Top tips based on NICE guidance care of dying adults in the last days of life (NG31)
For GPs and Primary Care Clinicians

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This 'Top tips' document supports the implementation of recommendations in the NICE guideline on care of dying adults.

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Early identification[1]

This top tips document is focused on care in the last few days of life. We know however that excellent care in the last days of life is much easier if it is well planned and if the wishes of the patient are known and documented well in advance of them becoming too unwell to make decisions.

Patients with a life limiting condition who are thought to be in the last year(s) of life should be identified and care and support planning carried out to identify early the likely needs. This will allow for well-planned symptom control and give the opportunity for patients and those important to them, to be linked into specialist palliative care services where appropriate and to build relationships with those who will be caring for them.

Identify the dying person

To be certain that a person is dying can be very difficult. Changes to their signs and symptoms should be assessed. Someone entering the last days of life may show progressive weight loss, increasing fatigue, social withdrawal, or loss of appetite. They may develop agitation, decreased consciousness, mottled skin and noisy or altered breathing. There may be accompanying changes in communication or mobility. Any improvement in condition may suggest recovery or stabilisation, even if only temporary.

When trying to determine if someone is in the last days of life it is essential to review underlying diagnoses and any already reported investigations. Information from the dying person and those important to them and assessments from the multidisciplinary team should be collected and may improve the accuracy of prognosis. New investigations at this stage are not usually necessary or helpful unless the results are likely to enable beneficial action such as platelet transfusion for catastrophic bleeding prevention or reversal of hypercalcaemia.

The dying person should have a review of their physiological, psychological, social and spiritual needs and current signs and symptoms at the time they are identified as likely to be in the last days of life. They should then be monitored at least every 24 hours. It is essential to make sure wherever possible, that the wishes around dying are known, clearly documented and shared with those involved

[1] Early identification is not within the scope of NICE guidance NG31 care of the dying adult in the last days of life but has been included in this document for completeness.

or likely to be involved in their care. The views of those important to the dying person about their care should also be assessed and noted.

Share prognosis and individualise care

Whilst telling someone they are entering the last few days of life is not easy it is often beneficial for the patient and those important to them. Consider the patient's capacity, wishes about what they want to know and who they want involved in decisions about their care. Be aware of any plans or wishes they have documented previously. Where the information is wanted a discussion to facilitate a shared understanding of the prognosis and any uncertainty around this should be had as soon as it is recognised that the person is entering the last days of life. This discussion should be honest and transparent and mindful of the level of involvement the dying person wants in planning their care. The most appropriate team member to share the dying persons prognosis should be identified based on their rapport with the dying person, confidence and competence. Those important to the dying person should be included in the conversation if the dying person wishes and prognosis should be discussed with members of the multidisciplinary team and discussions documented in the care plan.

An individualised care plan should be made in discussion with the dying person, those important to them and the multi-disciplinary team and shared with these people. This should include providing information on treatment and support available to the patient and those important to them including how to contact the healthcare team in and out of hours. Any specific wishes they have around dying and what should happen after death, cultural, religious, social or spiritual needs or preferences should be discussed and documented in the care plan. Time should be given for discussion of any fears or anxieties the dying person or those important to them may have. The care plan should include current care, anticipated care needs and preferred setting for care and death. All discussions and decisions going forward should be documented in the care plan.

Where wishes of the dying person cannot be met, explain reasons why to them and those important to them. Review the dying person's goals and wishes regularly at this stage in their care and ensure opportunities for further conversations around their care are offered.

Share decisions about care in the last days of life

Decisions about care in the last days of life should be shared with the dying person and those important to them where this is possible and wanted. Decisions should consider the dying persons current goals and wishes, cultural, religious social and spiritual preferences as well as any advanced statement or an advanced decision to refuse treatment. Any legal lasting power of attorney for health and welfare should also be considered. A named lead should be identified who is responsible for encouraging shared decision making in the dying persons last days. They should give information about how they and other services can be contacted and should ensure the dying person and those important to them understand any agreed changes to the care plan. It should be recognised that wishes around shared decision making may change and should be reviewed regularly. Specialist input to facilitate shared decision making should be sought where needed and the process should always be facilitated by experienced staff.

Arrange assessment for access to practical resources

An early assessment of the current and anticipated need for resources for the dying person will allow these to be put in place as soon as possible. It is vital to establish the need for services such as care at home, care at night or delivery of meals as well as support or assistance from organisations or volunteers and check the availability of these. There may also be the need for equipment to be arranged for the dying person and this should again be established as early as possible.

