Trinity Hospice
Compassion and care

Blackpool Teaching Hospitals NHS
NHS Foundation Trust

NHS
Blackpool Clinical Commissioning Group
Fylde and Wyre Clinical Commissioning Group

Fylde Coast guidance on advance care planning, palliative and end of life care for residential and nursing home residents (during Covid-19 outbreak)

Scope and aim of guidance

1) Provide information and support for those working with residential and nursing home residents (care home staff, care home teams, GPs and community teams) and to facilitate discussions about advance care plans with residents.
2) Information about support specialist palliative care can provide including symptom control guidance, training, virtual support and 24 hour access to advice.
3) Signposting to other guidance or resources.

Discussions with care home residents about future care

Many residential and nursing home residents are in the last year of their life. The perils of hospitalisation for these residents, such as delirium, are well known and many residents admitted to hospital would prefer to be treated at home. As far as possible we need to make every effort to provide care for this vulnerable group of patients in their home, keeping them out of hospital unless strictly necessary. Acute hospital staff will be dealing with large numbers of people infected by COVID-19 and older people will be vulnerable to contracting the virus if admitted. Older people with frailty, often with multiple long term conditions or dementia have depleted reserves making them far less resilient to acute illness.

Many frail older people will die over the coming months, of COVID-19 and / or of their underlying health conditions and frailty. It is important for all health and social care professionals to remember that death is a natural part of life and to have honest and sensitive conversations with our patients and families.

This is not about rationing or denying older people treatment. It is about making the right choice for that person and respecting their dignity. We want to know what is important to the resident and what their priorities are. Best practice is that this should be discussed with the residents (if they have capacity) and if the resident agrees, with those close to them.

If the resident (e.g. due to dementia) does not have capacity[1] to have these conversations then it should be discussed with those who know the resident best. In this situation, the loved ones are not making the decision for the resident (do not put that burden on them) but letting everyone know about the resident and what their wishes might be. If a resident without capacity has a Lasting Power of Attorney for health they must be consulted. If an advance decision to refuse treatment decision has been made and is relevant this must be respected.

These conversations are difficult at the best of times and even more so in the current situation where we may be having them remotely. With all the news in the media people are more likely to be expecting you to have these conversations and it is unlikely to come as a surprise. We do not wish to force conversations on people but be honest with yourself, is it that "I don't want to have this conversation", rather than "it will upset the resident and /or their family". **We should be offering these conversations to every care home resident and or those close to them.** Please let us know if there is a resident with whom you have not had a conversation with them, or their loved one and we can offer support.

It is unacceptable for advance care plans, with or without DNACPR form completion to be applied to groups of people of any description. These decisions must continue to be made on an individual basis according to need.[2]

What is a frailty score and how do I work it out for my residents?

The first thing to remember is that this score is only for older adults (over 65 years). Residents under 65 should have an individualised assessment. Residents of any age with stable long-term disabilities (for example, cerebral palsy, learning disabilities or autism) should not have those conditions assessed as part of the frailty score (NCG critical care).[3] "If someone needs a stick to walk because of a birth injury it doesn't make them frail." [4](RCP email)

Taking that into account the vast majority of care homes residents in the Fylde coast are over 65 and meet the criteria for frailty (clinical frailty score of five or more).

[1] Mental Capacity Act. http://www.legislation.gov.uk/ukpga/2005/9/contents

[2] https://www.rcgp.org.uk/about-us/news/2020/april/joint-statement-on-advance-care-planning.aspx

[3] https://www.nice.org.uk/guidance/ng159

[4] Royal College of Physicians email, March 2020

Clinical Frailty Scale*

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 category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.

3 **Managing Well** – People whose **medical problems are well controlled,** but are **not regularly active** beyond routine walking.

4 **Vulnerable** – 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 **Mildly Frail** – These people often have **more evident slowing,** and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 **Moderately Frail** – People 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 (cuing, standby) with dressing.

7 **Severely Frail** – **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 **Very Severely Frail** – 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 <6 months**, who are **not otherwise evidently frail.**

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.

Critical care and hospital care for residential and nursing home residents

According to the national guidance for COVID -19[5], patients with a clinical frailty score ≥ 5 have an uncertain benefit from critical care support and many will not be offered intensive treatment as it will be judged to be more harmful than helpful. This would include a significant proportion of nursing and residential home residents. This means we need to carefully consider the benefit of admitting frailer nursing and residential home residents to hospital with suspected or confirmed COVID-19 or other cause of an acute deterioration. This is not about rationing or denying care for these residents but about identifying those unlikely to tolerate or benefit from these treatments and communicating this to them and their families through honest conversation, exploring their preferences for future care.

