although it can be led and coordinated by local specialist palliative care services.

Patients who are undergoing palliative care are likely, by definition, to be at increased risk of both contracting COVID-19 and the consequences thereof. They should have had the opportunity in advance to consider their preferences for treatment in the event of them developing COVID-19 and, ideally, these preferences should have been documented as part of a Treatment Escalation Plan (TEP) (see p. 6 in Chapter 1).

It is important to note that most COVID-19 patients, including those with palliative needs, will recover, but palliative patients' recovery may be prolonged and they will need the support of the primary care team which includes a holistic approach to incorporate the social, cultural, psychological and physical needs of these patients (Greenhalgh et al., 2020). Research has suggested that community care should prepare for a plethora of post-COVID symptoms in patients that will need assessing and targeted symptom control (Garg, Arora, Kumar and Wig, 2020).

Patient Assessment

Assessment of the palliative care patient should include a full history and examination as well as observations including oxygen saturations. It is important to remember that patients with COVID-19 can have what has come to be known as silent hypoxia – this occurs when the patient has significantly low oxygen saturations but is relatively asymptomatic from a breathlessness perspective. It can precede a dramatic decline in clinical condition and has increased mortality (Gattinoni et al., 2020).

Physical Symptoms

It is important to elicit all the physical symptoms that the patient is experiencing and establish which of these are related to the pre-existing palliative condition and which are new and potentially because of infection with SARS-CoV-2, the virus which causes COVID-19. Physical symptoms may include breathlessness, cough, fever (a temperature of at least 37.8°C), loss of sense of smell, nausea, vomiting, diarrhoea, constipation, drowsiness, pain (including headache), neurological symptoms, fatigue, loss of appetite, dry mouth and thirst. Other symptoms could include anxiety, panic, confusion or disorientation. Public Health England (2020a) has stated that COVID-19 should be suspected in anyone with a new, continuous cough or a high temperature (at least 37.8°C) or a loss of, or change in, normal sense of taste or smell.

It is worth noting, however, that COVID-19 in care home residents will present with non-respiratory symptoms in up to 31% of cases (Graham et al., 2020). These include loss of appetite and reduced oral intake, new onset/worsening confusion, or diarrhoea. The clinician should seek clarity as to how long each symptom has been present for and whether it is a new acute problem (or has suddenly become much more of a concern) or whether it has been a previous feature of the patient's condition and is therefore attributable to their underlying palliative diagnosis. It is important with any new symptom to try to establish whether an underlying cause can be treated which would ameliorate the symptom (e.g. bacterial chest or urinary infection/thromboembolic disease etc.).

Underlying Conditions

The patient's premorbid performance status should be established, i.e. their status prior to the most recent decline because of the viral infection. There are several measures of performance status, including the WHO Performance Status Classification (see Chapter 1, p. 12). The clinician needs to attempt to establish the significance that the COVID-19 infection may be contributing to the clinical picture in addition to the pre-existing palliative condition. This will help to determine the appropriate level of intervention (see below).

The British Geriatrics Society (BGS) recommend that care homes use a form of 'soft sign' observation and recording tool as a way of monitoring residents' clinical status, documenting deviation from their usual conditions and recording discussions and decisions (BGS, 2020). The BGS also suggests that care home staff have access to (and are trained in the use of) simple equipment to take basic observations, such as thermometers, blood pressure monitors and oxygen saturation monitors. Consideration should be given to the addition of other investigations in the community, but their interpretation will need to be in the context of the underlying condition – for example, CRP (C-Reactive Protein – an inflammatory marker) can often be raised in palliative care patients with a malignancy. Renal function (or awareness of a history of renal impairment) would be useful as it can help determine the choice of some drugs or their doses). It would be important to establish whether the patient has had previous investigations during this exacerbation, such as viral RNA swabs for SARS-CoV-2 or a chest x-ray and whether the results are known. Viral RNA swab tests are not 100% accurate for detection of SARS-CoV-2 – estimations of their sensitivity and specificity vary, but are in the region of 70% and 95% respectively (Watson, Whiting and Brush, 2020). Watson, Whiting and Brush (2020) give illustrations for evaluation of a patient by including a combination of pre-test probability of the patient having the disease (from the patient's clinical presentation picture) and the swab result.

It is also important to remember that, whilst patients with underlying health conditions are at higher risk of morbidity and mortality from COVID-19, many palliative care patients may recover from the virus and the spectrum of symptom burden can range from asymptomatic to severe in this patient population, as it does the general population (Petrilli, 2020). However, known risk factors for rapid deterioration, severe disease and/or increased mortality are older age (> 60 years) and co-morbidities such as cardiovascular disease, diabetes mellitus, chronic lung disease, cancer and cerebrovascular disease (WHO, 2020a).

Decision Making and Transfer

Once the assessment of the patient is complete and the clinician is aware of the presence of any advance care planning documentation, then discussions need to take place with the patient and their family and caregivers as to the best course of action. A decision needs to be made about whether hospital admission would confer additional benefit. Patients with an underlying condition should not be excluded from the possibility of hospital admission and should have the opportunity to have a discussion regarding admission for symptom control and treatment of the complications of the COVID-19 infection. All conversations need to be open and honest. The decision about transferring the patient to hospital or not will depend on the clinical presentation, the requirement for supportive care (e.g. practical hands-on care and symptom control), the need for oxygen therapy and the availability of this in the community, the potential risk factors for further decline, and conditions (and availability of care and equipment) at home, including the presence of vulnerable persons in the household. If carers have medical conditions that mean they are shielding, they may find it difficult to provide the care that their loved one needs. The UK government provides guidance for this situation (Department of Health and Social Care, 2020a). Patients with mild or moderate COVID-19 (with or without signs of pneumonia, but without severe respiratory distress and with oxygen saturations of >90% on room air) may not require emergency interventions or hospitalisation; however, isolation is necessary for all suspected or confirmed cases to contain virus transmission (WHO, 2020a). As already mentioned, patients with other co-morbidities are at greater risk of significant decline because of COVID-19 and discussions about place of care will need to consider what measures would need to be taken were this to happen. In some areas, beds are available in alternative places of care, such as hospices or community hospitals, and these options could also be considered. Hospitals offer treatments that cannot be managed in the community, e.g. specialist drugs, intensive oxygen support, non-invasive ventilation, invasive ventilation, renal and cardiac support. These interventions may not treat the virus per se but may help support some patients to survive while their body fights the virus. Even for patients with no underlying health conditions, this sort of intensive support may not be successful (i.e. result in a survival to discharge) and, in the less than 60% of cases where it is, can still result in long periods of recovery (ICNARC, 2020; Rawal, 2017). Sadly, for those patients with underlying medical issues which have resulted in poor performance status and significant frailty (CFS >5), who are now sick enough to die from COVID-19, the outlook is very poor and the likelihood of them surviving intensive treatments is very small. In these cases, patients are unlikely to be offered intensive care interventions in hospital as the likelihood would be that they would not survive, but the intensive treatments would possibly prolong their dying and make it unpleasant and undignified (NICE, 2020).

