
Acute Leukaemia: End of Life Care

A Guide for
Nurses

Introduction

Around 4000 people are diagnosed with acute leukaemia annually in the UK, 3200 with acute myeloid leukaemia (AML) and 800 with acute lymphoblastic leukaemia (ALL). Although leukaemia is often thought of as a disease that affects young people, 42% of all new AML cases in the UK are diagnosed in individuals aged 75 or over.

Survival figures for both AML and ALL vary greatly with age: in the over-65s, only 15% with ALL and 5% with AML live for more than 5 years after diagnosis. For patients at the end of life with acute leukaemia, care needs to be centred on their comfort and palliation of symptoms. The aim should be to help the patient live well until they die.

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If you would like any information on the sources used for this booklet, please email communications@leukaemiacare.org.uk for a list of references.

About Leukaemia Care

Leukaemia Care is a national charity dedicated to ensuring that people affected by blood cancer have access to the right information, advice and support.

Our services

Helpline

Our helpline is available 8:30am – 5:00pm Monday - Friday and 7:00pm – 10:00pm on Thursdays and Fridays. If you need someone to talk to, call **08088 010 444**.

Alternatively, you can send a message via WhatsApp on **07500068065** on weekdays 9:00am – 5:00pm.

Nurse service

We have two trained nurses on hand to answer your questions and offer advice and support, whether it be through emailing nurse@leukaemicare.org.uk or over the phone on **08088 010 444**.

Patient Information Booklets

We have a number of patient information booklets like this available to anyone who

has been affected by a blood cancer. A full list of titles – both disease specific and general information titles – can be found on our website at www.leukaemicare.org.uk/support-and-information/help-and-resources/information-booklets/

Support Groups

Our nationwide support groups are a chance to meet and talk to other people who are going through a similar experience. For more information about a support group local to your area, go to www.leukaemicare.org.uk/support-and-information/support-for-you/find-a-support-group/

Buddy Support

We offer one-to-one phone support with volunteers who have had blood cancer themselves or been affected by it in some

way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call **08088 010 444** or email **support@leukaemiacare.org.uk**

Online Forum

Our online forum, **www.healthunlocked.com/leukaemia-care**, is a place for people to ask questions anonymously or to join in the discussion with other people in a similar situation.

Patient and carer conferences

Our nationwide conferences provide an opportunity to ask questions and listen to patient speakers and medical professionals who can provide valuable information and support.

Website

You can access up-to-date information on our website, **www.leukaemiacare.org.uk**.

Campaigning and Advocacy

Leukaemia Care is involved in campaigning for patient well-being, NHS funding and drug and treatment availability. If you would like an update on any of the work we are currently doing or want to know how to get involved, email **advocacy@leukaemiacare.org.uk**

Patient magazine

Our magazine includes inspirational patient and carer stories as well as informative articles by medical professionals: **www.leukaemiacare.org.uk/communication-preferences/**

Background

Around 4000 people are diagnosed with acute leukaemia annually in the UK, 3200 with acute myeloid leukaemia (AML) and 800 with acute lymphoblastic leukaemia (ALL). Although leukaemia is often thought of as a disease that affects young people, 42% of all new AML cases in the UK are diagnosed in individuals aged 75 or over.

Survival figures for both AML and ALL vary greatly with age: in the over-65s, only 15% with ALL and 5% with AML live for more than 5 years after diagnosis. For patients at the end of life with acute leukaemia, care needs to be centred on their comfort and palliation of symptoms. The aim should be to help the patient live well until they die.

The challenge of recognising end of life

NHS England defines end of life care as care provided in the last year of life. In acute leukaemia, this can be very difficult to predict. During their final year, patients with acute leukaemia are often undergoing intensive treatment designed to cure or delay the progression of their disease. It may only become apparent that the end of life is approaching once that treatment

ceases to be effective.

There may also be cultural and organisational challenges. Depending on the age of the patient, the focus in haematology units tends to be on treatment and survival. In some cases, both patients and members of their healthcare team may have unrealistic expectations of treatment success.

