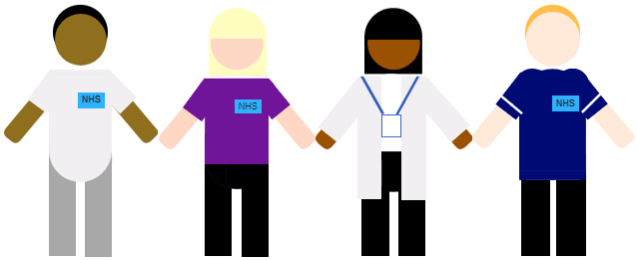
Oxford Health
NHS Foundation Trust

Staff guidance: last days of life care plan

Please use this guide to help patients complete their care plan



Community services

Last days of life care plan

Assess for signs and symptoms that a person may be entering the last days of life. Deterioration is usually over hours to days and includes reduced ability to communicate, level of arousal and ability to swallow. There may also be changes in breathing pattern, skin colour, sleep, deteriorating skin condition (Skin Care at Life's End, SCALE), increasing pain levels, fatigue and agitation.

Use knowledge gained from your assessment, the GP, the patient and those important to them to help determine whether the person is nearing death or has a reversible condition. Monitor for further changes at least every 24 hours. Use clinical judgement or discuss with the GP when a change suggests that the person's condition is deteriorating or could be stabilising or improving.

If a person's condition continues to deteriorate carry on using this care plan. If it improves go back to or start a palliative care plan.

When starting or changing to the Last Days of Life Care Plan you should use the Multi Professional Assessment (MPA) for all care needs. A Braden score should be completed on care notes.

A copy of the care plan should be uploaded to Care Notes and sent to the GP.

Page one: what do you understand about your health condition?

The person may have discussed the progression of their illness following recent conversations with their medical team or GP. They may have forgotten some of those conversations or not taken them in at the time. They may ask you for more information and it will be helpful if you have looked at their notes or had a discussion with their GP.

They may not wish to discuss their condition and not want to carry on with the care plan. This is ok and just needs to be documented in your records. You can re-visit the care plan at a later date if appropriate.

Page one: if you are unable to communicate your wishes regarding your treatment and care

The person may not always be able to communicate due to loss of capacity. People may become muddled or confused as their illness progresses or they develop an infection. They may wish to choose someone they trust to speak for them.

If they have nominated an attorney for health and welfare (LPA) then you/they need to write their name on page one in the 'people important to you' section of the care plan.

Page one: do you have any of the following documents?

Do not attempt cardio pulmonary resuscitation (DNACPR)

This only relates to resuscitation should the person's heart stop or they stop breathing, not to any other treatment. Their GP, specialist nurse or community matron will discuss this in more depth with the patient and there is also written information available.

This document will be completed by the doctor, specialist nurse or community matron. It should be first discussed with the patient and those close to them (if appropriate). A copy should be kept in the patients home and taken with them if they go into hospital. The Lions 'message in a bottle' is used in Oxfordshire. The bottle contains stickers for the front and fridge door to alert services that the person has a form in place. It is for guidance only and is not legally binding. It is for guidance only and is not legally binding.

Advance decision to refuse treatment (ADRT)

This is a legally binding document and refers to the refusal of medical treatment, for example if the person does not wish to have antibiotic therapy or cardiopulmonary resuscitation (CPR). The person can complete this document themselves or seek help from their GP. It must be signed, dated and witnessed. If it includes the refusal of CPR, words such as 'even if at risk to my life' must be included.

Advance statement

This is a statement that expresses the persons wishes. It is not legally binding but health professionals should follow it (if practical to do so). This care plan is an example of an advance statement.

Electronic proactive care plan (ePCP)

This plan is completed by the person's GP and records the persons preferred treatment options or ceilings of treatment. This may include their preferred place of care; a copy is usually printed out and given to the person. The GP will share the information with out of hours GPs (111 service) and the ambulance service.