Patients in the last few days of life are unlikely to benefit from hospital admission, and transfer to hospital may even go against their previously stated or documented preferences for care. Patients will need to be aware that the same symptom control medications should be available at home and in care homes as in the hospital. Visiting is also restricted in hospital – even for those who are very unwell and may not survive. At the end of life, patients can be supported to remain at home with good palliative care and the opportunity to have their family around them. Family members should be given advice about the best ways of protecting themselves from the virus – keeping a sensible distance from the patient when they can, frequently washing hands, wiping down surfaces regularly, not sharing utensils etc. (Public Health England, 2020b). In this situation, known contacts are at risk of contracting the virus and would need to self-isolate for 14 days, so potential visitors would need to bear this in mind.

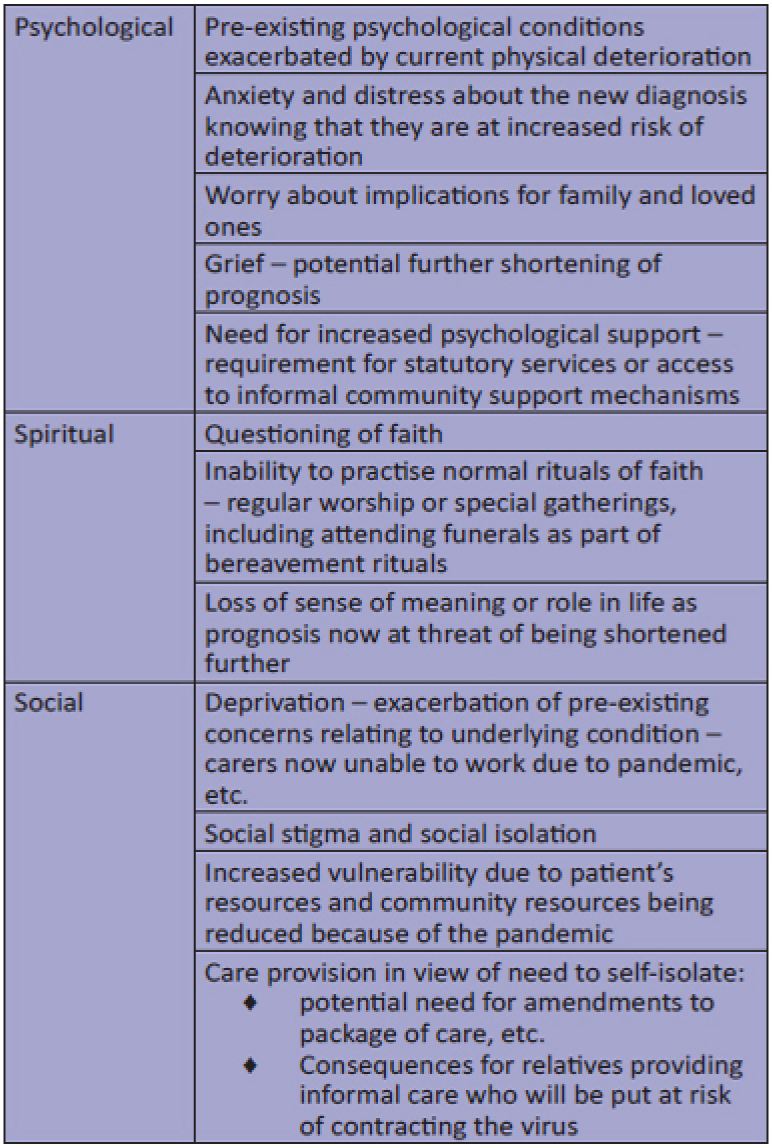
Palliative Care Considerations

Following thorough assessment and informed discussion, palliative care patients with COVID-19 remaining in a community setting for care are likely to fall into one of three categories:

- Patients at end of life.
- Patients with mild COVID-19 symptoms who do not require hospital admission at this time, but who are being monitored for signs of deterioration and who would accept hospital transfer were this to be necessary.
- Patients who are symptomatic of COVID-19, who meet criteria for hospital admission, but who choose to remain in a community setting for symptomatic management only and who are aware that they could deteriorate significantly from the disease and would choose to die at home.

Table 6.1 Considerations for palliative care patients in the community with symptoms of COVID-19

Physical	Symptoms of COVID-19: • fever • cough • breathlessness • anxiety and delirium
	Physical consequences and symptoms of underlying palliative condition and side effects of any treatment being received
	Availability of medications outside of a hospital environment at a time of potential medication shortages
	Performance status and frailty level
	Availability and appropriateness of viral RNA swab, or other testing modality, and significance of result
	Risk of deterioration from both COVID-19 and the underlying condition and worsening care advice
	Physical sequelae of COVID-19 infection: ♦ sudden dramatic decline in physical condition and risk of rapid death – ARDS and multi-organ failure (Wu et al., 2020; Zaim et al., 2020) ♦ dermatological manifestations (Galvas Casas et al., 2020) ♦ thromboembolic complications (micro and macro) ♦ renal failure ♦ endocrine disturbance ♦ acute coronary syndrome, arrythmias, myocarditis, pericarditis, cardiomyopathy, cardiac arrest



Psychological	Pre-existing psychological conditions exacerbated by current physical deterioration
	Anxiety and distress about the new diagnosis knowing that they are at increased risk of deterioration
	Worry about implications for family and loved ones
	Grief – potential further shortening of prognosis
	Need for increased psychological support – requirement for statutory services or access to informal community support mechanisms
Spiritual	Questioning of faith
	Inability to practise normal rituals of faith – regular worship or special gatherings, including attending funerals as part of bereavement rituals
	Loss of sense of meaning or role in life as prognosis now at threat of being shortened further
Social	Deprivation – exacerbation of pre-existing concerns relating to underlying condition – carers now unable to work due to pandemic, etc.
	Social stigma and social isolation
	Increased vulnerability due to patient's resources and community resources being reduced because of the pandemic
	Care provision in view of need to self-isolate: ♦ potential need for amendments to package of care, etc. ♦ Consequences for relatives providing informal care who will be put at risk of contracting the virus

Source: Adapted from Integrating Palliative Care and Symptom Relief into the Response to Humanitarian Emergencies and Crises: a WHO Guide, *https://apps.who.int/iris/handle/10665/274565*

Patients remaining in a community setting and their family and caregivers should be encouraged to seek support and advice from local palliative care services. If they are not yet known to these services, then an urgent referral should be made. In addition to symptom control advice, many community palliative care services can offer psychological, social and spiritual support. Concerns for palliative care patients in the community with symptoms of COVID-19 can be categorised in the same way as all palliative care considerations for patients – physical, psychological, spiritual and social (see Table 6.1). They will include concerns related to the underlying condition for which the patient is being managed palliatively as well as its treatment, any pre-existing issues and the superadded COVID-19 infection.

Managing Physical Symptoms

For each of the symptoms below, a full assessment of the patient should be completed as detailed previously. Before moving on to treating the symptom itself with pharmacological and non-pharmacological approaches, the clinician should, on each occasion, establish whether there is an underlying reversible cause that it is appropriate to treat. For example, a patient with lung cancer and COVID-19 may also develop a secondary bacterial chest infection which increases their breathlessness and cough. For patients who are of reasonable performance status and with a prognosis of weeks to months and the ability to swallow oral medication, a trial of oral antibiotics may be appropriate to see whether this contributes (along with other measures, if necessary) to improved symptom control. For patients who are dying with a prognosis measured in days who cannot reliably take oral medication, a trial of antibiotics would likely require administration by the parenteral route, which may need hospital admission. On balance, for this second group of patients, the balance of benefit versus risk may not tip in favour of antibiotics, but more towards symptom relief at home. A second example is the patient who is agitated at the end of life. A thorough physical assessment establishes that they have a full bladder. Catheterisation of this patient can be as effective for management of the agitation as medication in some cases.