Consider and monitor hydration and related symptoms

Support the dying person to drink if they wish to and are able, provide aids and advice on giving drinks safely to the dying person and those important to them. If there are swallowing problems or risks explain these to the dying person and those involved in their care. Offer mouth and lip care, help with teeth cleaning and frequent sips of water and encourage those important to the dying person to help with this should they wish.

An appropriate professional should assess hydration status preferably daily. Consider whether the dying person has a preference for or against clinically assisted hydration documented in an advance statement or advance decision. Consider level of consciousness, swallowing difficulties, level of thirst, risk of pulmonary oedema and whether even temporary recovery is possible.

If a dying person has distressing symptoms associated with dehydration, when oral hydration is inadequate, consider a trial of clinically assisted hydration. Where clinically assisted hydration is being considered discuss the benefits and harms. Explain to the dying person and those important to them that for someone in the last days of life clinically assisted hydration may relieve distressing symptoms or signs related to dehydration but may cause other problems and that it is uncertain if it will prolong life or hasten death. Address any concerns raised by the dying person or those important to them before starting clinically assisted hydration. Monitor at least every 12 hours for evidence of harm or benefit and reduce, stop or continue accordingly. Existing clinically assisted enteral and parenteral hydration should be reviewed and consideration given to continuing, reducing or stopping as a person nears death.

Review existing medicines and individualise symptom control

Existing medications should be reviewed in discussion with and stopped or continued with the agreement of the dying person and those important to them. Discuss benefits and harms of any new medications offered. The likely cause of a symptom, the dying persons preferences, benefits and harms and risks of a medicine should all be considered when choosing it for symptom control.

We often must accept a balance between control of various symptoms and side effects of medication particularly sedation and where the balance lies will be an individual decision. The dying persons individualised care plan should be used to help decide which medications are appropriate and any individual or cultural views should be considered. The route of administration should also be decided considering the persons preferences, swallowing safety and overall condition and the route likely to be most effective.

If injectable medications are needed avoid intramuscular injection and instead use the subcutaneous route. If more than 2 or 3 doses of any as required injectable medications are needed within 24 hours consider the use of a syringe pump to deliver medications. If a treatment for symptom management is new start at the lowest effective dose and titrate as clinically indicated, this should be informed by regular assessment of symptoms at least every 24 hours.

Assess and manage pain

Be aware that not every dying person suffers from pain. Where there is pain, assess the level of this, aim to identify the cause and treat any reversible cause such as retention of urine or constipation. Pain should be managed promptly, effectively and treated according to severity. Follow the principles of managing pain at any other time including matching analgesia to the severity of the pain and considering any preference the dying person has for how pain relief should be given. Where pain cannot be easily assessed, or expressed use a validated behavioural score to assess for pain. Consider non-pharmacological treatments for pain where appropriate.

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Assess and manage breathlessness

Aim to identify, and where this can be reversed, treat the cause of breathlessness. For example, antibiotics for infection or diuretics for pulmonary oedema. Consider non-pharmalogical options such as

fans, opening windows and reassurance[2]. Do not routinely start oxygen for breathlessness but offer this for known or suspected symptomatic hypoxia. Where breathlessness is distressing consider an opioid or a benzodiazepine or a combination of the two.

Assess and manage nausea and vomiting

Where nausea or vomiting occur, assess for the likely cause in the dying person. Consider medications, recent chemo or radiotherapy, psychological causes, biochemical causes (e.g. hypercalcaemia), raised intracranial pressure, motility disorder including constipation and ileus or bowel obstruction.

Discuss treatments for nausea and vomiting with the dying person and those important to them. Consider the likely cause and whether it is reversible, side effects, other symptoms and other medication being used. Consider non-pharmacological methods for treating nausea and vomiting as well as the use of medication.

First line choices include cyclizine and metoclopramide. Prochlorperazine can be given via the buccal route which can be helpful where absorption or persistent vomiting prevents oral administration. Low doses of levomepromazine or haloperidol can also be effective and like cyclizine and metoclopramide these can be given by subcutaneous injection or infusion where the oral route is not practical[3]. For those with obstructive bowel disorders and nausea or vomiting consider hyoscine butylbromide as the first line pharmacological treatment and if no improvement within 24 hours, consider another agent, such as octreotide.