Discussing end of life care

Haematology clinicians may be concerned that a discussion of end of life issues with the patient and their family could remove hope and damage trust, particularly when a strong relationship has developed with the patient during a long treatment period. Patients and relatives need to be encouraged to discuss their wishes for continuing treatment and/or involvement in clinical trials of novel therapies, but also to recognise when the focus of their care needs to change.

Use of specialist palliative care services

Specialist palliative care services are not always utilised to the maximum for patients with

acute leukaemia. Hospice and palliative care teams are often not used, even for patients receiving supportive care only. Improved integration of palliative care and haematology services would help to ensure that palliative care expertise is utilised earlier, for the benefit of patients. For example, in some units, palliative care specialists now join haematology multidisciplinary team meetings.

In contrast with patients with solid tumours, but in common with those with other haematological cancers, many patients with leukaemia who receive hospice care do so for only the last few days of their lives, often because of late referral or transfusion dependence. As most of these patients have active disease at the time of death, recognising that the end of life has been reached is a significant factor in maintaining patient comfort.

The place of death

Care at the end of life needs to be based on the wishes of the dying person and their family whenever possible. The traditionally accepted view is that the preferred place of death is home, followed by a hospice and then a hospital, which is often thought to provide poor-quality end of life care. However, this preference may not hold for patients with acute leukaemia and their families. The

long and close relationship that is often formed between patients, relatives and hospital staff can help people to feel safe and secure. Patients have confidence in 'their' staff's ability to care for them. Conversely, despite having to overcome the hurdles of lack of time and, sometimes, facilities (for example, provision of a single room), staff may want to maintain that strong relationship and provide care for their patients until the end.

There can be difficulties arranging for patients to be cared for at home. If a patient suddenly deteriorates, as is often the case in acute leukaemia, it can be difficult to arrange home discharge at short notice, with all the necessary services in place. Similarly, hospice beds may not be available when needed. The often cited barrier to hospice care – the ability to provide for transfusion – is less of a problem in the UK than the literature may indicate, as many hospices are now able and willing to provide this as needed.

Haematology staff may, understandably, be anxious about a family's ability to cope if a patient wishes to die at home. They may be concerned about potentially distressing symptoms, particularly bleeding or severe infection, which can cause patients to be re-admitted as an emergency.

Prognostic factors

Factors that affect the outlook for patients with acute leukaemia

- Older age
- High white blood cell (WBC) count at diagnosis
- Specific genetic abnormalities
- Transformation from chronic to acute leukaemia
- Time taken to achieve remission (longer than 4 weeks)
- Early relapse after initial treatment
- A previous blood disorder, such as myelodysplastic syndrome (MDS)
- The presence of leukaemic cells in the central nervous system, or extramedullary disease

Some patients may need end of life care almost from diagnosis. This is a delicate line to tread in busy haematology units that are focused on treatment and cure. Even then, identifying patients who are, or who are not, likely to do well is not straightforward. Although the median survival of older people with acute leukaemia

is similar to that for patients with solid tumours with a poor prognosis, 5–10% of over-65s achieve remission that lasts for 5 years or more with treatment. Advances in cytogenetics and molecular markers and minimal residual disease (MRD) monitoring are also making it easier to predict prognosis.

Signs of end of life

Identifying when the end of life phase has begun in acute leukaemia can be extremely difficult. The patient's disease status can change very suddenly and they can decline swiftly.

Signs that indicate a need for end of life care

- Uncontrolled high or unresponsive low WBC count
- Failure to achieve remission
- Worsening performance status
- Increasingly frequent need for transfusions
- Infections (viral, fungal, bacterial) that do not respond to appropriate treatment

Holistic needs assessment and personalised care planning

By definition, a holistic needs assessment should be carried out from initial patient contact onwards. However, recognising that the end of life phase has been reached will alter the focus and trigger the need for review.

Holistic needs checklist (assess current status and changes in...)