Full symptom control guidance can be found by referring to the sources outlined in Box 6.1.

Box 6.1 Further reading on symptom control and palliative care during COVID-19

- NICE COVID-19 rapid guideline: managing symptoms (including at the end of life) in the community (NICE, 2020)
- The BMJ best practice guidance (BMJ, 2020)
- Royal College of General Practitioners and the Association for Palliative Medicine. Community Palliative, End of Life and Bereavement Care in the COVID-19 pandemic (RCGP, 2020)

The following medication advice is all gathered from the sources listed in Box 6.1 and has been collated with information on the individual medications sourced from the Palliative Care Formulary (Twycross, 2018). Alternative sources of information are referenced specifically. Regions and services will have developed their own specific symptom control advice for palliating the symptoms of COVID-19 and these should be accessed and used, as they will detail the region-specific information. It is important to note that this guidance only refers to management of symptoms for patients being managed palliatively. Some of this guidance may not be appropriate for patients being treated actively. Most of the advice collated below concentrates on the use of 'as required' doses of medications as this will be the focus of intervention from community services.

Background regular medications will need reviewing based on the patient's response to the 'as required' medication and advice for these adjustments is available from community specialist palliative care teams. Patients with **renal impairment** (estimated glomerular filtration rate <30 ml/min) should be given equivalent doses of oxycodone in preference to morphine or codeine. Advice should be sought from specialist palliative care teams or a conversion table used. Patients who are being prescribed opioids for the first time will benefit from consideration of co-prescription of an antiemetic and a laxative. Laxative doses may need to be increased when opioid doses are increased. Nausea and constipation should be avoided as they could contribute to the other underlying symptoms that the patient is experiencing.

Drug Administration

As patients become less well, their ability to manage oral medication diminishes. At this point it is important that their access to important symptom control medication is not interrupted. Injectable forms of analgesia, anxiolytics, antiemetics and antisecretory medication should be easily available in the community setting. These can be administered as stat doses and as a continuous subcutaneous infusion via syringe pump, which allows ongoing control of symptoms through the combination of several drugs in one pump if required. As part of anticipatory care planning, symptom control medications (including injectable medication) and prescription charts should be made available in patients' homes and care homes so that the medications are available when they are needed. The government has produced guidance that allows care homes and hospices to give medications which have been dispensed for an individual patient, and which are no longer required, to a second patient when named patient or stock medications are unavailable for that second patient (Department of Health and Social Care, 2020b). The patients all still need legal community drug administration records, but this guidance may help when medications are in short supply.

It is also important to note that many routes and indications for medications used in palliative care are not in line with the marketing authorisation for that drug. However, the off-label medication use is in line with normal palliative prescribing practice (see Twycross, 2018) and is in line with the General Medical Council guidance (GMC, 2020).

Fever

Pyrexia is a raised body temperature above the normal range (at least 37.8°C tympanic). Not all patients with COVID-19 will exhibit pyrexia.

Non-pharmacological Approaches

- Keep the room cool.
- Fans should be avoided in the context of COVID-19 due to the risk of spreading the disease to other people present. However, for those patients isolating in a room alone, windows and doors can be opened to allow fresh air to circulate and a fan can be used when the patient is alone, but should be switched off when others are in the room (Public Health England, 2020c).
- Try to keep the patient hydrated using oral fluids.
- Use a cool flannel to cool the face.

Pharmacological Approaches

Paracetamol is the first line antipyretic agent to be used if patients are symptomatic of a raised body temperature. Ideally, it should be administered orally, but can be given PR if appropriate infection control precautions are instigated because SARS-CoV-2 RNA has been found to be present in faecal samples of some infected patients. Ibuprofen can be used in the short term for management of pyrexia in patients with COVID-19 (Wu, 2020). Initially there were some concerns with using non-steroidal anti-inflammatory drugs, but no evidence has been found at present of severe adverse events in COVID-19 patients taking this class of medication or of effects as a result of the use of NSAIDs on acute healthcare utilisation, long-term survival or quality of life in patients with COVID-19 (WHO, 2020b). Ibuprofen should only be taken at the lowest effective dose for the shortest period needed to control symptoms.

Cough

Cough is a reflex that attempts to clear the airway and is precipitated by stimulation of airway cough receptors by a chemical irritant or foreign body. Patients should try to follow the advice regarding cough hygiene ('catch it, bin it, kill it') – coughing into single-use tissues that are disposed of and then washing their hands. Following assessment of the symptom and identification (and treatment, if appropriate) of any underlying reversible causes, specific symptom management can include non-pharmacological and pharmacological approaches.

Non-pharmacological Approaches

- frequent drinks
- suck boiled sweets
- teaspoon of honey
- keep room air humidified
- avoid smoking
- prop the head up when sleeping

Pharmacological Approaches

Palliative medications used to treat cough (antitussives) which occurs because of lower respiratory tract pathology either act peripherally (soothing the pharynx) or centrally on the cough reflex centre in the brainstem. A peripherally-acting antitussive should be tried first line for the palliative management of cough of any cause (including COVID-19) – simple linctus is the most commonly available option. If this is ineffective, then opioids are the alternative treatment option. Opioids suppress the cough reflex in the brain. For opioid-naïve patients, codeine linctus can be tried first line and, if this is ineffective, oral morphine IR solution can then be substituted at an appropriate dose – for patients who have found codeine linctus ineffective and have normal renal function, the morphine starting dose for cough should be morphine sulfate IR 2.5 mg orally as required up to 4 hourly. For patients already receiving opioids for pain control, it would be inappropriate to add in codeine to their regime and they should just use a breakthrough dose of their usual 'as required' opioid, and the background dose of opioid medication can be increased if the cough responds to opioids. If these measures are ineffective, specialist palliative care teams can give advice on alternative approaches. Patients in the dying phase who cannot manage oral medications should trial 'as required' parenteral opioids to assess effectiveness for cough management and then background opioids can be commenced or adjusted accordingly. Morphine sulfate injection would be the first line parenteral opioid, but oxycodone is an alternative for patients with renal impairment.

Breathlessness and Anxiety

Breathlessness is the feeling a patient is said to have when they report a sensation of discomfort with breathing. It can be due to many respiratory and non-respiratory causes. For patients with underlying respiratory conditions, disease-specific advice can be accessed from lots of different sources, including the charitable sector, on managment of the condition during the pandemic. Patients who are breathless will often also be anxious and this can result in an increase in their symptoms of breathlessness. Following assessment of the symptom and identification (and treatment, if appropriate) of any underlying reversible causes, specific symptom management can include non-pharmacological and pharmacological approaches.