Lasting power of attorney (LPA)

LPA can only be made when the person has the capacity to make relevant decisions regarding their treatment and care. The nominated attorney can then make decisions in the person's best interests (as long as these are practical and achievable) once the person has lost their capacity.
The document has to be registered with the Office of Public Guardian.

Page two: do you have any issues or priorities regarding your end of life care that you would like to discuss?

The person may have symptoms that are difficult to manage, such as pain or nausea and vomiting. Specialist palliative care teams will be able to help you manage with these symptoms, either by completing a joint visit or giving advice over the telephone.

The person may want to reflect on their religious or other beliefs and important aspects of their life. They may want to say goodbye to people who are important to them.

They might want to listen to music or have their bed in a certain position, e.g. where they can view the garden

Page two: what matters most to you? Is there anything that worries or scares you that you would like to talk about?

The person may want to talk through what they and those important to them can expect to happen when they are approaching death, for example physical changes and the likely sequence of events.

They may be scared that they will be in pain or they may be worried about how their spouse or partner will cope with their death, They may have feelings of guilt or remorse they would like to share with someone.

Remember that physical symptoms and psychological and spiritual distress go hand in hand and improving any one aspect of their health may improve others; for example if they are less anxious they may also have less pain or agitation.

Page two: are there any spiritual or religious preferences you would like to discuss?

The person may have rituals or cultural practices that will help them at the end of life. There may be a specific person known to them that they would like to see.

The person or those important to them may want to work through feelings of anger, anxiety or regret. It is important to be there as a supportive presence, to listen and help them accept that they are dying. You can encourage the person to reflect and assist them in recognising purpose, value and meaning to their life if appropriate.

Page two: do you have any thoughts regarding your preferred place of care? Are there things that may influence your decision? For example, management of your symptoms or concerns about those close to you?

The person may wish to be cared for at home or they may no longer feel they can stay at home due to their increased needs and the burden on their loved ones.

Suggest ways you may be able to help them stay at home by offering supportive visits and night care. They may be eligible for NHS funding to provide a formal care package.

The person may prefer to go into a hospice for their last days if they have symptoms that are difficult to manage. This will depend on their need and whether a bed is available.

Page three: it may be helpful to record anything else you would like to happen.

It might be helpful for the person and those important to them to record where they would like to be buried or cremated when they die and any other wishes they have such as funeral plans.

Page three: are any of the following in place?

Marie Curie night care

The person or their informal or formal carers may need some support at night or require help to manage their symptoms.. If they would like help at night you can refer them to the Marie Curie night sitting service.

Marie Curie is a free service and partially funded by Oxford Health. It is coordinated locally by Continuing Health Care (CHC, central team). The service is run on a priority basis and can provide registered nurses and senior healthcare assistants to sit from 10pm until 6.30am. You can only request a sit for the forthcoming night.

Contact CHC at Abingdon between 9am and 3pm to refer to Marie Curie. Outside these hours contact Marie Curie directly.

Some areas may also have help available from local charities such as Lawrence Home nursing or Kate's Home nursing in the North West of the county.

Social or NHS funding for your care

The person may be eligible for NHS funding for care in their last days through CHC; agency or in-house carers (Community Care Support team) may be able to visit to assist with their care. Refer for NHS 'Fast Track' CHC funding if appropriate. Forms can be found on the intranet.

Page three: do you have a implantable cardiac defibrillator (ICD)?

Attempts to prolong the persons life by the defibrillator function of their device may no longer be appropriate or a priority for them. Deactivation of the shock function may spare them and those close to them the indignity and distress of ICD shocks that no longer serve any useful purpose.

The heart failure or cardiac team will usually have discussions with the person around these issues and ideally come to an agreement with the person and those important to them. The defibrillator function can be deactivated in clinic or done in an emergency in the community by placing a ring magnet over the device.

Page three: do you have anticipatory medications?

Ask the GP to prescribe sub cut *anticipatory medication* for use if the person has increased symptoms that are not being managed by oral medication.