Assess and manage anxiety, delirium or agitation

Explore the cause of anxiety or delirium, with or without agitation, with the dying person and those important to them. Where there is agitation in isolation exclude unrelieved symptoms or bodily needs such as a full bladder or rectum. Treat reversible causes such as renal failure or hyponatraemia, where appropriate to do so. Consider non‑pharmacological management of agitation, anxiety and delirium in a person in the last days of life.

Consider a trial of a benzodiazepine to manage anxiety, and consider a trial of an antipsychotic to manage delirium. Trial either for non-specific agitation being guided by the likely cause. Where treatment is ineffective or causes unwanted sedation seek specialist advice.

Assess and manage noisy respiratory secretions

Assess the cause of noisy respiratory secretions and establish whether they have any impact on the dying person or those important to them. Reassure them that while distressing unlikely to cause any discomfort, discuss any fears or concerns they have as needed. Consider non-pharmacological management such as positioning and reassurance[4].

Consider a trial of medication if they are causing distress to the dying person, consider glycopyrronium bromide or hyoscine butylbromide or hyoscine hydrobromide. Monitor improvements at least 12 hourly and preferably more regularly, monitor for side effects particularly delirium, agitation dry mouth and sedation and treat as needed. Consider changing or stopping medication if noisy respiratory secretions are still causing distress after 12 hours or if there are unacceptable side effects for the dying person.

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[2] NICE recommend considering non-pharmacological management for breathlessness but the examples are outside of the guidance as the evidence for specific measures was not reviewed.

[3] The NICE guidance NG31 does not give specific examples of antiemetics other than for bowel obstruction but these are examples commonly used in the primary care setting.

[4] NICE recommend considering non-pharmacological management for noisy respiratory secretions but the examples are outside of the guidance as the evidence for specific measures was not reviewed.

Consider anticipatory prescribing

Use an individualised approach to anticipatory prescribing and specify indications and doses for the medication prescribed. Consider what medication might be needed to manage symptoms such as agitation, anxiety, breathlessness, nausea and vomiting, noisy respiratory secretions and pain, where possible discuss prescribing needs with the dying person, those important to them and the others involved in their care.

Prescribe these as early as possible but remember to review them if the needs of the person change. When prescribing anticipatory medications consider the likelihood of symptoms occurring, the benefits and harms of prescribing or not prescribing these medications, the risk of sudden events such as catastrophic haemorrhage or seizures which may need urgent symptom control and the place of care and time it would take to obtain medications. Before and after administering these medicines, symptoms should be reviewed. the patient should be monitored at least daily for benefits and side effects and the care plan and prescriptions altered as needed and feedback given to the lead healthcare professional.

Know your palliative care team[5]

Whilst most end of life patients can be managed in the community, there will always be those patients who have complex needs. It is therefore essential to have good links with palliative care specialist teams to be able to access advice and support where this is needed. If there is uncertainty regarding prognosis, use of drugs or other complex end of life situations it may be necessary to take advice from a palliative care specialist. It is also important given that services and referral routes vary widely to be aware of services local to your patients so they can access these at appropriate times.

Bereavement care

It is important that care and support continue beyond the person's death. Firstly, timely completion of the necessary paperwork helps the experience of those people important to the dying person. Secondly, we also need to remember that everyone who dies leaves someone behind who may need bereavement care. This may be as simple as sending a card or contacting them by phone when completing the death certificate but the aim should be to make the bereaved feel supported and be sure they know how to access further care should they need it.

[5] Sections on know your palliative care team and bereavement care are largely beyond the scope of NG31 NICE guidelines but have been included in this document for completeness.

Some useful links

RCGP Palliative and End of Life Care Toolkit

Your patients and their families and carers can get help and support using the Marie Curie Information and Support service. Our range of services include:

- Marie Curie's free phone Support Line, 0800 020 2309, offering confidential, emotional and practical support. Open six days a week from Monday to Friday, 8am to 6pm and Saturday, 11am to 5pm.
- Live web chat service: https://www.mariecurie.org.uk/help
- Online community forum, https://community.mariecurie.org.uk/ - a safe place where people can engage in peer to peer support to connect and share experiences with others
- And the Marie Curie website which contains a wealth of clear and easy to digest information* and support materials that cover all aspects of living with or being there for someone with a terminal illness. https://www.mariecurie.org.uk/help

Marie Curie also provides a Palliative Care Knowledge Zone; our free and easy-access online information and support service for health and social care professionals.
https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone