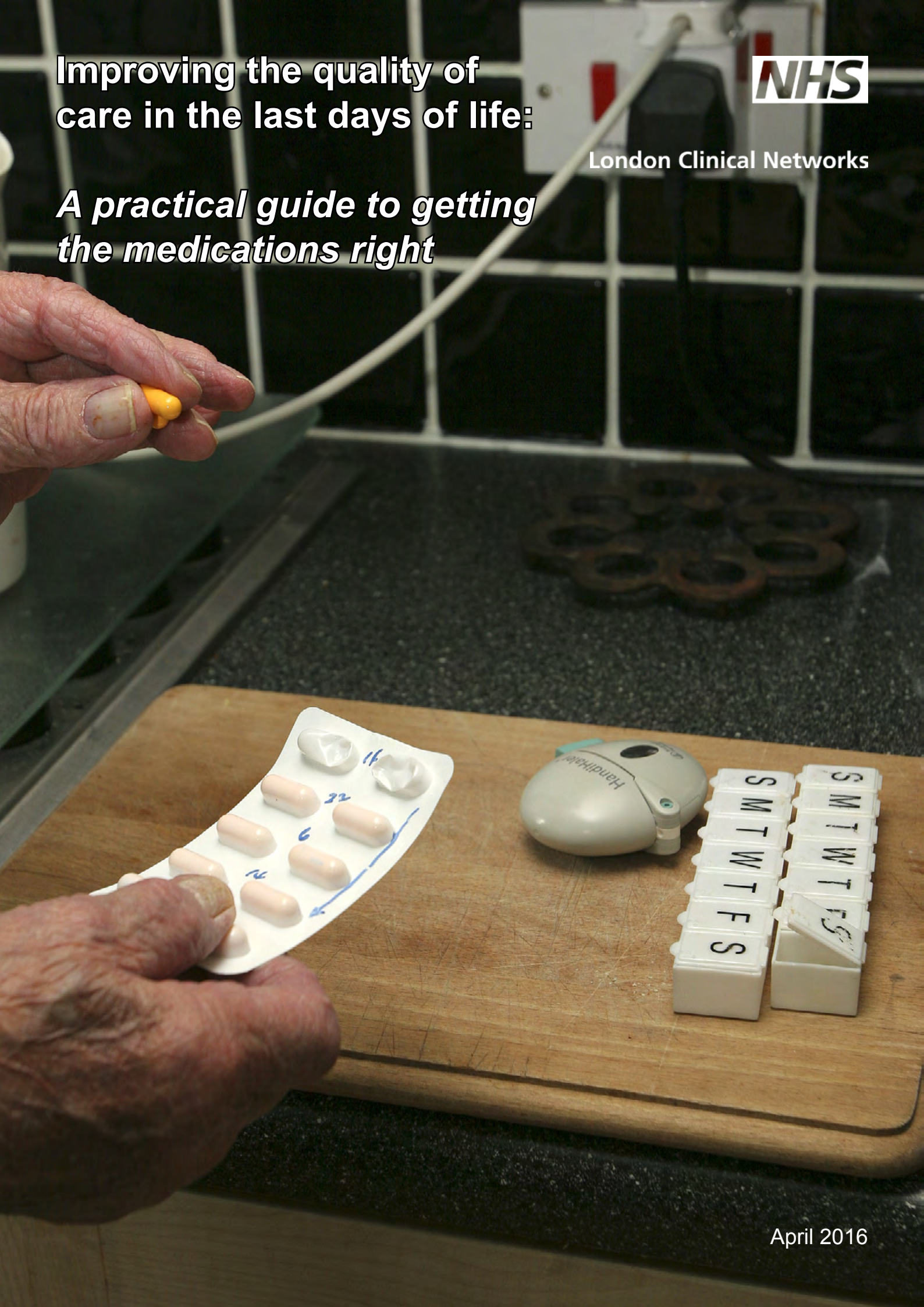
Improving the quality of care in the last days of life:

A practical guide to getting the medications right

NHS
London Clinical Networks



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Introduction

This document identifies best practice in the way medications should be managed in the last days of life. It sets out high level, evidence-based recommendations to help guide those responsible for care to review their processes and consider ways to make change where necessary.

This document aligns with Statement 11 in the NICE Quality Standard 13, *End of life care for adults*[1] by addressing what needs to be done with people's medications so that the care they are offered remains coordinated and delivered in the best way possible.