- The patient's physical needs
- The patient's emotional and social needs
- The patient's spiritual and cultural needs, particularly faith beliefs about death
- Family relationships and the patient's home situation
- Family and carers' views and needs

Potentially, the most difficult aspect of these discussions is knowing when to initiate them. The National Institute for Health and Care Excellence (NICE) recommends that those involved in planning and delivering care

should develop systems to help identify patients who are likely to be approaching the end of life (see Signs of end of life, above). In general, addressing the possibility of death sooner rather than later results in better-quality discussions that are more relaxed and conversational rather than pressured and rushed.

Most patients with acute leukaemia understand that their disease is potentially life-threatening. Those whose condition is considered life-limiting may want to discuss their prognosis, the realistic aims of their treatment and future care planning with their caregivers but, in some instances, find it difficult to bring the subject up. These conversations are often best initiated by the patient's clinical nurse specialist with whom they are likely to have a very close relationship. The clinical nurse specialist is best placed to help and support these conversations with family members and can help to continue the dialogue with

the patient's haematologist.

Patients and families often welcome the chance to have these conversations. Conversely, health professionals may avoid discussing death and end of life for fear of causing anxiety and loss of hope. It may help to view these discussions as an opportunity for patients to gain some control over their situation. Early, frank conversations about end of life care provide the patient with a chance to think about, voice and record their wishes for care in their last weeks and days, even if the end of life phase is still some way off.

A useful starting point can be a conversation about the patient's understanding of their condition and likely outcome of treatment. Discussion of prognosis must take place ahead of any discussions about end of life care. Depending on how this is received by the patient, further discussions may then develop around the patient's future priorities and

expectations of their care.

It should be noted, however, that even when haematology staff recognise the need for advance planning, some patients may find it difficult to accept that cure is no longer an option and will resist attempts to broach the subject.

Preferred priorities for care. A preferred priorities for care (PPC) document is one way to record a person's wishes for their future care. Documenting these discussions can help to ensure continuity of care across all members of the patient's healthcare team, ensuring that they are all aware of the stage of discussion that has been reached. Some NHS Trusts have their own PPC or advance care planning documentation; these vary in the level of detail.

Example of details covered by a PPC document

- The patient's understanding of their condition and prognosis
- The patient's fears and concerns

Holistic needs assessment and personalised care planning (cont.)

about the future and end of life care

- Any specific religious or cultural needs, beliefs or practices to be adhered to
- Who the patient would like to be involved in their care - check whether the patient has discussed this with their family
- Where the patient would prefer to die (home, hospice or hospital)
- How open the patient wants their medical team to be: include anything they do not want to be told
- Lists of specific medical interventions that the patient can express their feelings about: for example, ventilation and resuscitation
- Any wishes that the patient would like to fulfil if possible, such as going on holiday or attending a special family event

Advance care planning and PPC documents help people to plan and exercise control over their

future care and support needs, including medical treatment. NICE says that advance care planning should be offered to everyone who is at risk of losing the capacity to make decisions because of progressive illness. Advance care statements and PPC documents are not legally binding, but medical staff must take them into account when putting a care plan in place and be able to justify any departure from the plan.

Advanced care decisions and directives

Further to putting a plan in place for their preferred priorities of care, patients may find it reassuring to formalise their preferences, particularly regarding treatment measures to be taken in an emergency.

An advance care decision or directive (also known as a living will) is a legally binding document that formalises the decision to refuse specific medical treatment in particular circumstances. To be legally binding, an advance decision to refuse life-saving treatment (such as ventilation) must be in writing, signed and witnessed. Patients may also set up a lasting power of attorney, which allows one or more named individuals to make medical (and/or financial) decisions on the person's behalf.

Patients need to understand that these legal documents will only come into force in the event that they can no longer make decisions for themselves. Setting them up in advance does not mean that the patient will lose control over what happens to

them, just that the framework is there for their wishes to be adhered to in the future. They should also understand that they can change their minds about anything in the plan at any time.