Make sure that the medication is written up on the appropriate electronic Decision to Administer (DTA) form. The medication can be kept somewhere safe until it is required.

If the person requires symptom control teams such as the Hospital at Home team (central, west or south of county) or Out of Hours (OOH) can visit overnight if necessary to administer the medication. Please ensure OOHs have a 'special note' and update the relevant teams regarding the patients condition.

Page three: are you on the NHS organ donor register?

If the person wants to donate their tissue after their death they will need to be on the NHS organ donation register. It is very important that the family/close friend understand and support their decision because their support is needed for donation to go ahead.

Please note: people who die at home will not be able to donate their organs only their tissues for example, corneas.

Further advice and support details

Community nurse team

If the person is no longer able to go to the surgery due to a deterioration in their condition consider referring to/offering regular palliative care visits.

Clinical nurse specialist/hospice:

There will be a community specialist palliative care team based at your local hospice. The specialist nurse will be able to help you with any uncontrolled symptoms your patient has such as pain or breathlessness and the need for psychological care.

Community matron

If you need help with coordinating your patient's care or if the patient has complex conditions you can refer to your local community matron. This can be done via an email to your ILT admin team to via single point of access (SPA).

Out of Hours

The Out of Hours service provides medical support when the GP surgery is closed. A paramedic or doctor will come out to visit the patient during the evening or overnight if necessary.

Hospital at Home

The Hospital at Home team are available during the out of hour period (south, west and central regions). You need to request that your patient is added to their palliative list. Ideally the patient should have anticipatory medication available with an electronic DTA administration chart so that the clinician is able to assist patient with symptom control.

The team consists of nurses and paramedics who work alongside the GP OOHs service and provide care to known patients/those referred through OOHs.

Other

The person may have someone else involved in their care such as a charity or care provider. They may want to put their details on their care plan.

Multi-professional assessment

Complete a holistic assessment involving the person and those important to them in their care planning if appropriate. Write individual care plans for each of their care needs and symptoms:

Nutrition and hydration

Reassure the person and those important to them that it is natural for a person to stop wanting to eat and drink in their last days. Subcutaneous fluids are not usually helpful; liaise with the GP if subcutaneous fluids are felt necessary. Consider stopping food or fluids via a PEG if in place.

Nausea and vomiting

If nausea and vomiting are present please consider recent opioid therapy, hypercalcaemia, bowel obstruction, constipation and anxiety.

Liaise with prescriber or specialist nurse about appropriate anti-emetic medication. Consider subcutaneous route if the patient continues vomiting or there is poor oral absorption.

Swallowing problems

Swallowing problems may occur in the last days. Advise carers to position the person as upright as possible when eating or drinking. A beaker may be preferable to use rather than a straw (takes effort, may cause coughing). If the person's consciousness levels reduce, or they are unable to swallow safely suggest mouth care only.

Oral hygiene

Assess the person for a dry mouth, sore mouth and oral thrush (white spots that are removed easily). Consider artificial saliva (spray/sticks), mouthwash, soft toothbrush and drinks with ice. Moutheze is a oral cleaner that is available through eProcurement, it is a replacement for the pink sponge swabs previously in use. There are also gels available if the persons mouth is dry.

Encourage family and cares to assist with mouth care or giving drinks, if they wish to.

Skin care

The persons skin condition may deteriorate in the last days. Consider ordering Quattro or a Premier active (hybrid) mattress. The premier active (hybrid) mattress is most comfortable if person is under-weight or cachexic), the motor can be switched on or off as appropriate. Assess whether it is appropriate to move patient or seek help from your local therapy team.

Consider 30 degree tilts to relieve pressure and use the Easy Roll or Wendy Lett slide sheet system to aid moving person in bed to relieve pressure and help prevent pain.

Request or prescribe barrier cream if the person is wearing pads and emollient for dry or itchy skin. Refer to the wound care formulary.

