

### End of Life Care Plan

**Palliative Care** – Can have a palliative diagnosis for years e.g. heart failure, COPD, frailty, dementia

**End of Life** – Last 12 months of life

**Dying Phase** – Last days/hours of life

**Supportive Care Register** – anyone in last 12 months of life should be on the register in the home and also on the GP Supportive/Palliative Care Register in the practice. Supportive care register can be broken up into 3 categories – Green= last 12 months but no imminent risk anticipated; Amber = last few months where some deterioration in condition is noted; Red = last few weeks/days/hours of life where death is the likely outcome.

**Five Priorities for Care of the Dying Person** – *Recognising* that someone is dying; *communicating sensitively* with them and their family; *involving them* in decisions; *supporting* them and their family and *creating a plan of care* that includes adequate hydration and nutrition.

Name of Resident

DOB

Room

**Section A – Resident has a changing condition and could be in last 12 months of life.**

Wishes need to be established for future care and treatment in accordance with the residents own wishes and preferences wherever possible, or with relatives/carers if a best interest decision is required. This will be done after a mental capacity assessment has identified that the resident lacks capacity. If someone has been appointed as a Lasting Power of Attorney (LPA) for Health and Wellbeing they should also be involved if capacity is missing.

A long term condition is one that, at present, cannot be cured, but can be managed by medication and other therapies. Examples are diabetes, COPD, heart disease, kidney disease. How much an individual can take control/manage their disease will depend on what stage of their disease trajectory/healthcare journey they have reached.

**Section A will be used when it is recognized that a resident has a progressive illness that will ultimately end in death and where they are thought to be in the last 12 months of life. Any resident on Continuing Healthcare Funding must have this section completed. Consider applying for Funded Nursing Care if the resident has been self-funding.**

Advance Care Planning is optional for residents. If a resident has capacity and does not want to answer these questions or express any wishes regarding their future care and treatment, then document this in the notes and inform the GP. Ensure the resident knows that they can change their mind at any time.

Consider capacity – have you done everything possible to ensure a resident can be involved (MCA, 2005)?

Has a ReSPECT/DNACPR form been completed? Check it is valid and applicable. Is there a review date indicated?

Use the following prompts as a guide and record responses in the care plan.

- Have you explained why this information is helpful to ensure that we care for the person in a way that is acceptable to them?
- Check whether the person wants anyone else to be present during this conversation. If so, who is their main contact?
- Who do they wish to be involved in future decision making and who do they want to be with them as their condition deteriorates?
- Are any other health and social care professionals involved in their care? If so, who are they and what is their role? Ensure contact numbers are recorded e.g. Specialist Nurses, Palliative Care Team, SALT, Dietician etc. Any subsequent changes should be communicated with those identified.
- Has the resident/relative any strong views, wishes or preferences for their future care, especially if their condition starts to deteriorate?
- Does the resident have any existing advance care planning documentation, e.g. an advance decision to refuse treatment, have they appointed an LPA, completed a Preferred Place of Care document, have they made a Will etc.? If so, where is the documentation and ask if it is possible to have a copy?
- Has the resident any strong views on treatments e.g. blood transfusions, IV antibiotics, going into hospital? If so, ensure these are documented. (ReSPECT includes an escalation plan as well as resuscitation status).

- What is their view on how they would like to be cared for as their condition deteriorates?
- Where would they want to be cared for? At home or in hospital/hospice etc?
- Are there any religious/cultural or spiritual beliefs that are important to them now and in the future/after death?
- Are there any requirements around resuscitation? Explain the GP may have to be involved in these discussions.
- Has the resident got any funeral wishes or do they want any help in arranging this?
- Are there any specific requirements for when they die? For example, clothing, jewellery they would like to be worn, burial or cremation, preferred funeral director etc.
- Ensure drug and therapies are reviewed.
- Ensure funding is reviewed.
- Ensure the resident/relative knows that changes can be documented at any time while the person has capacity.
- Ensure if any changes are made then any relevant health and social care professional is updated with the new plan.
- Ensure the resident is on the GP Supportive/Palliative care register.
- Consider DOLs/Liberty Protection Safeguards are in place/reviewed.

**Assessed Needs**

**Expected Outcomes**

Assessed by.....(Name/Signature)  
.....(Role) Date .....

Section A Care Plan

Date/Time      Care Plan

Name / Signature

Role

Date

**Section B – The resident has a changing condition that requires a medical/nursing/MDT reassessment and review of needs. They are thought to be in the last few months of life (Amber) and have increasing need.**

This is a good time to ask the ‘surprise question’ to staff: ‘Would you be surprised if this resident would die in the next 6-12 months?’ If the answer is no, then you must ensure that the resident has been entered on to the home’s and your GPs supportive care register. Apply for Continuing Healthcare Funding (CHC) and ensure all equipment is in place.