Non-pharmacological Approaches

- Keep the atmosphere calm and unrushed where possible with lots of reassurance.
- Keep the room cool.
- Fans should be avoided in the context of COVID-19 due to the risk of spreading the disease to other people present. However, for those patients isolating in a room alone, windows and doors can be opened to allow fresh air to circulate and a fan can be used when the patient is alone, but should be switched off when others are in the room (PHE, 2020c).
- Breathing techniques and changing body positioning for management of breathlessness.
- Avoiding lying flat as this can exacerbate breathlessness and cough.
- Relaxation and anxiety management can help with symptoms of breathlessness – there are many techniques for this (in addition to the breathing techniques described below); the patient may already have a favoured technique (such as mindfulness or butterfly hug) and it is worth reminding them to use these.

Good body positions for relief of breathlessness include sitting upright in a chair with feet flat on the floor and arms supported on a pillow allowing the shoulders to relax. An alternative is to lean forward with arms resting on a pillow placed on top of a table in front of the chair. If lying down is more comfortable, then this should be lying on one side propped up with pillows under the upper body. Tuck the top pillow into the neck to support the head. Rest the top arm on a pillow placed in front of the chest and the top leg on another pillow. Once in a comfortable position, patients should be encouraged to relax muscles that may be tense, such as the muscles of the jaw and arms.

Patients should then be encouraged to concentrate on slowing their breathing – particularly expiration – and using their abdominal muscles to breathe. Some patients use the breathing hand (slowly tracing a path up and down the fingers of one hand with the forefinger of another and breathing in as they trace up the digit and breathing out as they trace down). Others use the rectangle method (finding a rectangle in the room, such as a TV or window, and breathing in as they move their eyes slowly along the short edge and out as they move their eyes along the long edge). They may find additional benefit in pursing their lips when exhaling and dampening their cheeks with a cool flannel.

Local services may have their own resources and breathing space packs that can be accessed. A useful resource is a leaflet developed on behalf of the NIHR ARC Palliative and End of Life Care Theme (NIHR, 2020).

Pharmacological Approaches

Refer to Table 6.2 on pages 64–67 for an example of specific drugs and doses, but also refer to local guidance.

Opioids are used routinely as pharmacological symptomatic management for patients with palliative needs who are breathless, despite optimal management of the underlying condition. They reduce the normal increased ventilatory response to low blood oxygen levels, high levels of CO2 and exertion, and therefore reduce respiratory effort and thus a reduced sensation of breathlessness. The opioids do not need to cause respiratory depression to influence breathlessness. For breathless COVID-19 palliative patients who are not already receiving a regular opioid for pain or breathlessness, it is probably most appropriate for a community healthcare professional to advise them to take a small 'as required' dose of oral immediate relief opioid (patients with eGFR >30 ml/min should be given morphine; patients with eGFR <30 ml/min should be given oxycodone), although evidence is now suggesting that regular MR opioid confers more benefit (Johnson and Currow, 2020). Patients who are already taking regular MR opioids for pain or breathlessness should be advised to take a quantity of IR oral morphine equivalent to 1/24 of the total 24-hour oral morphine dose. This can be increased to 1/12 of the total 24-hour oral morphine dose if ineffective. Patients in the dying phase can receive an equivalent dose of subcutaneous morphine (or oxycodone) as required for breathlessness. Local specialist palliative care services can give advice about further increases if needed and whether to start/increase background regular opioid medication. Continuous subcutaneous infusion of morphine via a syringe pump is likely to be helpful with addition of midazolam for associated anxiety, and the doses of these should be titrated to response.

Pharmacological management of breathlessness should also consider the relationship between breathlessness and anxiety as relief of anxiety can also improve the patient's symptom burden. Benzodiazepines do not relieve breathlessness in themselves, but can be helpful as anxiolytics – particularly in those patients who need short-term relief of anxiety and who cannot wait for other anxiolytics such as SSRIs to start to work or who are in the dying phase and require parenteral administration. Oral benzodiazepines that can be used on an ‘as required’ basis for management of anxiety associated with breathlessness include lorazepam (oral tablets can also be administered off-label via the sublingual route which speeds the onset of action). Midazolam is the parenteral benzodiazepine of choice for palliative care. Cancer patients who are breathless at rest in the last few days of life benefit more from a combination of opioid and benzodiazepine than from either drug class alone and this approach should be considered for patients dying with COVID-19 (Navigante et al., 2006). Patients dying with COVID-19 may become severely breathless in the last few days to hours of life as a result of an ARDS-type picture and clinicians should be prepared that they may need repeated administrations of medication and the doses may need to be increased. Community prescription charts should take this potential into account and allow for dose increases if required. Some areas have adapted their community prescription charts accordingly with larger ranges of opioids and benzodiazepines in case patients exhibit this sudden increase in symptoms of breathlessness, although various case reports and case series suggest that this is unnecessary in most cases.

Chest Secretions

Patients at the very end of life can accumulate secretions in the upper airway. Patients with COVID-19 may do this as a direct result of local airway inflammation and infiltrate, and this may be exacerbated if they develop a rapid onset ARDS-type deterioration. In many cases, chest secretions do not appear to distress the patient, but they can be very distressing for loved ones to hear. In most cases, when chest secretions become problematic, the patient is too weak to swallow – in many cases the patient is already unconscious. However, anecdotally, patients suffering with an acute respiratory deterioration with COVID-19 can be aware and very distressed with their increased breathlessness and cough, and significant chest secretions can be a contributory factor in these cases. Antisecretory medication will not dry up secretions that have already accumulated in the respiratory tract and will only serve to reduce additional secretions. Therefore, if chest secretions are starting to accumulate, then early treatment with an injectable antisecretory offers the best chance at managing this symptom effectively. Commencement of the antisecretory as a continuous subcutaneous infusion via syringe pump soon after the administration of the first or second 'as required' dose is usual best practice. Patients who are distressed with co-existent breathlessness or anxiety should have those symptoms managed accordingly.

It is important to bear in mind that antisecretories reduce the fluid content of secretions and, therefore, can increase the viscosity of the secretions and, in some cases, make them more difficult to clear. In these cases, the dose of the antisecretory may need to be adjusted to find a suitable balance that affords the patient the best level of symptom control. Antisecretories will also dry saliva and patients must therefore receive frequent mouthcare to avoid them becoming uncomfortable or distressed because of dry, coated mouths.

The first-choice drug for this symptom is hyoscine butylbromide as it does not cross the blood–brain barrier and cause CNS effects, and it does not require dose adjustment in renal failure. Many regions use glycopyrronium as their first line injectable antisecretory. In patients with renal failure, lower doses of this may be sufficient.

Delirium

Delirium is an acute confusional state characterised by a global disturbance in cerebral function affecting consciousness, attention, cognition and perception with a course that may fluctuate over a period of hours. It is a common cause of disturbed behaviour in medically ill patients. Delirium develops over hours to days and the symptoms and their severity can fluctuate over relatively short periods of time. The symptoms and signs include cognitive impairment, altered levels of consciousness with changes in the level of arousal on a spectrum of hyperalert (hyperactive delirium) to hypoalert (hypoactive delirium) and possible fluctuations between the two extremes over relatively short periods of time, disorders of the sleep-wake cycle, impaired attention, mood changes, hallucinations and delusions (abnormal thoughts) which are usually persecutory and can be the basis for aggressive behaviour. The symptoms of delirium are distressing for the patient, their relatives and caregivers, and expose the sufferer to the risk of further harm, e.g. falls. Therefore, avoidance is far better than treating the symptom when it arrives and lots of healthcare institutions will have guidance on measures to try to avoid delirium and use screening tools to try to detect delirium at early stages.