NHS England's publication *Actions for end of life care: 2014-16*[2] sets out its commitment for statutory and voluntary partners in health and social care to work together to develop a vision for end of life care in future. This work is being carried out by the Ambitions for End of Life Care Partnership[3]. The Partnership aims to transform experiences of end of life care by focusing on what would improve person-centred care, encouraging local communities to engage with the need for high quality care at the end of life, highlighting what would enable better coordination of care in the last days of life, and supporting networks of facilitators and champions.

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Introduction

The Transform Programme[4] aims to improve the quality of end of life care within acute hospitals across England. This includes a focus on rapid discharge processes with adequate supplies of injectable medications to see the dying person home. Giving people medications in this way has been shown to work by a number of local practice examples[5, 6]. Furthermore, information about the medications sent home with the dying person must be accurate and shared on time with those that need to know[7, 8, 9, 10]. This must include information for the person being treated and those important to them, as well as those providing the treatment. Collectively this can avoid the types of omissions and delays that can lead to adverse events and the real risk of people coming back into hospital. People moving between care settings who are prescribed injectable medications for administration by a syringe pump and, where some of these may be prescribed on a pre-emptive basis, present a particular challenge when it comes to reconciling medications in this way[9].

NHS England, in conjunction with National Voices, states that advice about medications (including their purpose, how to take them and potential side effects) and delivery of those medications where a patient wants are essential for person-centred coordinated care[11]. This entails information on how to give these safely and on time to protect the dying person and the people around them from harm.

Improving pain and symptom management is essential to ensuring high quality end of life care. A national bereavement survey, VOICES, found that just 16.8 per cent of respondents felt that this had been adequately managed at home[12].

Furthermore, half of the respondents in a Marie Curie survey said that pain not being managed adequately would be a top concern[13]. A public engagement exercise conducted by the Choice in End of Life Care Programme Board showed many people wanted choice over their place of care and death, and with this better symptom control, including pain relief which is offered in a timely way by well-trained staff with access to the appropriate guidance and documentation[14, 15, 16].

Improving access to medications and information about them is essential to keeping patients and those important to them involved.

Relatedly, improving how medications are prescribed, accessed, administered and disposed of should be considered significant enablers to meeting contemporary policy when it comes to offering people a greater choice in how they wish to be cared for at the end of life.

More recently, a report published by the Health Select Committee looking at the state of end of life care since the independent review of the Liverpool Care Pathway recommended 24/7 access to specialist palliative care and symptom control, thereby emphasising the importance of systems that deliver medications and the necessary documentation when and where they are needed[17]. The Parliamentary and Health Service Ombudsmen in its *Dying without dignity*[18] report highlights the same problems with evidence drawn directly from complaints into end of life care; in the same way it is reasonable to assume that systems to optimise medications will undoubtedly contribute towards improvement.

Schemes that allow people to continue administering their own medications in the inpatient setting are an important way of symbolising hope and control for them, and those important to them in what can seem an uncontrollable situation[19]. These schemes offer people the opportunity to explore better ways to take their medications when they are away from the inpatient setting including, where appropriate, ways that family and others important to them can become involved. Collectively, this approach can improve the quality of medication taking by avoiding delays in administration and potential adverse effects that can happen as a result and run the risk of people coming back into hospital and at a time they and the people important to them would rather not.

Introduction

When it comes to medication in the last days of life, good quality care provides:

1. Information about medications	» Helps the dying person, and those important to them, understand and get the most from their medications. » Offers information in ways that take into account developmental level, learning disabilities, and any speech, language and other communications needs. *See page 5*
2. Ways to share information about medications	» Ensures accurate information about the dying person's current medications follow them as they move between care settings. » Addresses the risks particularly with medications given via a syringe pump and where medications have been prescribed pre-emptively. » Offers ways for those important to the dying person to take part in this process. *See page 5*
3. An agreed list of medications	» Includes medications to treat symptoms that are likely to occur in the last days of life. » Includes medications for complex cases that can be used on the advice of specialist palliative care. » Considers choices already agreed in local clinical guidelines. *See page 6*
4. Guidelines and supporting documentation	» Ensures medications can be prescribed and administered safely and on time. » Is accessible by members of staff, who are familiar with their content. *See page 9*
5. Ways to obtain medications when they are needed	» Considers a variety of solutions, including pre-emptive prescribing. » Explores more innovative ways to access medications in urgent situations. *See page 10*
6. Ways to dispose of medications when they are finished	» Offers the family and those important to the dying person the opportunity to become involved. » Supports the healthcare professional to do this when necessary. *See page 12*
References	*See page 14*

1. Information about medications

-- Offer written information to the dying person (where appropriate) and those important to them about the medications that may be used in the last days of life.