Some patients, unsuitable for critical organ support, may still benefit from hospital based care. This ward based care may include investigations for the causes of a deterioration in health, oxygen therapy and possibly other treatment such as IV antibiotics or IV fluids. However any potential benefit needs to be very carefully balanced against the burdens of an acute admission, which can be considerable. For susceptible patients it can involve a significant worsening of confusion or delirium. It may mean an increased symptom burden from the actual transport and new environment. There is a risk of hospital acquired infections in patients least able to fight one (this being particularly relevant at a time when the exact cause for an acute illness is unlikely to be known for certain prior to admission). In many circumstances conservative treatment/support in a residential or nursing home may be safer and more likely to succeed. It should also be recognised that at present, Blackpool Teaching Hospitals are not allowing visitors. A person admitted to hospital would be alone, separated from their familiar carers and family. This is not the way that many people would choose to complete their lives.

Local data (not COVID-19 related) reflects the poor prognosis for nursing home residents, demonstrating that these residents were significantly less likely to survive an acute medical admission compared to elderly people living in the community and one third of nursing home residents did not surviving an acute admission with over a half dying within 6 weeks of admission. These figures were even higher for nursing home residents with multiple comorbidities.[6]

Decisions around ceilings of treatment are difficult and may need to be made quickly, which is why we recommend talking with care home residents and their families in advance and finding out their views: “hoping for the best and planning for the worst”. Advance Care planning is of value at any time for palliative and frailer patient with underlying health conditions. The current risk of an acute deterioration from COVID-19 infection makes it even more important. Agreeing a plan for emergency care and treatment will help create a personalised recommendation for a person’s clinical care in a future emergency in which they may not be able to express choices.

[5] https://www.nice.org.uk/guidance/ng159
[6] https://pmj.bmj.com/content/86/1013/131.long

Advance Care Planning[7]

Background

The UK population is aging and many more people are living with chronic illness and multiple comorbidities. A third of all patients admitted unexpectedly to hospital are in the last year of life. **Advance Care planning is of value at any time** for palliative and frailer patient with underlying health conditions. The current risk of an acute deterioration from Covid-19 infection makes it even more important.

In the event of an acute deterioration from Covid-19, NICE Guidance (March 2020) indicates patients with a frailty scale score of five or more have an uncertain benefit from critical organ support. Most patients in residential care will have frailty score of five or more. Generally people in NURSING beds will be more / fully dependent and have a clinical frailty score of 7 or above (severe)

Recommend

Open, honest and sensitive conversations should take place regarding ceilings of treatment and overall goals of care with all palliative and frailer patients (where appropriate). Acknowledging this and discussing what is important to the patient and family may inform decisions around **ceilings of treatment**.

This enables those with significant potential to recover to receive the appropriate level of care and that those unlikely to survive an acute deterioration (from whatever cause) receive good, appropriate, individualised and patient centred care at end of life.

Consider a DNACPR in line with national guidance

Consider discussions around preferred place of death and care

Sensitively explore ceilings of treatment with patients and families

Example treatment levels from 'Coordinate My Care', a London based EPaCCs

Level 1: Full active Treatment including CPR

Level 2: Full active treatment including acute hospital settings but not CPR

Level 3: Treatment of any reversible conditions including acute hospital settings but not for CPR or ventilation

Level 4: Treatment of any reversible conditions but only in home/nursing, home/hospice setting

Level 5: Symptomatic treatment only: Keep comfortable

Document in Clinical notes and EPaCCS (Electronic Palliative Care Coordination system)

[7] From Fylde Coast guidance on community symptom management in the last days of life where there are shortages of syringe drivers or insufficient healthcare professionals to facilitate frequent subcutaneous injections (during Covid-19 outbreak)

A paper copy of any individualised advance care plan/ceilings of treatment decision may also be helpful in residential and nursing care homes to be kept with the DNACPR form (if completed) as well as ensuring the practice complete the EPaCCS (Electronic Palliative Care Coordination system).

A locally agreed paper version of an emergency care plan is not available, but a framework for this has been suggested by the Resuscitation Council, called ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) https://www.resus.org.uk/respect/.

The out of hours information form, click here, should be completed for all residents.

Taking into account the frailty scores of a majority nursing homes residents and a significant proportion of residential home residents we would expect that the ceilings of treatment to be level 3 to 5 for the majority of these patients.

