

End of Life care

Compassionate approaches to dying with dignity, preparing for death and ensuring a pain-free transition

DNAR

Do Not Attempt cardiopulmonary Resuscitation (DNAR)

There are instances when a person's health may or has deteriorated to a level where resuscitation would if successful leave them in a worse condition compared to before their heart or lungs stopped working. Some examples include patients with terminal cancer, Motor Neurone Disease or other condition where life expectancy is poor. Although doctors do not require patient/family consent to implement a DNAR, it is usual practice for doctors to discuss DNARs with the patient or where difficult to discuss with next of kin.

Usually completed by a GP or a hospital doctor, there is no time limit on a DNAR and can be indefinite. If the persons condition change, there is a requirement to review the DNAR in place.

If you disagree with a DNAR, you should book an appointment with your GP to discuss. A clinician attending should have access to any DNAR in place which may be a copy of the document at the patients home and on both the GP system as well as the local out of hours GP service database. Wishes relating to DNAR can be recorded in an Advance Decision document (Living Will).

If you have not heard of a DNAR and you or someone close to you has a terminal illness, then talk to your GP or any healthcare provider that you may have appointments with to further understand the current position. To have a DNAR in place you do not have to be terminal and can record your wishes based on circumstances within an Advanced Decision document (Living Will) and inform your GP of your wishes and were possible share a copy of the document.

A DNAR is not legally binding, and a clinician may depend on the circumstances decide not to accept the request and initiate resuscitation, in the event the person is revived if the reason for undertaking the resuscitation is not justifiable there could be legal consequences.

End Of Life Medications

Pain Relief and Anticipatory Medication

During the final stages of an illness, managing symptoms is crucial. Medications may be needed to control symptoms as health deteriorates. If oral medication isn't possible, alternatives like injections or syringe drivers can be used.

Pain relief varies based on the severity, from mild painkillers like paracetamol to stronger options like morphine. Common medications for end-of-life care include:

- **Midazolam:** To control restlessness
- **Levomepromazine / Haloperidol:** To help control sickness

- **Glycopyrronium:** To manage excess airway secretions
- **Morphine / Diamorphine:** For pain relief

These medications can be given individually or through a syringe driver, which delivers a mix of drugs over 24 hours for continuous symptom control.

Discuss pain management options with your GP or Macmillan nurses early in the illness. As the condition progresses, treatments need regular reviews to ensure patient comfort. For syringe drivers, the process involves:

- The GP completing a community nurse authorisation form to set up the syringe driver and prescribe medication doses.
- The GP issuing a prescription for the necessary medications.

Make sure the authorisation form and prescription are obtained timely, especially before weekends and bank holidays, to avoid any delays in accessing the needed medication.

Ordering Medication

During the final stages of an illness, the ability of a person to take the usual preparations orally may become difficult. Some medications may need to be changed from solid to liquid preparations or in the final stages where oral treatment is not possible may require intravenous medication through an injection or syringe driver. Certain medications may not be readily available at your pharmacy and may need to be ordered in advance of the prescription due date resulting in delay in receiving the treatment. Discuss with the GP the following during the final stages of an illness:

- Are all the prescribed medications still necessary or can any be stopped?

- Are there any new medications that need to be started to alleviate any pain or discomfort including agitation.
- Check with the pharmacy on who is ordering the medication and how long would it take to receive the medication. Does it need collecting or will it be delivered. Also check after death how can any surplus medication be returned to the pharmacy.
- Discuss with the GP/ McMillan nurse/ district nurse on appropriateness and plans relating to a syringe driver during the final hours to provide comfort and pain relief to the dying.
- After death inform the GP of the passing to ensure all future requests for medication can be cancelled.

Evening and Weekends

GPs across the country provide services to their registered population on Monday to Friday 8am to 6.30pm, they are not expected to be available outside these hours (including weekends and bank holidays). The period outside these hours is covered by other services including 111, BARDOC (out of hours GP services), Urgent Treatment Centres (Rochdale Infirmary) and A&E departments (Royal Oldham, Fairfield General Hospital and North Manchester Hospital), these are only for emergencies and not routine care. With a terminal illness, sometimes it is difficult to know when the patient condition will deteriorate or when the patient may pass away. If this occurs in the evenings or weekends then there could be significant amount of stress, frustration, and confusion if adequate planning has not taken place during the in hours (Monday to Friday 8am to 6.30pm) period with your GP.

Talk to the GP about any provisions in place over the evening or weekend.

Is Death Expected?

Expected versus Unexpected Death

After a death, the next steps depend on whether it was expected or unexpected.

Expected Death

An expected death occurs when a person dies of natural causes due to an illness they were known to have. If the illness was linked to certain conditions, like asbestos exposure leading to lung disease, it might be treated as an unexpected death and referred to the coroner.

For an expected death, the doctor who cared for the patient during their last illness and saw them within 28 days before death or shortly after, will issue a Medical Certificate of Cause of Death (MCCD). This certificate allows the funeral director to move the deceased to a place of rest. If the funeral director removes the body before the MCCD is issued and the doctor later decides they can't issue it due to new information, the body might need to be transferred to the coroner, causing complications.

From summer 2024, community medical examiners will review the MCCD and parts of the deceased's medical records to confirm the cause of death. The MCCD cannot be sent to the registrar until the medical examiner agrees, delaying further funeral planning.

Unexpected Death

An unexpected death is when a person was not expected to die, has no obvious cause of death, or died from a notifiable cause (see coroner's office section). In these cases, the clinician who pronounces death will call the police, who will then contact the local public mortuary at Oldham Royal Hospital to transfer the body. The GP or any other doctor cannot influence the next steps until the coroner's office completes their process and determines the cause of death.

The coroner might discuss the case with the deceased's GP, conduct an inquest, or perform a post-mortem. Not all referrals to the coroner result in a post-mortem; sometimes an MRI scan can be privately funded to determine the cause of death and avoid a post-mortem.

Special Notes

Special notes are not a national process as different areas have different systems. Across Rochdale Borough, the local out of hours service provider BARDOC has an electronic system where GPs can record health information related to terminal patients. GP surgeries are usually open Monday to Friday 8am to 6.30pm following which the out of hours service would support any medical support in the community through calling 111. The doctors at BARDOC do not have access to the GP medical records and so do not understand the patient's current condition, treatment, and future plans and whether the GP will be able to certify the death on the next working day. Special Notes allow GPs across the borough to record information relating to their patients on BARDOC computer system ensuring that any clinic or home visits are supported by information provided by your GP to ensure both your and the GP wishes are acknowledged. In terminal illnesses, the special notes can guide a GP at the weekend to obtain clarity on whether your GP will be able to issue a certificate on the next working day to forward to the registrar office to issue the death certificate which would allow a burial or cremation to proceed. Although not legally binding, without the special notes if a person dies and there is no assurance of whether the GP will issue a certificate (MCCD) then the out of hours service would have to manage the death as an 'unexpected death' resulting in the Police being called who would have the deceased transferred to the local public mortuary at Royal Oldham Hospital where the deceased would remain until the next working day when the Coroners office is open to process the death. This can be very traumatic to family and carers and can be avoided by

ensuring that the GP regularly updates the special notes on the out of hours computer system (ADASTRA).

Talk to your GP to enquire whether a special notes document has been created on BARDOC ADAstra system.