This should address:

» Optimising medications, for example stopping medications that are no longer providing symptomatic benefit or may cause harm, as well as switching medications to alternative routes of administration to meet the dying person's condition, their ability to swallow and their individual preferences. Explaining these changes can avoid confusion and unnecessary concerns felt by the dying person and those important to them[19, 20].

» The purposes of injectable medications that are placed in the home in particular where these have been prescribed on a pre-emptive basis and how to store them safely.

» How the dying person (where this remains appropriate) and those important to them can help, should they wish to do so, with the transfer of information about the medications if the dying person needs to go to hospital. For example, taking the documents used to record the administration of injectables so that the clinical team have an accurate medication list.

» What to do with unwanted medications, including after death.

» How people who are important to the dying person can help return a syringe pump.

» How people who are important to the dying person can get more help.

-- Written information should be in plain language.

» Aim to keep everything short and simple. Avoid using more words than are needed to say what you mean. Don't use a long word if a short one will do the job.

-- Consider all communication levels and needs.

» Other ways of communicating information should be available that take into account developmental level, learning disabilities, and any specific speech, language and other communication needs[11].

2. Ways to share information about medications

-- Have guidelines to confirm what medications and doses are being administered via the syringe pump.

» This is essential when people transfer across a care setting, and should be done without delay[21, 22, 23, 24].

-- Share information through a variety of ways.

» Details of the medications and doses may be added to the discharge letter, a copy of which should be included in the bag of medications for review when these are administered.

» Attach an additive label to the syringe. The label should include the medications, doses and diluent.

» Provide at least one other source of information in addition to the additive label. For example, a referral letter, a supplementary monitoring chart, or a copy of the previous inpatient medication chart both showing current medications and doses in the syringe pump.

-- Consider the quality of the documents used during the transfer of care.

» Include instructions that help the healthcare professional to seek out the most appropriate sources of information about current medications and doses.

» Detail where to get more help if these are unavailable or unclear, including out-of-hours.

-- Ensure documents are properly handled during the transfer of care.

» Community charts that record the medications and doses should remain with the dying person when they transfer care (and this instruction should be clearly stated on the chart).

» A tick box on the community charts may be used to prompt the member of staff to attach the additive label to the fresh syringe every time.

» Offer the dying person (where appropriate) and those important to them the opportunity to get involved in transferring information about the medications.

3. An agreed list of medications

-- Choose medications to treat symptoms that are likely to occur in the last days of life.

(*Table 1, page 7*)

Take the following into account:

- Include preparations that allow administration by routes in addition to parenteral (eg oral/ enteral, transmucosal, transdermal and buccal [oromucosal] routes), providing they are safe, effective and appropriate to the wishes of the dying person and those important to them *(Table 2, page 8)*.
- Therapeutic choices based on the dying person's clinical condition, for example considering alfentanil or fentanyl as the opioid of choice where there are signs suggestive of renal failure or alternatives to first-line medications where these have failed.
- Where a range of strengths exist, include the lowest strength so that people who have not received the medication before for symptom control can be started on this and titrated upwards according to clinical response.
- Limit the range of other strengths to avoid mistakes when prescribing and administering, in particular for strong opioids[25]. However, keep enough to give a range of useful doses. Limiting the range can help storage problems and potential waste from unused and expired stock.
- Choice of medications should be in line with local guidance as this will avoid confusion and mistakes.
- Include medications to be able to treat complex cases with the advice of specialist palliative care *(Table 3, page 8)*.
- Quantities of medications should meet local need. This should be regularly reviewed.

3. An agreed list of medications

Table 1: **Consider the following medications for use in the dying person**

Symptom/ condition	Medication	Recommended injection strength(s) to include	Further considerations
Pain and breathlessness	Morphine	10 mg/ mL 30 mg/ mL	Alternatives include diamorphine. There is a high risk of prescribing and administration error if both are used in clinical practice.
	Oxycodone	20 mg/ 2 mL 50 mg/ 1 mL	
	Alfentanil	1 mg/ 2 mL 5 mg/ 1 mL	Alternatives include fentanyl. This class of drug is considered the strong opioid of choice in renal failure. There is a high risk of prescribing and administration error if both are used in clinical practice.
Nausea and vomiting	Cyclizine	50 mg/ 1 mL	The causes of nausea and vomiting in the last days of life are multifactorial. Medications should be available that address each of the likely causes. Refer to clinical guidance when considering choices.
	Haloperidol	5 mg/ 1 mL	Useful when symptoms are thought to be due to a biochemical abnormality in the blood.
	Hyoscine butylbromide	20 mg/ 1 mL	Consider in nausea and vomiting associated with obstructive bowel disorders.
	Levomepromazine	25 mg/ 1 mL	Multi-receptor blockade makes this a useful choice when symptoms are thought to be due to more than one cause.
	Metoclopramide	10 mg/ 2 mL	Prokinetic properties make this a useful choice when symptoms are thought to be due to slowed transit of the gut.
Anxiety and agitation	Midazolam	10 mg/ 2 mL	
Noisy respiratory secretions	Glycopyrronium bromide	200 mcg/ 1 mL 600 mcg/ 3 mL	Alternatives include hyoscine hydrobromide and hyoscine butylbromide.
Miscellaneous	Water for injections	10 mL	Alternative diluents and flushes include sodium chloride 0.9%.
	Sodium chloride 0.9%	1000 mL	For clinically-assisted hydration used according to local clinical guidelines.

3. An agreed list of medications

Table 2: Consider the following medications for use in the dying person who remains able to take medications safely and effectively by routes other than injection, and it remains their wish to do so

Medication	Preparation	Recommended product strengths to include
Buprenorphine	Transdermal patch	5 mcg/ hr., 10 mcg/ hr., 20 mcg/ hr.
Diazepam	Rectal solution	10 mg/ 2.5 mL
Fentanyl immediate release	Sublingual, buccal and nasal preparations	Alternatives include fentanyl. Choose strengths depending on the product selected. The dose available from preparations may be too high for use in paediatric patients.
Fentanyl	Transdermal patch	12 mcg/ hr., 25 mcg/ hr., 50 mcg/ hr.
Lorazepam	Sublingual tablet	1 mg
Midazolam	Oromucosal solution (pre-filled oral syringe)	2.5 mg/ 0.5 mL, 5 mg/ 1 mL, 7.5 mg/ 1.5 mL, 10 mg/ 2 mL Other unlicensed formulations are also available and may have different doses. Refer to product literature.
Morphine	Modified release tablet/ capsule	5 mg, 10 mg, 15 mg, 30 mg, 60 mg, 100mg
	Oral suspension (modified release granules)	20 mg, 30 mg, 60mg
	Immediate release tablet	10 mg, 20 mg
	Immediate release liquid	10 mg/ 5 mL
	Immediate release liquid concentrate	20 mg/ 1 mL
Oxycodone	Modified release tablet	5 mg, 10 mg, 20 mg, 40 mg, 80 mg
	Immediate release liquid	5 mg/ 5 mL
	Immediate release liquid concentrate	10 mg/ 1 mL

Table 3: Consider the following medications for use in the dying person with complex needs and with advice from specialist palliative care

Medication	Recommended injuection strength(s)	Further considerations
Dexamethasone	4 mg/ 1 mL	Symptoms that suggest an underlying inflammatory component where a corticosteroid may be of benefit.
Furosemide	20 mg/ 2 mL	Symptoms caused by fluid overload and oedema and where a diuretic may be of benefit.
Ketorolac	30 mg/ 1 mL	Symptoms that would benefit from a non-steroidal anti-inflammatory drug and where oral and rectal routes are not appropriate.
Octreotide	100 mcg/ 1 mL	Consider 2nd line to hyoscine butylbromide used in obstructive bowel disorders.
Phenobarbital	200 mg/ 1 mL	May be used for management of seizures or, predominantly in adult patients, added to midazolam for difficult to control cases of terminal agitation.

4. Guidelines and supporting documentation

-- Clinical guidelines should be evidence-based.

» This is essential when it comes to choosing the most appropriate medications and doses.