If the ceiling of treatment is level 3 (treatment of reversible condition, including hospital admission if appropriate) it is important to consider what specific treatment the hospital may provide (i.e. pining of hip fracture, treatment of other long term conditions, oxygen therapy, intravenous fluids or antibiotics) and if the condition is reversible. This is particularly relevant given the potential for increased symptom burden, isolation and disorientation resulting from an admission.

Low Oxygen levels in a patient who was felt to be rapidly deteriorating and irretrievably dying from their illness would not be an indication for an admission to Hospital. In this situation a symptom based approach for breathlessness, using non-pharmacological management, Morphine and/or Benzodiazepine (as described in *Clinical Practice Summary*) should be used.

For a patient with a ceiling of treatment of level 4 to 5 we would try and avoid hospital if at all possible and try and support their care in their residential or nursing home. But an admission may be considered if supportive measures do not adequately control symptoms, for example, fractured neck of femur and again this would require review and an individualised approach.

For those patients who remain for attempted Cardiopulmonary Resuscitation

For any resident being cared for in a residential or nursing home that is either suspected or confirmed as having COVID-19 infection and does not have a do not attempt cardiopulmonary resuscitation (DNACPR) decision in place. If a cardiac arrest is confirmed, follow the procedure below as described by the Resuscitation Council UK Guidelines; https://www.resus.org.uk/media/statements/resuscitation-council-uk-statements-on-covid-19-coronavirus-cpr-and-resuscitation/covid-healthcare/)

1. For those confirming cardiac arrest:- **Cardiac arrest is confirmed by inspection of the patient and feeling for a pulse. Do not listen or feel for breathing by bending down to the**

patient's mouth. If cardiac arrest is confirmed call for help and start chest compression only CPR. When initial help arrives, instruct them to contact 999. Continue until return of spontaneous circulation, help arrives or you become exhausted.

2. For those responding to a cardiac arrest:- Call 999 and report ''**Cardiac arrest, COVID-19 suspected. Address…''.**
   Do not enter the room unless PPE for an aerosol generating procedure (AGP) is available and you are trained to use it.

Support for care home residents in isolation

Older adults, especially in isolation and those with cognitive decline/dementia may become more anxious, angry, stressed, agitated, and withdrawn during the outbreak/while in isolation. Provide practical and emotional support. Share simple facts about what is going on and give clear information about how to reduce risk of infection in words older people with/without cognitive impairment can understand. Repeat the information whenever necessary. Instructions need to be communicated in a clear, concise, respectful and patient centred way, working with their families.

Where can I get additional support?

Out of hours Care Co-ordination telephone 01253 955750

Blackpool care home team via neighbourhood hubs - 8.30 am – 6.30 pm

BLACKPOOL			
North Neighbourhood	Moor Park Health Centre Bristol Avenue, Bispham, FY2 0JG	Reception: 9 57390	bfwh.northshore@nhs.net
Central Neighbourhood	Whitegate Drive Health Centre, 150 Whitegate Drive, Blackpool, FY3 9ES	Reception: 9 53040/41	bfwh.central.nhs.uk
Central West Neighbourhood	Whitegate Drive Health Centre, 150 Whitegate Drive, Blackpool, FY3 9ES	Reception: 9 53040/41	bfwh.dncentralwest@nhs.net
South Neighbourhood	South Shore Primary Care Centre, Lytham Road Blackpool, FY4 1TJ	Reception: 9 53001	bfwh.southshore@nhs.net

Fylde & Wyre Care Home Service - 8.30am- 4.30pm Monday to Friday please use your normal point of contact outside these hours.

Wyre Care Home Team- 01253 955123 Fylde Care Home Team- 01253 952340

What about specialist palliative care support?

The community team at Trinity has expanded their virtual clinic to become "Trinity Virtual Hub". The hub will be held Monday- Friday 9-11am to support care homes, nursing homes and the enhanced primary care teams in community. The neighbourhoods, Care home team and Clifton can contact us between these times using Cisco Jabber for support in managing their palliative care patients.