The underlying cause of the delirium can include the COVID-19 infection itself with direct CNS effects, hypoxia, secondary bacterial infection, medication or withdrawal from medication or drugs and alcohol, dehydration, constipation and urinary retention. Following assessment of the symptom and identification (and treatment, if appropriate) of any underlying reversible causes, specific symptom management can include non-pharmacological and pharmacological management. Agitation at the end of life (referred to as terminal agitation) always has an underlying cause (either physical or psychological, or a combination of the two,) but the possibility of investigating or treating this when the prognosis is short can be limited and so the symptoms are managed rather than the underlying cause. However, some causes are easy to identify and treat even at the very end of life, such as pain, urinary retention and constipation.

Non-pharmacological Management

- A calm, unrushed approach with the patient.
- Regular re-orientation with reassurance and familiar surroundings, faces and voices. Good explanations to the patient and their family.
- A well-lit room and attempts to correct any sensory impairments, e.g. wear glasses and hearing aids.
- Rehydration.

Pharmacological Management

Drug treatment should only be used for cases of severe distress because of delirium or if treatment of the underlying cause and non-pharmacological interventions are insufficient. The consensus remains that antipsychotics are the first line treatment for delirium – both hypoactive and hyperactive with haloperidol being first choice (NICE, 2010). Agitation at the end of life (terminal agitation) can be as a result of hyperactive delirium and so antipsychotics should be considered in this setting too, but benzodiazepines (midazolam) are an alternative if anxiety is a predominant feature and features of delirium are not so apparent. The primary aim of treatment of delirium is to manage the delirium without causing excessive sedation if this is possible. Sometimes – particularly at the very end of life – this is difficult to achieve and some sedation is required to help the patient to feel more settled. Ideally this balance should be discussed with the patient if possible, but certainly with their family and caregivers when setting out the goals for treatment.

Haloperidol is a first-generation antipsychotic, but is less sedating than some of the other older antipsychotics. The recommendation is that doses are started low and only increased if necessary. Haloperidol can be given orally and by subcutaneous injection. Levomepromazine is a typical first-generation phenothiazine antipsychotic and is more sedating than haloperidol. This side effect can be useful for the symptomatic treatment of a hyperactive delirium. Levomepromazine can also be administered orally and subcutaneously.

Specialist palliative care teams can give advice when these approaches have failed to manage the delirium.

Pain

Pain is not a predominant symptom of COVID-19, but patients can have musculoskeletal pain or chest pain. Palliative care patients may well have pre-existing pain that continues to be an issue due to their underlying condition and is unlikely to recede if they have a more rapid decline because of co-existent COVID-19 infection. Ideally pain should be managed with regular oral analgesia, starting with non-opioid analgesics, and titrating up to opioid analgesics and co-analgesics according to response. Patients should have access to 'breakthrough pain relief' that can be taken as required between the regular doses of analgesia. For patients taking regular opioids, this breakthrough dose should generally be 1/6 of the total 24-hour opioid dose. Patients commenced on opioids should always have a laxative co-prescribed. Antiemetics should also be taken as needed or regularly. If the pain control is not optimised and the doses need to be increased, the amount of PRN medication that has been required should be taken into account and it should be clarified that the opioid medication is effective, as well as confirming that the patient is not experiencing intolerable side effects. Dose increases should not exceed 30–50% in a 24-hour period and clinicians should remember to increase the breakthrough dose accordingly. However, dose increases should not take place if side effects are occurring and clinicians should seek specialist advice. Injectable forms of analgesia should be available in a patient's home if they are expected to deteriorate and enter the terminal phase in the following few weeks (and this decline could be more precipitous if they also have COVID-19). Patients who are on regular background doses of opioid who are unable to swallow a dose of their analgesia as a result of deterioration in their condition should have an equivalent dose of opioid commenced in a syringe pump as soon as possible in order that there is no interruption to their pain management. If there is to be a delay in commencing a syringe pump for some reason, the patient should be assessed and receive additional 'as required' doses of injectable analgesia in order that they do not suffer from pain or opioid withdrawal. Patients' co-analgesics should also be reviewed to assess whether they can be substituted in any way by injectable forms of medication, e.g. non-steroidal anti-inflammatory drugs. The correct doses of opioids for breakthrough pain or for conversions to alternative type or form of opioid can be found on opioid conversion charts. Specialist palliative care teams will also be able to give advice on this and most have 24/7 advice lines.

Table 6.2 Summary of drug and dose guidance for palliation of symptoms of COVID-19

Note: Please refer to the accompanying text for information regarding non-drug management and information for special cases, e.g. renal failure

Symptom	Oral management options	Injectable/alternative route management options for end of life care
Fever	Paracetamol 1 g PO QDS	Paracetamol 1 g PR QDS
Cough	Simple linctus 5–10 mg PO QDS if ineffective: Codeine linctus 30–60 mg PO QDS or Morphine sulfate immediate release solution 2.5 mg PO 4 hourly	Morphine sulfate injection 10 mg via a syringe pump over 24 hours and 2.5–5 mg SC 4 hourly PRN
Breathlessness	Oramorph 2.5–5 mg PRN (or equivalent opioid) Consider morphine modified release 5 mg bd (titrate up to maximum 30 mg daily if solely for breathlessness)	Morphine 1.25–2.5 mg SC PRN titrated up if needed ARDS COVID-19 symptoms – doses may need to be increased by at least 50%: Morphine 2.5–5 mg SC PRN. Titrate to response and repeat 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
Anxiety associated with breathlessness	Lorazepam 0.5 mg SL PRN	Midazolam 2.5–5 mg SC PRN ARDS COVID-19 symptoms – doses may need to be increased by at least 50%: Midazolam 2.5–5 mg SC PRN for associated agitation or distress. Titrate to response and repeat 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
Delirium	Haloperidol 500 microgram PO/SC at bedtime and 2 hourly as required If necessary, increase in 0.5–1 mg increments Consider a higher starting dose (1.5–3 mg PO) when a patient's distress is severe and/or immediate danger to self or others If necessary add: Lorazepam 500 micrograms – 1mg PO BD and PRN (max dose 4mg in 24 hours)	Haloperidol 500 microgram/24h CSCI or SC at bedtime and 2 hourly as required. If necessary, increase in 0.5–1 mg increments Consider a higher starting dose (1.5–3 mg SC) when a patient's distress is severe and/or immediate danger to self or others If necessary add Midazolam 2.5–5 mg SC PRN 1–2 hourly