End of life symptom management

The holistic needs assessment may identify symptoms associated with end of life and progressing disease. Symptoms need to be regularly assessed as the patient's needs may change rapidly.

Principles of managing end of life symptoms

- Assess and try to diagnose any specific causes of symptoms before attempting to treat them
- Treat any potentially reversible causes of symptoms first
- Consider non-pharmacological management as well as treating symptoms with drugs
- Think about the goal of your interventions and remember to take your patient's preferences into account

If medication is required, the aim should be to maintain comfort but balanced with any sedative effects. This balance will vary, depending on the wishes of the patient and family.

It is better to treat symptoms sooner, rather than later. If treatment is delayed, symptoms

often become more difficult to manage. For persistent symptoms, regular medication is preferable to 'as required' (prn). Intractable symptoms should be referred to the specialist palliative care team.

Most reported symptoms at end of life in acute leukaemia

- Pain
- Bleeding
- Delirium and confusion
- Breathlessness
- Weakness and fatigue
- Infection-related complications

Pain

Proliferation of leukaemic cells in the bone marrow may cause bone pain in patients with advanced leukaemia. Other causes of pain include treatment side effects, such as sore mouth and constipation, and stiffness due to weakness and lack of movement. Patients may also have painful comorbidities, such as arthritis. Many patients will have more than one cause or site of pain and each needs to be assessed

separately.

Pharmacological options

The World Health Organization's (WHO) analgesic ladder provides a framework for prescribing painkillers appropriately, moving from non-opioids (paracetamol) to weak opioids (codeine) to strong opioids (morphine, buprenorphine, oxycodone). Analgesia is much more effective when given regularly as prescribed, rather than waiting for pain to reoccur. Listen to the patient – if they say they are in pain, they are – and escalate the dose or type of painkiller accordingly. The WHO advice is the right drug, at the right dose, given at the right time.

Patient choice should dictate the route of administration. By mouth is usually preferable. If this is not possible, other options include subcutaneous injection, subcutaneous delivery via a syringe driver or transdermal patches.

When prescribing painkillers, it is important to take pre-emptive action to try and prevent side

effects, such as nausea and constipation. Most people starting any opioid medication, including codeine, should be prescribed regular laxatives.

Other non-analgesic drug therapies, such as steroids, can help with pain management. However, non-steroidal anti-inflammatory drugs (NSAIDs) are not routinely given to patients with acute leukaemia because of the risk of bleeding. Anxiolytics may be prescribed to reduce anxiety, and antidepressants or anticonvulsants to treat nerve pain.

Pharmacological pain management is complex, so it is best to consult with the specialist palliative care team when it becomes challenging: for example, when needing to switch from one drug or route of administration to another.

Non-pharmacological options

Non-pharmacological options, such as relaxation and distraction, may also help to manage pain. Physiotherapy and careful positioning will help with

End of life symptom management (cont.)

pain due to frailty and weakness.

Bleeding

Thrombocytopenia (low levels of platelets) is common in acute leukaemia and can lead to haemorrhage. In one small series, a quarter of patients with AML had bleeding at the end of life. Platelet transfusions can still be given during end of life care to manage distressing bleeding. However, this can be logistically difficult, unless the patient is in hospital or able to attend hospital day care from a hospice or home. Some hospices do offer transfusions, but not routinely; it varies from area to area.

Minor to moderate bleeding may be controlled or reduced with tranexamic acid. Any drugs that can exacerbate bleeding, such as NSAIDs, should be stopped. Infection can cause bleeding (haemoptysis or haematuria), so treatment of infections may be necessary to help control it (see below). Individual management will depend on the site of the bleed.

Large-scale catastrophic bleeding is rare but can occur in acute

leukaemia because of low platelet levels. Gastrointestinal bleeds are particularly associated with impending death. If patients wish to be cared for at home, it is very important that you warn the patient and carers of the possibility of a catastrophic bleed and explain how to manage it. Practical measures can be taken in advance, including having dark-coloured bedclothes or towels to hand to help disguise the blood and prescribing a dose of buccal midazolam for use in an emergency. This is placed between the cheek and the gums to help manage patient distress. Families who witness this type of event will almost certainly need extra support afterwards and during the period of bereavement. Patients identified as being at high risk of a catastrophic bleed should be 'encouraged' to consider end of life care in hospital rather than at home.