Fylde Coast Palliative and End of Life Care Guidelines, April 2020 (Specialist Palliative Care: Dr Gillian Au, Dr Andrea Whitfield, Dr Harriet Preston, Dr Amy Gadoud and Dr Martin Davidson) General Practice (Dr Adam Janjua and Dr Ben Butler-Reid) and Clinical Lead Frailty (Dr Andrew Weatherburn)

The health care professional phoning into the hub will call (01253) (9)52597 which will be answered by one of the admin team. They will inform the nurse that the health care professional is waiting and they will either put them through or take contact details. Their details will then been put into" Trinity Virtual Hub" for the specialist palliative care nurse to see. There will be a nurse present 9-11am and they will only be unable to answer immediately if they are on another call. This can be used both for video and audio requests for support but please utilise the video as it's so much easier to have a discussion when you can see who you are talking to and allow your patients to talk to us if you are with them.

TRINITY VIRTUAL HUB CALL VIA CISCO JABBER (01253) (9)52597

MONDAY TO FRIDAY 9-11am

Trinity hospice have enhanced the medical support to the community specialist palliative care team who will also be available for advice to GPs, community teams and care home staff, via the number below.

24 HOUR SPECIALIST PALLIATIVE CARE ADVICE ACROSS THE FYLDE COAST COMMUNITY

VIA TRINITY HOSPICE: 01253 952 566

Good practice in providing symptom control at end of life is described in the *Clinical Practice Summary* and is helpful for all patients dying of any illness including COVID-19: Guidelines on consensus to managing Palliative Care Symptoms (NHS North West Coast Strategic Clinical Network 2017), https://www.nwcscnsenate.nhs.uk/files/4615/0661/0362/Clinical_Practice_Summary_-_Lancashire__South_Cumbria_Consensus_Guidance.pdf.

We have also produced Fylde coast specific guidance on community symptom management in the last days of life where there are shortages of syringe drivers or insufficient healthcare professionals to facilitate frequent subcutaneous injections (during Covid-19 outbreak). https://d2xm0co24ybbse.cloudfront.net/wp-content/uploads/2020/04/05100856/Fylde-Coast-End-of-Life-Guidelines-Covid-19-preparation-Final.pdf

Both of this guidance provides information on non-drug measures to help with symptoms such as breathlessness and delirium (acute confusion), where the care home team can play an invaluable role.

There is also national guidance on residential care provision during the COVID-19 crisis. Which provides information for service providers, https://www.gov.uk/government/publications/covid-19-residential-care-supported-living-and-home-care-guidance/covid-19-guidance-on-residential-care-provision. A resource pack for care homes from Public England Health England is also available for guidance.

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Click here for PHE NW Care Home Covid-19 pack

Verification of death

Verification of an expected death for patients, who have died from COVID-19 or other cause, can be undertaken by any registered healthcare professional (HCP) who has undertaken the specific training. COVID-19 is a natural cause of death.

- In working hours the HCP verifying the death must inform the patients GP.
- Out of normal working hours the HCP verifying death must inform the Urgent Care Centre who is then responsible for informing the patients GP.
- The HCP should notify the next of kin and liaise with them regarding contacting the funeral director.

Click here for Verification of Expected Death form

Additional training

For any training on verification of expected deaths by registered staff or syringe pump training please contact Vivienne Trott on Vivienne.trott1@nhs.net or 01253 957178

Care of the dying and care after death

Contact with relatives and loved ones is important; where visiting is not possible please consider the use of digital technology (i-Pad, Skype etc.)

Please discuss with the patient and loved ones any personal wishes. Mementoes / keepsakes (e.g. locks of hair, thumbprints) can be offered and taken **at time of death.** These **CANNOT be offered once the deceased is in a body bag.** If your clinical area has the capacity to take these, please offer them when liaising with family.Mementoes / keepsakes must be placed in a sealed bag and the family advised not to open the bag for 72 hours.

Local Fylde Coast guidance has been produced regarding the care of people after death in the community.

Click here for Community ACP & Care After Death guide

Other resources

General advice for health professionals regarding palliative care and COVID-19 is available: https://www.trinityhospice.co.uk/covid-19-information-for-healthcare-professionals/

Fylde Coast guidance on community symptom management in the last days of life where there are shortages of syringe drivers or insufficient healthcare professionals to facilitate frequent subcutaneous injections (during Covid-19 outbreak)

https://d2xm0co24ybbse.cloudfront.net/wp-content/uploads/2020/04/05100856/Fylde-Coast-End-of-Life-Guidelines-Covid-19-preparation-Final.pdf

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British Geriatric Society Coronavirus: Managing delirium in confirmed and suspected cases: https://www.bgs.org.uk/resources/coronavirus-managing-delirium-in-confirmed-and-suspected-cases