Symptom	**Oral management options**	**Injectable/alternative route management options for end of life care**
Delirium at end of life		Levomepromazine 12.5–25 mg SC stat and hourly as required (caution in the elderly, 6.25–12.5 mg) If necessary, titrate dose to response. Maintain with 50–200 mg/24h CSCI or, alternatively, smaller doses given as a SC bolus at bedtime and as required Midazolam (can be used in addition to levomepromazine for management of associated anxiety) 2.5–5 mg SC/IV stat and hourly as required if necessary, increase progressively to 10 mg SC/IV hourly as required Maintain with 10–60 mg/24h CSCI
Pain	Step 1: Regular paracetamol (1 g four times a day) - dose reduction is advisable in old age, renal impairment, weight <50 kg Step 2: Regular codeine 30–60 mg four times a day (stop paracetamol if ineffective) Step 3: Regular opioid - opioid-naïve/frail/elderly: morphine sulfate IR 2.5–5 mg PO 4 hourly - previously using regular step 2 (e.g. codeine 240 mg/24h): morphine sulfate IR 5 mg PO 4 hourly or morphine sulfate MR 20–30 mg BD frail/elderly: use lower starting dose of IR 2.5 mg PO 4 hourly or MR 10–15 mg BD eGFR <30 seek advice Monitor closely for effectiveness and side effects	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 pain is constant, prescribe morphine 4 hourly SC injections or as 24-hour continuous infusion via a syringe pump (McKinley T34) Conversion from oral to SC morphine: oral morphine 5 mg ≈ SC morphine 2.5 mg 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

Source: Based on '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. V3 accessed 3/7/20

Nausea and Vomiting

Nausea and vomiting are not typical features of COVID-19, but they may be experienced by patients with palliative needs because of the underlying condition or because of side effects of medication commenced because of infection with COVID-19. An antiemetic should form part of the anticipatory injectable medication supply that is provided to patients being cared for in the community. The choice of antiemetic will depend on several factors: the cause of the nausea or vomiting; oral antiemetics already being taken regularly and the effectiveness of these; risk of side effects and other anticipatory medications being provided. As patients dying with an infection are at significant risk of delirium and the antipsychotics used for delirium also have antiemetic properties, it seems sensible that haloperidol and levomepromazine are used as the anticipatory antiemetics for patients who are not currently taking an alternative antiemetic orally. Persistent nausea or vomiting should be managed with medication administered regularly and, even for patients not at the very end of life, this may be most effectively achieved using a continuous subcutaneous infusion via a syringe pump. Once control of the symptom has been achieved, if the patient is able to take oral medications, the syringe pump can be stopped, and the medication converted to a regular oral dose instead. Patients at the end of life will likely require ongoing delivery of an antiemetic via syringe pump until they die.

Verification of Expected Death

A special edition of care after death guidance has been produced by a group representing Hospice UK, the National Nurse Consultant Group for Palliative Care, the National Association for Hospice at Home, the Royal College of Nursing and the Royal College of General Practitioners that takes into account all the guidance changes as a result of COVID-19 and provides clear procedures for the verification of expected death (Hospice UK, 2020). It provides a competency assessment tool for nurses and details the changes in the verification procedure that have taken place as a result of the pandemic, such as the use of PPE and the order of the verification process itself in order to minimise the risk of cross-contamination. The government has also released guidance for verification of death in times of emergency that identifies that non-competent individuals can verify death whilst being supported remotely through video-communication with step-by-step guidance by a competent clinician (DoHSC, 2020c). Most regions will have adapted the guidance in line with their own community services and clinicians should make themselves aware of their local policy and competency checklists.

Verification of death (verification of life extinct/confirmation of death) is an important part of the care of the deceased and needs to be carried out in a timely manner (within 1 hour of death in hospital and 4 hours in the community) whilst ensuring that the dignity and cultural needs of the deceased and their family and loved ones are respected wherever possible within the limitations of managing the infection control risk. A competent clinician can verify death that has not occurred under suspicious circumstances (all suspicious or unexpected deaths should be referred to the police and the coroner). A death from COVID-19 does not require automatic referral to the coroner, but other circumstances of that death may warrant a referral. Where the death is entirely unexpected and a clinician is in attendance, there is an expectation that resuscitation attempts should be made. However, if the clinician is confident that there are signs of irreversible death, then resuscitation attempts do not have to be started, but the clinician needs to justify this decision-making clearly in the medical records.

The process for verification of expected death during the coronavirus pandemic requires the use of the correct PPE, donned and doffed appropriately. The clinician carrying out the verification needs to have all their equipment prepared, together with the means to clean that equipment after the verification and then be able to store it clean in preparation for its next use. The order of the verification process has changed to minimise cross-infection and the clinician needs to be aware of the new procedure. The identification of the deceased needs to be confirmed. Family members or carers who are present should be asked to maintain a safe distance or leave the room as there is still a risk of disease transmission from the deceased if they are moved during the period shortly after death. They will also need to be informed that the official time of death of the deceased may be different from the time they understand the person to have died. The clinician carrying out the verification needs to document the process in the medical records – many organisations have specific verification of death forms that may have been adapted in accordance with the new processes.

Further Reading

- Association for Palliative Medicine. Priority medicines for palliative and end of life care during a pandemic: https://apmonline.org/wp-

content/uploads/2020/04/priority-meds-for-end-of-life-care-290420-final-2.pdf.

- Association for Palliative Medicine. COVID-19 and palliative, end of life and bereavement care in secondary care: https://apmonline.org/wp-content/uploads/2020/03/COVID-19-and-Palliative-End-of-Life-and-Bereavement-Care-22-March-2020.pdf.
- Navigante AH et al. 2006. Midazolam as adjunct therapy to morphine in the alleviation of severe dyspnoea perception in patients with advanced cancer. *Journal of Pain and Symptom Manag*ement 31, 38–47.
- 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: https://www.pcrs-uk.org/sites/pcrs-uk.org/files/resources/COVID19/NHS-London-Primary-and-Community-Care-Respiratory-Resource-Pack-during-COVID-19-V3final-160420.pdf.
- The RCGP resource hub is a really detailed EoLC guidance with flow charts, advice for carers (Illora Finlay), priority meds for eoLC: https://elearning.rcgp.org.uk/mod/page/view.php?id=10537#RCGP.
- Restore2: https://westhampshireccg.nhs.uk/wp-content/uploads/2020/02/CS49286-RESTORE2-full-version.pdf,

Bereavement

COVID-19 has greatly affected bereavement and the way in which people grieve as people have been separated from their loved ones in the dying phase, whether they die in the community or the acute sector. If a person enters the dying phase in a hospice or nursing home, there may be restrictions on who can be with the dying person, and with tight regulation around contact often only one visitor is allowed at the bedside. Even if a person dies in the home, this contact is restricted to only family members in that household having contact if appropriate (Moore et al., 2020).

Anticipatory and Disenfranchised Grief

Being with a dying person is part of the process of bereavement. Seeing the dying process prepares us as humans for the death of those we love and is often referred to as 'anticipatory grief'. However, due to the possibility of cross-infection and also in part because of the unknown disease trajectory of COVID-19, families and loved ones have been denied this vital time (Wallace et al., 2020). The blocking of anticipatory grief for families leads to what is described as 'disenfranchised grief', whereby members of social groups cannot participate in the usual rituals of burials and funerals which are normally practised in society (Wallace et al., 2020).

In addition the cultural aspects that may help us to better deal with our grief can be taken away during a pandemic, for instance, the numbers restricted at funerals and no social gathering allowed after the funeral to allow grievers to console and support each other. We as a society are unable to celebrate fully the lives of the people we have lost through COVID-19 and therefore a large section of the UK are at risk of depression and psychological stress in bereavement (Carr, Boerner and Moorman, 2020).