Delirium, confusion and other neurological problems

As the end of life approaches, delirium becomes increasingly

common, rising to almost 9 in 10 patients receiving palliative care in the last hours or days of life. Patients with ALL are likely to have CNS involvement, which can cause confusion, altered mental status, headaches, seizures and loss of consciousness.

Patients may become acutely confused and hallucinate, with varying levels of consciousness. Delirium can be hyperactive, with patients becoming agitated and sometimes paranoid, or hypoactive, with patients becoming drowsy and withdrawn.

Delirium, confusion and restlessness due to the side effects of medications, infection, lack of oxygen or electrolyte imbalance can be reversed. Dehydration is also a potential cause of confusion and can exacerbate opioid neurotoxicity – a complication of opioid painkillers that causes severe sedation, cognitive impairment, delirium and hallucinations. The patient may have constricted pupils, slowed breathing and muscle jerking or twitching, and their skin may become hypersensitive to touch.

Restlessness can be caused by physical discomfort due to pain, lying in an uncomfortable position or having an extended bladder or full rectum. It may also be related to psychological distress, particularly in patients who have had difficulty coming to terms with their illness.

Management of delirium and confusion depends on individual circumstances. Reversible causes should be treated or minimised as much as possible. However, if a patient is close to death, starting antibiotics to treat an infection, for example, may not be appropriate. If the patient is agitated, check for all potential physical causes, making sure that the patient is as comfortable as possible. Minimising surrounding stimuli may also help – subdued lighting and as little noise as possible. Ensuring continuity of care with as few staff changes as possible and explaining all procedures quietly and calmly will also help to minimise confusion.

If the patient is obviously distressed, a low dose of an antipsychotic such as haloperidol may be necessary, particularly if

End of life symptom management (cont.)

they are agitated or hallucinating. If this does not help, the dose can be increased or another drug added, such as midazolam or a benzodiazepine, but this is best done with specialist palliative care advice, as sedative side effects can make the situation worse.

Breathlessness

Breathlessness is a common symptom, with 40–80% of people experiencing shortness of breath at the end of life. In acute leukaemia, the main causes of breathlessness are likely to be anaemia (low red blood cells) or infection (low white blood cells).

When managing breathlessness in dying patients, potentially reversible causes should be considered first. Transfusion of packed cells will temporarily reduce symptoms of severe anaemia and should be considered if the patient's haemoglobin level is below 70 g/L. However, eventually transfusions may be needed so often that they become untenable. At some point, the decision to stop transfusions

will need to be made, which can be difficult for the patient and family to accept.

Current advice in palliative care is not to start oxygen (O₂) unless blood levels are so low that they are causing distressing symptoms. Patients with O₂ saturation below 90% may benefit but, in general, pharmacological management is preferable. Opioids and/or benzodiazepines can slow breathing and calm anxiety, providing some relief.

Breathlessness is often episodic. Any increase in activity, talking or eating can trigger an attack. Planning nursing interventions (such as washing and changing bedding) carefully can reduce stress on the patient. Positioning is also important. Leaning the patient forward on pillows arranged on a tray table may help.

The feeling of being unable to breathe is understandably frightening for patients. It can help to have a management strategy prepared; this will help the patient to feel they have some control and relieve anxiety. As

well as positioning, low-breathing techniques can be taught, such as ‘pursed lip breathing’, ‘square breathing’ or the ‘calming hand’. A fan blowing air across the face can be comforting. Visualising a well-loved place or looking at favourite photos can also be calming.

If breathlessness in someone near the end of life is very distressing, it may be necessary to give drug therapy continuously through a syringe driver. It is important to discuss this with the patient and family, as continuous opioids and benzodiazepines will cause a degree of sedation. The aim should be to balance the sedative effect with symptom relief.