If a resident/family has previously declined to be involved in advance planning discussions, this is a good time to revisit this topic. If a care plan has previously been agreed, then check this is still accurate and meets needs.

Remember to consider capacity – have you done everything possible to ensure a resident can be involved (MCA, 2005)?

Has a ReSPECT/DNACPR form been completed? Check it is valid and applicable. Is there a review date indicated?

Use the following prompts as a guide and record responses in the care plan.

- Has the resident got an irreversible life-threatening illness?
- Is the resident/family aware that their condition is deteriorating (and do they know what to expect)?
- Has the withdrawal or withholding of treatment such as antibiotic therapy and alternative feeding been discussed? These issues form part of general ‘end of life’ discussions. If the resident lacks capacity, involve friends/family or consider an Independent Mental Capacity Advocate (IMCA).
- Check that any previous advance care planning is still relevant i.e. does the escalation plan need reviewing? Check ReSPECT is still fit for purpose. Amend the plan if needed.
- Review medication therapy and need.
- If any other professionals are involved in the resident’s care then ensure they are involved/updated e.g. GP, Community Palliative Nurse, Specialist Nurse, Community Matron, Consultant.
- Ensure MDT notes and communication is updated and kept together.
- Consider DOLs/Liberty Protection Safeguards are in place/reviewed.

Assessed Needs

Expected Outcomes

Assessors Name/Signature

Role

Date

**Section C - The resident has a deteriorating condition that requires a medical/nursing/MDT reassessment and review of needs. They are thought to be in the last weeks of life (red phase).**

Significant conversations with the GP/resident/family and health and social care professionals (H&SC) should be discussed and recorded to enable the right care, at the right time, in the right place.

If you have not already done so, apply for CHC funding (which may be through the fast track route). Consider any equipment that is needed and any additional staffing requirements.

Use the following prompts if advance care planning has previously been declined. At this stage it is important that everyone is clear on possible care options and wishes. If residents cannot or do not want to be involved, then a best interest decision should be made by the MDT.

A DNACPR/ReSPECT plan MUST be instigated which should preferably be done with the resident/family/GP to ensure that unplanned admissions to hospital and resuscitation attempts are avoided wherever possible. Consider the residents capacity at every stage and ensure this is assessed/documenting accordingly.

Encourage the GP to use a 'Recognising Dying' form. If a GP refuses, then ensure it is documented in the notes that death is the likely outcome and that family/significant others (Including other H&SC professionals/Out of Hours Service/EMAS) are informed of this. Involve the resident and family/significant others in decision making and care planning wherever possible (Five Priorities for Care, LACDP, 2014).

Use the following prompts to ensure that all aspects of care are planned for:

- Is the resident/family/significant other aware that their condition is deteriorating?
- Has the withdrawal or withholding of treatment been discussed e.g. antibiotic therapy, PEG feeds etc.? Decisions about these need to be made separately to DNACPR/ReSPECT but are part of end of life discussions.
- Ensure drug therapies/medication are reviewed. Consider the route of medications.
- Ensure 'Just in Case' medications are prescribed and available.
- Is there a Preferred Priority of Care in place? (This should have already been agreed with the resident and family and have been communicated with the GP, Out of Hours service, Consultant, Palliative Care Team, EMAS etc.). This should be person led and reflect advance planning wishes.
- Consider discontinuing blood testing, observations, and other invasive procedures. Remember, if you are not going to offer treatment, don't do the test!
- Ensure any involvement from the GP, H&SC professionals is documented in the MDT notes.
- Ensure the supportive care register is updated (to red)

- Consider DOLs/Liberty Protection Safeguards are in place/reviewed.

**Assessed Need**

**Expected Outcome**

Assessors name/Signature

Role

Date

Assessed Needs Care Plan – Section C

Date/time    Plan of Care

Name/Signature

**Section D – The resident has deteriorated sufficiently that you believe they are in the last few days/hours of life (dying phase - red).**

Signs to indicate that this might be the case are when the resident is:

- Spending most of the time in bed
- Has fluctuating conscious levels – this might include confusion, agitation and drowsiness
- Is eating and drinking very little (swallow might be unsafe and they might have difficulty swallowing tablets)
- Changes in skin i.e. mottling of the skin, colour (cyanosis)
- Changes in breathing i.e. breathing may be less frequent, noisy, laboured

**Remember:**

- Ensure Recognising Dying Form, DNACPR/ReSPECT form are completed and Just in Case medications are prescribed and available to use.
- Ensure family/significant others are aware of deterioration and that the resident may be dying.
- Ensure staff are aware of the plan and goals of care.
- Monitor the effect of any interventions to ensure comfort and dignity are maintained.
- Be aware of any specific requirements before and after death e.g. sacrament of the sick before death, whether you can touch/provide care after death or whether a member of the residents' family/faith does this care.
- Seek advice from the Derbyshire Alliance for End of Life Care website, [www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk)