Royal College of General Practitioners and the Association for Palliative Medicine: Community Palliative, End of Life and Bereavement Care in the COVID-19 pandemic:

https://elearning.rcgp.org.uk/mod/page/view.php?id=10389

National COVID-19: guidance for care of the deceased:

https://www.gov.uk/government/publications/covid-19-guidance-for-care-of-the-deceased

Admission and Care of Residents during COVID-19 Incident in a Care Home:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/878099/Admission_and_Care_of_Residents_during_COVID-19_Incident_in_a_Care_Home.pdf

e-Learning for Health

Health Education England e-learning for Health (e-LfH) has created an e-learning programme for COVID-19. It is free to access without logging in for the entire UK health and care workforce, including the NHS, independent sector and social care. New content has been added on end of life care and critical care. https://www.e-lfh.org.uk/programmes/coronavirus/

The End of Life Care COVID-19 Core sessions: https://portal.e-lfh.org.uk/Catalogue/Index?HierarchyId=0_45016&programmeId=45016

This video link demonstrates how to have sensitive but honest and realistic conversations with our care home residents and their families https://vimeo.com/296832370/4e276bbbf2

This video from a GP with Morecambe Bay Clinical Commissioning Group (https://reimagininghealth.com/a-difficult-conversation-about-covid-19-care-planning/) highlights the need for a sensitive approach when talking to patients about advance care planning.

Appendix 1

British Geriatric Society: Managing the COVID-19 pandemic in care homes: https://www.bgs.org.uk/resources/covid-19-managing-the-covid-19-pandemic-in-care-homes

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Key recommendations

1. Residential and nursing homes should have in place standard operating procedures for individual residents with suspected and confirmed COVID-19 infection, including appropriate infection control precautions to protect staff and residents.

2. Residential and nursing home staff should be trained to check the temperature of residents displaying possible signs of COVID-19 infection, using a tympanic thermometer (inserted into the ear).

3. Where possible, residential and nursing home staff should be trained to measure other vital signs including blood pressure, heart rate, pulse oximetry and respiratory rate. This will enable external healthcare practitioners to triage and prioritise support of residents according to need.

4. All staff working with residents in residential and nursing homes should recognise that COVID-19 may present atypically in this group. It may be necessary to use barrier precautions for residents with atypical symptoms following discussion with General Practitioners or other primary healthcare professionals.

5. Where possible, primary care clinicians should share information on the level of frailty of residents (mild, moderate, severe frailty) with residential and nursing homes, and utilise the Clinical Frailty Scale to help inform urgent triage decisions.

6. If taking vital signs, care homes should use the RESTORE2 tool to recognise deterioration in residents, measure vital signs and communicate concerns to healthcare professionals.

7. Residential and Nursing homes should have standard operating procedures for isolating residents who 'walk with purpose' (often referred to as 'wandering') as a consequence of cognitive impairment. Behavioural interventions may be employed but physical restraint should not be used.

8. Residential and Nursing homes should work with General Practitioners, community healthcare staff and community geriatricians to review Advance Care Plans as a matter of urgency with residents. This should include discussions about how COVID-19 may cause residents to become critically unwell, and a clear decision about whether hospital admission would be considered in this circumstance.

9. Residential and Nursing homes should be aware that escalation decisions to hospital will be taken in discussion with paramedics, general practitioners, Blackpool Teaching Hospital and other healthcare support staff. They should be aware that transfer to hospital may not be offered if the benefit of an admission is outweighed by the burden and that conservative treatment within the home (with the input of supportive and palliative care if needed) may be a more effective therapeutic option. Care Homes should work with healthcare providers to support families and residents through this.

10. Advance Care Plans must be recorded in a way that is useful for healthcare professionals called in an emergency situation. A paper copy should be filed in the nursing or residential home records and, where the facility already exists, an electronic version used which can be

shared with relevant services.

11. Residential and nursing homes should remain open to new admissions as much as possible throughout the pandemic. They should be prepared to receive back care home residents who are COVID positive and to isolate them on return, as part of efforts to ensure capacity for new COVID cases in acute hospitals. They should follow the advice from Public Health England when accepting residents without COVID back when there are confirmed COVID cases within a home.

12. Residential and Nursing homes should work with GPs, Practice pharmacists and local pharmacists to ensure that they have a stock of anticipatory medications and the community prescription chart, to enable, at short notice, palliative care for residents.

13. All professionals should consider setting up multiprofessional local or regional WhatsApp groups, or other similar fora, to provide support to care home staff who may feel isolated and worried by the pandemic.