Good and frequent mouth care is very important, as breathing through the mouth is very drying. Sipping on cool drinks through the day may help.

Weakness and fatigue

Just about everyone with a terminal illness will feel weak and fatigued at some point. In acute leukaemia, this may result from

anaemia, poor nutrition and loss of weight and condition during extended treatment. Fatigue can be very upsetting and frustrating, as it restricts activities and is often unrelieved by rest. At the end of life, patients with acute leukaemia will spend most of their time asleep, resting or in bed.

Management is largely practical. Transfusion may help and steroids are sometimes prescribed to help with appetite and energy levels. Keeping a record of how the patient feels at different times of day can help to identify when they have the most energy. They can then prioritise activities accordingly, with planned rests in between. While appropriate, encourage the patient to get up and take gentle walks as, paradoxically, exercise may reduce fatigue and improve sleep.

Patients can feel distressed and guilty about how fatigue affects them and their interaction with family and friends. Relaxation exercises during rest periods

End of life symptom management (cont.)

can help to relieve anxiety and stress and allow energy levels to recover. Complementary therapy/reflexology can also help.

Infection

Bone marrow insufficiency and chemotherapy-induced neutropenia (low level of neutrophils) puts patients with acute leukaemia at high risk of infection. A minor infection can become life-threatening sepsis within hours. Indeed, bacterial and fungal infections are a common cause of death. Common sites of infection include the mouth and throat, skin, lungs, urinary tract or bladder, and the area around the anus.

Antibiotics and antifungals can be given to alleviate the symptoms of some infections (for example, to control bleeding) and febrile episodes, thereby making the patient more comfortable. However, the broader public health issue of antibiotic overuse cannot be ignored. The challenge is to balance compassionate care for end of life infections with responsible antibiotic usage. This is where knowledge

of the patient's care preferences through advanced planning and advanced directives is essential (see above).

Other end of life symptoms

While we cannot provide an exhaustive list of all possible symptoms encountered at the end of life here, other symptoms that patients with acute leukaemia may experience are briefly outlined below.

Sickness

Haematology nurses are well versed in the management of nausea and vomiting caused by chemotherapy, but in advanced acute leukaemia, sickness may be due to other causes. These include intracranial or gastrointestinal disease, infection and constipation and the side effects of medications. Selection of appropriate antiemetics will depend on the cause, although sickness is often multifactorial. There may be contraindications related to antiemetic prescribing: for example, 5-HT3 antagonists can cause

constipation, and prokinetics such as metoclopramide should not be prescribed alongside anticholinergics such as cyclizine, as the latter reduces the effect of the former.

Pain medications are a frequent cause of nausea, which can be exacerbated by treatment-related constipation. Antiemetics may be given along with laxatives when opioid medication is started, and then tailed off if nausea and vomiting is not an issue.

If oral medication is contraindicated, some antiemetics can be used in a syringe driver. Usual non-pharmacological methods can also be employed, such as acupuncture, ginger ale and relaxation techniques.

Bowel problems

Constipation is a common and uncomfortable problem, exacerbated by immobility, weakness, dehydration, poor nutrition and medications used to control other symptoms. Patients and relatives may not realise that lack of bowel movements

is an issue if the patient is not eating. Prevention is key, with monitoring of bowel movements, good hydration and prophylactic prescribing of laxatives alongside painkillers. Once constipation is established, a combination of a softener and stimulant laxatives is usually needed to resolve it. Oral therapies are preferable to rectal, particularly in patients with leukaemia in whom rectal examination poses a bleeding or infection risk. The aim of laxative treatment is patient comfort, rather than establishing any particular frequency of bowel movements.

Diarrhoea is frequently caused by infection but may also be a side effect of medication due to overuse of laxatives. Diarrhoea that comes on suddenly after constipation can indicate overflow. Profuse, watery diarrhoea is more likely to be caused by infection. The history, pattern and stool type can help to identify the cause, which is essential for effective treatment. Diarrhoea due to laxative use should settle within 24 hours once laxatives are stopped. The laxative

End of life symptom management (cont.)

regimen should then be reviewed before they are reintroduced.