Assess for pain levels before each move and advise carers to administer analgesia if appropriate 30 mins before e.g. personal care or repositioning the patient.

Consider use of Wendy Lett sheets rather than slide sheets as less turning required.

Advise carers on how to use the slide sheets or how to turn or move the patient safely.

Ensure their bed is at the lowest height if there is a risk of falling out of the bed. Assess the safety and benefits of providing bed rails. Complete the appropriate risk assessment(s).

Seek advice from your therapy team, especially if complex moving and handling issues.

Pain

Assess pain levels and whether pain is constant or on movement only. Is pain generalised or in a specific locality? Be aware that pain levels often increase in the last days. Remember not all people will have pain.

Use the pain tool if appropriate for example, if someone is unable to verbally communicate. Consider liquid morphine before movement or personal care if pain on movement, if prescribed.

Consider a subcutaneous syringe driver route if the person has swallowing problems or probable poor absorption via oral route.

Liaise with GP or specialist nurse if the pain is intractable or difficult to manage.

Personal care

Involve the person and those close to them in decisions regarding their personal care needs. If their informal carers (family members and friends) become exhausted discuss any formal care that may be available e.g. through fast track funding.

Continence needs

Advise the patient on buying pads or pull up pants. Provide pads in an emergency if possible e.g. if the patient is becoming bed bound.

Consider the persons dignity and privacy. Use a urinary bottle or commode if the person is able to transfer. Use a wheeled commode if appropriate so that the bathroom can continue to be used.

Lower abdominal pain may be caused by retention of urine or constipation. Check when the person had their bowels last opened. Complete a PR if appropriate and liaise with the GP about treatment. Consider a convene or catheter if they experience pain on movement and urine retention is suspected.

Cognition, delirium and dementia

A person may become confused, especially with certain conditions such as liver failure or brain involvement. Some people may suffer from hallucinations which can be very distressing.

Confusion may also be caused by a delirium due to a reversible cause such as infection or overdose of opioids.

Liaise with the GP or specialist nurse and consider medication if appropriate.

Breathing

Assess for any breathing difficulties and excessive secretions. Positioning may help or use of medication such as subcutaneous midazolam (if causing distress) or hyoscine butylbromide (to help reduce secretions).

Consider fan therapy. Oxygen therapy is not usually helpful unless the person has long-term condition or is hypoxic. A small dose of oramorph may help if the person is able to swallow.

The person may also require non-invasive ventilation or suction under certain circumstances e.g. neurological conditions.

Consider a syringe driver to aid breathing and comfort in last days if required.

Seek advice from a specialist nurse (palliative or respiratory) or GP as appropriate.

Anxiety, agitation and distress

A person may become agitated in their last days of life due to biochemical imbalances or organ failure. Assess for pain and consider medication such as midazolam or analgesia, as appropriate, to help to calm them. Seek help from a specialist if necessary.

Psychosocial wellbeing

A reassuring and supportive presence or calming music may be helpful. Check in their care plan to see if they have any wishes documented. Consider whether the person would like e.g. a priest, to visit to perform a ritual such as the last rites.

Medications

Some people are intolerant to opioids such as morphine sulphate or may have poor kidney function and may require a substitute such as oxycodone (partially synthetic opioid). Always start with lowest dose if opioid naïve and titrate as necessary.

Consider a subcutaneous route, either giving (as required) subcutaneous injections or set up a syringe driver if more than two to three doses are required over a 24 hour period. If the person has a fentanyl patch leave it in place if considering a syringe driver (see syringe driver policy).

If a range of doses is given for a syringe driver, ensure only 1.5 times to original dose is prescribed.

Review medications with the GP or specialist nurse and consider stopping any that are not providing symptomatic benefit.

Concerns and complaints

We aim to provide you with a high quality service at all times. However, if you have any concerns, complaints or comments about your experience of our service then please tell a member of the team or contact the Patient Advice and Liaison Service on freephone 0800 328 7971.

If you need the information in another language or format please ask us

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