Support during COVID-19

A study by Mayland et al. (2020) has looked at how to best support the bereaved through COVID-19 by reviewing research on the impact of previous pandemics on grief and bereavement. The loss of rituals that are practised in dying and death potentially increases the risk of complicated grief and this should be addressed in COVID-19 with strategies such as the following:

- Employing different ways of connecting with loved ones (e.g. video calling).
- Ensuring that dying patients have individual care plans and discussing these to verify that they support the patient's beliefs as much as possible.
- Planning with the loved ones of the deceased about future memorials and celebrations after restrictions are lifted (Mayland et al., 2020).
- Empowering caregivers in the community to participate in the care of their loved ones at home during COVID-19 with the support of the community palliative care team.
- Involving the family in advance care planning so they are aware of the wishes of their loved ones (Chidiac et al., 2020).

8

Professional Resilience

COVID-19 has put a huge strain on the welfare of clinicians, partly due to an increased number of critically ill people in the community along with the high mortality rate and infectious nature of COVID-19, but also because of the personal challenges to clinicians such as potential self-infection, self-isolation and their responsibilities to their own families (Maben and Bridges, 2020; Wu, Connors and Everly, 2020).

It has been suggested that the following factors must be recognised when supporting clinicians during the COVID-19 pandemic:

1. **Evidence-based psychological support** is needed. Evidence and theory should be underpinned by expert opinion such as that used in the military and during other infectious outbreaks worldwide.
2. **General well-being** of clinical staff should be addressed – for example, by paying attention to breaks for drinks, meals and rest.
3. **Peer support** is important. Encourage team and colleague support, perhaps via a buddy support network.
4. **Good leadership** – research into members of the armed forces has indicated that team cohesion is needed both between peers (horizontally) and from managers to their team members (vertically) to establish good and effective psychological support in organisations

5. **Long-term recovery** – it must be acknowledged that for some clinicians, the psychological recovery from COVID-19 may take time and interventions by management may have to be implemented for many months after the peak of the pandemic (Annachiara et al., 2020; Maben and Bridges, 2020). Psychological recovery may also take time as clinicians do not always have the time to process their emotions because of the time constraints of practising within the context of a crisis of a pandemic (Wu et al., 2020).

The need to support professionals who witness trauma is already well evidenced and embedded into psychological theory (Bowlby, 1988). The suffering of patients, families and loved ones during the COVID-19 pandemic, witnessed by healthcare professionals, may cause moral distress for clinicians and it has been suggested that this can lead to mental burnout. Subsequently psychological and spiritual support is essential to healthcare professionals during times of increased pressure (Borasio et al., 2020).

During a study of clinicians' resilience and experiences of the pandemic, three main themes emerged:

1. The need for greater responsibility of clinicians to be fully aware of their duty to support the wellbeing of their patients.
2. The ability to adapt to working in the totally new context of COVID-19, such as PPE and greater-than-ever workloads.
3. Increased resilience amid challenges – with clinicians citing the importance of social support as well as self-management to cope in highly stressful situations (Liu et al., 2020).

Not only has COVID-19 affected clinicians' mental health, but the population as a whole also risks living in a society with additional health problems, such as stress, clinical depression, anger, insomnia and fear and will contend with healthcare systems that are potentially weakened due to the pandemic (Torales, et al., 2020).

9

Case Studies*

Case Study 1: Head of Community Palliative Care

By Oliver-Jon Tidball, Head of Community Team, Heart of Kent Hospice

Rachel

Rachel is a South African lady in her early 60s with a primary diagnosis of metastatic right-sided breast cancer which was diagnosed 21 years ago. She had several significant admissions to the acute sector with headaches, global decline, confusion and increased anxiety. During her last admission, most of her symptoms improved, but her physical condition was such that she was discharged to a local nursing home under fast-track continuing healthcare funding and was referred to a hospice for best supportive care from the community team. On referral to the community palliative care team, her disease had progressed to include bone, pulmonary, lymph node, skin and cerebral metastases. She has a past medical history of type 2 diabetes mellitus and depression with anxiety.

* Although these case studies are based on real-life events they have been written and adapted specifically for the purposes of this publication. No identification with actual persons (living or deceased), places, buildings, and products is intended or should be inferred.

Rachel is a devout Christian and used to be a regular attendee at her local church. She is visited regularly by her vicar. She is divorced and the family do not have contact with her ex-husband John. Rachel has three grown-up children; her eldest child Paul is estranged from her and the family, but she has guardianship of his two daughters (aged 14 and 9) following his divorce seven years ago. Wendy, Rachel's daughter, has moved into the family home with her husband to care for her two nieces and her younger brother David, who suffers from Attention Deficit Disorder.

You are called out by nursing staff at the nursing home following a fall and Rachel's rapid deterioration in the last 48 hours. Rachel is now pyrexial, refusing oral intake and disorientated, and is holding her lymphoedematous right arm and crying out when this is touched.

Rachel has anticipatory injectable medications prescribed both for syringe pump and as required administration. She has a fully completed and authorised Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form and a Treatment Escalation Plan (TEP) in place. All advance care planning documentation states that Rachel's preferred place of care is her nursing home and she does not want to be admitted to hospital again.

- What do you assess to be Rachel's physical needs?
- What do you assess to be Rachel's psychological, social and spiritual needs?
- Does Rachel need to be admitted to the hospital? Give the rationale behind your answer.

- Are there any other members of the multi-disciplinary health team who should be involved in Rachel’s care ?

Case Study 2: Community Clinical Nurse Specialist

By Jacquie Hackett, Community Clinical Nurse Specialist, Heart of Kent Hospice, Kent

Cyril

Cyril is a 90-year-old man with a history of prostate cancer and COPD. He has had several recent admissions to hospital with urinary retention and now has a urinary catheter in situ.

Cyril lives with his wife Edith; they have just celebrated their diamond wedding anniversary. Cyril has deteriorated significantly over the last few months and he now requires help with personal care, has a BD care package and relies on his wife for all meals and drinks. Due to COVID, they have been shielding and have depended on their family for all their shopping.

Until recently, Cyril had not wanted to discuss his wishes for his care; however, due to his recent experience of admission to hospital, with no visitors allowed, he has decided that he does not want to go back into hospital and he wishes to remain at home. This was discussed with his hospice CNS and a DNACPR form and treatment escalation plan (TEP) were completed; stating that Cyril wished to remain at home and be given appropriate treatment within the community setting.

Cyril became acutely unwell. He was pyrexial and appeared to be muddled. He had gone off his food, was not drinking and had become more breathless than usual.

Edith dialled 111, who sent a paramedic crew. On arrival it was apparent that Cyril had an infection; it was uncertain if it could be COVID-19. The crew advised that it was in Cyril's best interests to go to hospital. Edith informed them of Cyril's wishes to remain at home.

- What information could the paramedic crew utilise to support the decision making to remain at home?
- What treatments/interventions could be considered within the community setting?
- What additional support might be required to help care for Cyril?
- Many older people who have COVID present atypically; what symptoms might you observe in this case?
- If Cyril's condition worsened and COVID was suspected, what medications might be required to manage his symptoms? What is the difference in the doses prescribed to manage severe distress and breathlessness of a patient with COVID?