Having diarrhoea can be exhausting. Even for patients at the end of life, drug therapy may be indicated for infections causing severe diarrhoea. Loperamide is the antidiarrhoeal of choice in palliative care. If possible, patients should be encouraged to increase their fluid intake to replace what has been lost.

Care in the final hours or days

Good nursing is paramount when caring for a dying person in their final hours.

Nursing aims in the final hours or days of life

- Treat and manage specific symptoms
- Prevent the development of any further problems
- Anticipate future needs and make sure that the tools are in place to manage them

The nurse of the dying patient needs to communicate with the medical team about the effects of prescribed medications on symptoms so that any necessary changes can be made as quickly as possible. The patient is likely to become less able to communicate as their condition worsens, so you will need to interpret cues about their needs from signs of restlessness or agitation.

The provision of good-quality basic nursing care to a dying person can be very satisfying. Ensuring the patient is clean, dry and as comfortable as possible, providing regular mouth care and

helping with good positioning can prevent many potentially distressing problems.

Families may become concerned about diet and hydration and need reassurance that, while it is fine for the patient to have anything they feel like, it is also fine if they cannot or do not want to eat or drink. Lack of fluid is thought to have little impact on a dying patient's comfort or how long they live. Excess fluid may accumulate in the lungs or stomach, causing vomiting and increased respiratory secretions and urine output, all of which can increase distress.

Noisy breathing due to increased respiratory secretions (often called the 'death rattle') can be very upsetting for relatives. It is better to prevent this with medication as secretions can be difficult to remove, even with suction. Medications such as hyoscine can be given through a syringe driver, by subcutaneous injection or in a skin patch.

Care in the final hours or days (cont.)

Anticipatory prescribing

The condition of the dying patient can alter rapidly, so good care includes anticipating the patient's needs, including prescribing medicines they may need. This is particularly important if a patient is going home, but it is also helpful when a need arises in any setting out of hours. Medication may be needed at short notice to manage agitation and anxiety, breathlessness, nausea and vomiting, noisy respiratory secretions or pain. The route of administration should also be considered. Oral preparations will not be any use if the patient is no longer able to swallow.

Nursing intervention and management

As key members of the healthcare team, nurses have an important and central role in providing palliative and end of life care for their patients. The checklists below summarise best practice recommendations for planning and carrying out end of life care for patients with acute leukaemia.

Planning for the end of life phase

- Development of refractory disease may be an appropriate time to initiate discussions about end of life care.
 - Use principles of good communication to help patients discuss their situation. Encourage them to talk about their fears and anxieties, ask questions and begin to make plans that reflect their wishes and concerns, including where they want to be when they die and any measures they do not want to be taken.
 - Ensure the patient and family understand the difference between advance care plans and advance care directives, and how and when each may be used.
- Encourage the development of an advance care plan (preferred priorities of care) using your Trust's approved documentation. Ensure cultural, spiritual or religious beliefs that might affect end of life care are included in the advance care plan or directive.
 - Ensure that plans for advance care decisions and directives (including 'do not attempt resuscitation' orders) are clearly communicated within the healthcare team. Be aware of any advanced care decisions/directives already in place.
 - Provide information to help patients and families prepare for the end of life so that they can begin to make necessary arrangements and fulfil personal wishes.

End of life care in the last weeks or days

- Be alert for signs that the patient is entering the last days of life.
- Carry out regular assessments

Nursing intervention and management (cont.)

of holistic needs and ensure recommendations for care in the last days of life are followed.

- Liaise with the medical team to review all medications. Stop those that are no longer necessary, with the agreement of the patient and family (as appropriate).
- Regularly assess symptoms (including any comorbidities) and review medications accordingly. Use appropriate scales/measures for pain and other symptoms and report unrelieved or poorly managed symptoms to the medical team.
- Discuss referral for specialist palliative care with the medical team. Seek specialist advice early, especially if the patient's symptoms do not improve promptly with treatment or if they experience undesirable side effects, such as unwanted sedation.
- Ensure that the patient consents to referral for specialist palliative care and understands why they are being

referred and what this means for them.