**Remember – We have **ONE CHANCE TO GET THIS RIGHT!****

<i>Physiologic Changes</i>	<i>Signs/Symptoms</i>	<i>Intervention</i>
<i>Cardiac and Circulation Changes</i>		
Decreased blood perfusion	Skin may become mottled and discolored. Mottling and cyanosis of the upper extremities appear to indicate impending death versus such changes in the lower extremities.	Provide good skin care. Turn patient every 2-3 hours if this does not cause discomfort. Lotion to back and extremities. Support extremities with soft pillows. Air mattress
Decreased cerebral perfusion	Decreased level of consciousness or terminal delirium. Drowsiness/disorientation	Orientate resident gently if tolerated and this is not upsetting. Allow resident to rest. Familiar staff. ?Open-visiting, familiar family/friends Soothing environment – music, smells Medication if required
Decrease in cardiac output and intravascular volume	Tachycardia Hypotension Central and peripheral cyanosis and peripheral cooling.	Comfort measures. Space out activities. Consider stopping invasive tests e.g. bloods, blood sugars
<i>Urinary and bowel function</i>		
Decreased urinary output	Possible urinary incontinence. Concentrated urine. Restlessness from constipation	Keep resident clean and dry. Use pads/pants for comfort and dignity Use barrier creams. Record if incontinent of urine/faeces and amount. This will help to eliminate if retention or constipation is a cause of agitation. Consider a catheter if skin starts to break down or if resident is large and difficult to provide incontinence care.
<i>Food and Fluids</i>		
Decreased interest in food and fluid.	Weight loss/dehydration	Do not force fluid or foods. Provide excellent mouth care – Twice daily brushing with soft toothbrush and non-foaming toothpaste if resident allows or MouthEze swabs in fluid of choice. Stop weight monitoring

		Reassure resident/relatives that this is normal – metabolism is decreasing and body systems are shutting down/working less efficiently
Swallowing difficulties	Food pocketed in cheeks or mouth/choking with eating/coughing after eating	Soft foods and thickened fluids as tolerated. Fortify foods with full fat cream, butter, milk powder etc. if able to swallow safely to increase calories. Consider portion size and make food look attractive. Stop feeding resident if choking or pocketing food – explain rationale to family. If on a PEG/artificial feeding regime then consider reducing the volume to prevent vomiting as absorption will reduce. Explain to family this is normal.
<i>Skin</i>		
Skin may become mottled or discolored.	Patches of purplish or dark pinkish color can be noted on back and posterior arms/legs. Lips and extremities may become blueish.	Keep sheets clean and dry. Apply lotion as tolerated. Explain to family this is normal.
Pressure ulcers may develop from pressure of being bedbound, decreased nutritional status.	Red spots to bony prominences are first signs of Stage I tissue damage and open sores may develop.	Relieve pressure to bony prominences or other areas of breakdown with turning and positioning every 2 hrs if tolerated. If resident has increased pain or discomfort with position changes, decrease the frequency. 30 degree tilt can be used. Special mattress as needed. Report changes in skin to nursing staff. Consult tissue viability team if pressure damage occurs and skin breaks down. Goals of wound care for Stage III and IV pressure damage should be to promote comfort and prevent worsening rather

		than healing since healing most likely will not occur.
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<i>Respiratory</i>		
Retention of secretions in the pharynx and the upper respiratory tract.	Noisy respirations – usually no cough or weak cough.	Head of bed up at 45 degrees. Can fold small soft pillow or towel behind neck for extra support. Consider repositioning. Consider medication. Avoid suction wherever possible. Reassure relatives that is more distressing for them than the resident. Resident would be trying to cough if distressed.
Dyspnoea/breathlessness	Shortness of breath	More common in residents with underlying chest pathology e.g. lung cancer, COPD, heart failure. Oxygen at 2-3 litres may help for some residents and often helps families to feel better. Nurse upright, well supported by pillows. Loose fitting clothing. Ventilate the room or provide a fan. Provide reassurance. Distraction may help.
Cheyne-Stokes respirations	Notable changes in breathing.	A gentle fan blowing toward the patient may provide relief. Educate families that this is normal as the resident is dying.
<i>General changes</i>		
Profound weakness and fatigue.	Drowsy for extended periods. Sleeping more.	This is normal. Educate family.
Disoriented with respect to time and a severely limited attention span.	More withdrawn and detached from surroundings. May appear to be in a comatose-like state.	This is normal. Educate family.
Resident may speak to persons who have already died or see places others cannot see.	Family may think these are hallucinations or a drug reaction.	If resident appears frightened may need to treat with medication. Otherwise, educate family that this is normal and common.