Case Study 3: Paramedic

By Ashley Steward, Registered Paramedic with South East Coast Ambulance Trust

Bernard

Bernard is a bed-bound 84-year-old man diagnosed with stage 4 metastatic bladder cancer. He lives at home alone and has carers visit 4 times a day. He has recently been discharged from hospital following investigation into his ongoing lower back pain and weakness in one leg.

Since being discharged, Bernard has felt increasingly unwell and has continued to experience severe lower back pain. Less than a week after being discharged, he complains of weakness in both of his legs and feels significantly shorter of breath and fatigued. Subsequently, His carer calls 999 and an ambulance is dispatched.

- What are your first impressions of Bernard's possible medical conditions?
- What pandemic-related procedures, policies and guidelines should the paramedic crew be familiar with prior to attending Bernard in his home?
- What risk factors can you identify that may have put Bernard at risk of contracting COVID-19?

On assessment, the paramedic crew identify Bernard to be acutely unwell (pyrexial, tachypnoeic, hypotensive). The crew also establish that he is displaying symptoms of malignant spinal cord compression (MSCC), which they quickly identify as a palliative care emergency. The crew go on to explain to Bernard the need for a time critical transfer to hospital. Bernard has a DNACPR; however, he does not have a treatment escalation plan, ACP or just in case (JIC) medication. Bernard agrees to hospital admission, but he anxiously asks the crew if his daughter could be informed and attend hospital with him. Unfortunately, due to COVID-19 restrictions, the hospital currently has a strict 'no visitors' policy. This being the case, his daughter asks if there is any way for her to see her dad before he is transferred to hospital. She states that she can be on scene within 20 minutes. Bernard appears distressed at the possibility of going to hospital alone and trusts the paramedic crew to do what they deem best for his treatment.

- How would you manage this situation?
- What ethical considerations should be considered and who could be contacted for additional support in decision making?
- How will a 'no visitors' policy affect Bernard's care and what impact may this have on his relatives?

- What pertinent information needs to be documented and communicated regarding Bernard's current palliative care package?

Case Study 4: Paramedic

By Harriet Evans, Registered Paramedic, London Ambulance Service

Richard

Richard is a 79-year-old male living in a nursing home. He is normally bed-bound due to advanced Parkinson's disease, but does not have any issues communicating with staff on a regular basis. A 111 call is made on a Saturday morning by the nurse on duty for Richard as he declined during breakfast this morning and was presenting as drowsy and not engaging well with staff, which they noted as not being normal for him.

Richard does not have a DNACPR or any advance care planning documentation in place, despite his advanced Parkinson's disease, and his family have not been able to visit recently due to the visiting restrictions. Upon speaking to the out of hours GP, the decision is made to dispatch an ambulance.

- What are your initial impressions of differential diagnosis for Richard's presentation?
- What limitations are imposed on the situation, given that it is 'out of hours' for Richard's normal GP?
- What factors may affect the crew's decision making as to the level of PPE to apply when entering the nursing home to treat Richard during COVID-19?

A paramedic crew arrives to find that Richard is unresponsive. His oxygen levels are below 50%, but he is breathing for himself at a slightly elevated rate. He is also tachycardic and hyperthermic; however, his blood pressure is stable and his blood sugar is normal. On examination of his lungs, bilateral basal crackles can be heard.

Upon further questioning of the nurse on scene, the crew find that multiple residents have already died at this nursing home of possible or confirmed COVID-19 and that Richard had developed a slight cough over the last few days, but had not been short of breath. He has otherwise been well recently with no other new illness or deterioration noted by staff and does not have any chronic respiratory issues.

- How would you manage Richard's condition?
- Does the new information provided by the nurse on scene change your plan of management?
- How may lack of regular visitation by family, during the pandemic due to restrictions, have contributed to the situation developing in this way?
- Should the crew undertake family involvement in decision making on scene? And what ethical considerations will the crew have to consider?

Case Study 5: District Nurse

By Becca Lee, District Nurse, Kent

Amir

Amir is a 93-year-old man with a history of chronic kidney disease stage 4, type 2 diabetes and hypertension. He has no pre-existing respiratory conditions.

Amir lives alone with his wife; they have been married for 72 years. Amir has a private care package, involving three visits per day.

Amir has been seen by the local district nurses for many years as he is housebound. The clinical care given by district nurses includes blood tests, observations, wound dressings and ear irrigation.

At the beginning of the COVID-19 pandemic, Amir and his wife requested a DNACPR. A treatment escalation plan (TEP) was discussed with the couple at this time and was completed with their consent.

Amir became pyrexial; he was swabbed for COVID-19 and received a negative result. Ten days after the COVID swab he suddenly became acutely unwell; he was hypoxic with extreme shortness of breath.

The district nurses were called urgently to the house and, following a full assessment, commenced end-of-life care with anticipatory medications. Given Amir's symptoms, the district nurses believed he had COVID-19, even though he had a negative result 10 days earlier.

Amir died the following day. He continued to be in respiratory distress until he died as the doses of anticipatory medication did not seem to have any effect.

- As a community nurse, how would you have managed Amir's symptoms?
- What information would Amir and his wife have needed?
- What information would the carers have needed?
- How would you have supported your team in this situation?

Case Study 6: Discharge of Patients with Palliative Needs from the Acute Sector to the Community

By Sophie Trent, Registered Nurse, ITU, Darenth Valley Hospital, Kent

Mae

Mae is a 64-year-old Asian woman. She lives at home with her husband who has pulmonary fibrosis. Over the past several years, she has supported him in his daily living activities and the day-to-day running of the household as his carer. Mae develops a headache which is ongoing for 3 days; due to the current pandemic, she is unable to see her GP and takes herself to hospital. She is routinely swabbed for COVID-19, which returns a positive result and she is transferred to the designated COVID-19 area for treatment, where she will be kept for 24-hour observation.

Mae has a daughter who is 36; however, they do not live within the same household. Her daughter has children of her own and is unsure how to manage the situation whilst maintaining social distancing to not bring further risk to her father or to her family.

Mae is observed over the next 24 hours and is deemed medically fit for discharge. However, she is now unable to return home and support her husband due to her continued COVID-19 status and his high risk of mortality.

- What might Mae's concerns be when she tested positive for COVID-19?
- What additional risks are there to the BAME community?

- How can we support Mae’s family while she is unwell and what services might you consider for Mae’s husband?
- What are the risks of discharging her home to her normal routine?
- What are your professional responsibilities as a clinician?
- How can you ensure a safe discharge whilst supporting Mae’s social needs?

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COMMUNITY PALLIATIVE CARE AND COVID-19

A handbook for clinicians who care for palliative patients with COVID-19 in community settings

This handbook is an essential guide to caring for the community palliative care patient in relation to COVID-19, when the patient's preferred place of care is at home or the hospice. It will guide you through appropriate care procedures and protocols in managing end-of-life patients who show symptoms of COVID-19.

Key features include:

- Difficult conversations and communication skills
- Symptom management
- Advance care planning
- Caring for stable patients with palliative needs and those who are at end-of-life
- Supporting the family and friends of the patient
- Your own well-being as a healthcare professional

Supported by applicable case studies from a range of community care settings, this guide will be relevant to anyone affected by the challenges of COVID-19 when managing end-of-life patients or caring for older people, including paramedics, nurses and palliative care providers.

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