- Advise the patient and family of the importance of reporting changes in symptoms and provide details of the appropriate healthcare team to contact.
- For patients who are dependent on blood products, regularly assess the benefit of transfusions. Before withdrawal, discuss why transfusion may no longer be appropriate with the patient and their family.
- Consider the use of complementary therapies to help with symptom control and to promote physical and psychological wellbeing.
- When appropriate, provide family members with access to written information on bereavement support facilities, both local and national.

Preparing the patient for end of life care at home

- Prior to discharge, find out about the availability of, and

refer the patient to, local palliative care services for follow-up in the community. Liaise with them to ensure continuity of care.

- Make other relevant referrals to ensure a full support package is in place (including any equipment needed). As well as palliative care services, this may include other allied healthcare professionals, social services and primary care providers. Liaise with them to ensure continuity of palliative care.
- Discuss anticipatory prescribing with the medical team, including the palliative care team, as necessary.
- Consider whether the patient may benefit from attending a day hospice (or hospital day unit), if available.
- Clarify who is responsible for which aspects of ongoing palliative care: for example, monitoring of pain control and potential analgesic dose changes. This is usually a

haematologist in conjunction with palliative care services.

- Provide the family with relevant contact details for help and advice, including out-of-hours numbers. Decide whether patients (and relatives) should contact the acute oncology service and/or accident and emergency, or the community palliative care team for advice and intervention. This can be confusing for patients so instructions need to be clear, especially as the most relevant contacts may change in the last days to weeks of life.
- Maintain communication with the community teams and ensure they are updated about advance statements and directives and any changes in treatment.
- Promote continuity of care and emotional support for the patient and family members.

Summary

Managing end of life care in patients with acute leukaemia has its challenges. Identifying when someone is nearing the end of life is particularly difficult as a patient's condition can change rapidly. The frequent development of close relationships between haematology nurses and their patients means that you are well placed to broach discussions with patients about their wishes should their disease become terminal. This close relationship may also mean that patients and relatives are more comfortable staying in hospital during this last phase of their illness. Improved planning and effective liaison with colleagues in palliative care can help you to ensure your patient's comfort. Their support can help to ensure a death that is as peaceful and dignified as possible and make the experience as positive as possible for the patient's family.

Further reading

NICE Guidelines and Clinical Knowledge Summaries

Care of dying adults in the last days of life [NG31]

<https://www.nice.org.uk/guidance/ng31>

Published December 2015.

End of life care for adults: service delivery [NG142]

<https://www.nice.org.uk/guidance/ng142>

Published October 2019.

Palliative care – general issues

<https://cks.nice.org.uk/palliative-care-general-issues#!scenario>

Last updated April 2020.

Marie Curie Palliative Care Knowledge Zone

<https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone>

Accessed May 2020.

Palliative Care Guidelines Plus

<https://book.pallcare.info/index.php>

Last updated May 2020.

The Palliative Care Handbook: a good practice guide (9th edition)

Wessex Palliative Physicians

https://www.ruh.nhs.uk/For_Clinicians/departments_ruh/Palliative_Care/documents/palliative_care_handbook.pdf

Published November 2019.

The Gold Standards Framework Proactive Identification Guidance (PIG) (6th edition)

Royal College of General Practitioners

<https://goldstandardsframework.org.uk/PIG>

Published December 2016.

Leukaemia Care is a national charity dedicated to providing information, advice and support to anyone affected by a blood cancer.

Around 34,000 new cases of blood cancer are diagnosed in the UK each year. We are here to support you, whether you're a patient, carer or family member.

Want to talk?

Helpline: **08088 010 444**

(free from landlines and all major mobile networks)

Office Line: **01905 755977**

www.leukaemicare.org.uk

support@leukaemicare.org.uk

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