-- Include laws and best practice on how medications are prescribed.

» This should include controlled drugs (and "off-label" use[26]) in a number of clinical settings, and how medications are transported, administered, monitored and disposed of, as collectively this sets down the framework that allows medications to be used safely and without delay[27].

-- Guidelines should include:

» Information on how the dying person's medications is shared across care settings (*See Section 2*).
» How to calculate analgesic equivalent doses and apply this safely to meet the clinical needs of the dying person.
» How to switch between different opioid preparations that maintains symptom control and avoids adverse effects.
» How to administer when required (*PRN*) medications safely and effectively, including the community where PRN dosing may be difficult. Also, the use of safeguards that prompt referral when repeating doses becomes ineffective.
» Clinical decision support algorithms to explain these processes as clearly as possible.
» How to prescribe medications on a pre-emptive basis where there is a clear need and it is safe to do so.
» Ways to minimise risk with the medicinal use of controlled drugs. Share good practice with expert safety groups such as Local Intelligence Networks and the London Opioid Safety and Improvement Group[28].

-- Supplement guidelines with charts that help with ordering, prescribing, administering, monitoring and disposing of medications.

Use templates that allow pre-population of data where appropriate and safe. This can streamline the process and reduce errors and delays.

Examples include:

» Instruction sheets to help GPs prescribe the correct medications and quantities and where to get the prescription dispensed, for example the location and opening times of community pharmacies that stock palliative care medications.
» A chart that authorises the healthcare professional to administer medications, for example in the home. These charts include the medications for each of the symptoms likely to be seen in the dying person, the dose or dose range over which the medication can be titrated according to clinical need, the date and prescriber's signature. Medications can be prescribed on a pre-emptive basis.
» A chart to record the stock balance of controlled drugs and avoid supplies running out.
» A chart to record the medications and doses being administered by the syringe pump, including checks to monitor the pump is running correctly.
» An example of these kind of charts is available from the London Cancer Alliance[29].

5. Ways to obtain medications when they are needed

-- Make sure the correct medications are available, on time, where they are needed.
Medications in suitable quantities with the appropriate documentation to support safe and effective administration is fundamental to getting things right.

-- Understand the journey that the dying person takes to reach home.
As this may be another place they know as home and where medications need to be available, there may be more than one opportunity where procedures can be set up to improve access around the clock.

-- Procedures should offer a range of ways to get hold of medications.
In other words, people who will need medications that are rarely kept in stock by a community pharmacy, will need them outside normal working hours and without delay.

-- Use processes that are run by different healthcare professionals to engage a mix of knowledge and skills and the opportunity to improve education and training.
In particular, for the generalist members of staff working within the home setting.

5. Ways to obtain medications when they are needed

Table 4: Consider the following approaches to facilitate access to medications

Approach	Comments
Pre-emptive prescribing of medications	» Guidelines for prescribing medications in anticipation of future need. » Prescribe when people are discharged from an inpatient setting where stock will be readily available to meet the prescription, for example from hospital or hospice to home. » Consider for a child being transferred from hospital to a children's hospice, where stock medications may not be available. » Consider for people at home so there is time to arrange for supplies of medications from their local community pharmacy. » Guidelines should offer information to: » The dying person (where this is appropriate) and those important to them about what the medications are for. » The healthcare professional that supports the safe and effective administration and disposal of unwanted medications, and how to get help.
Prescribing and obtaining medications in plenty of time	» Guidelines should include a process for repeat prescribing following discharge to ensure a fresh supply of medications is obtained before the discharge supplies run out. » Guidelines should support community members of staff to request prescriptions on time and avoid medications running out. » Guidelines should include instruction sheets to help GPs prescribe the medications on time, correctly for controlled drugs, and in suitable quantities so that corrections and delays can be avoided. » Guidelines should include where to get the prescription dispensed, for example those community pharmacies that stock palliative care medications and what their opening times are.
Community pharmacy holding an agreed stock of medications	» Community pharmacy services can be commissioned to provide additional services, including the availability of specialist medications for palliative care. » This includes education and training for community pharmacy staff to provide advice to GPs and nurses looking after the person at home, and who to contact for specialist advice. » This is a contracted service that can be arranged via a number of different routes, for example local authorities, clinical commissioning groups and local NHS England teams. » Guidance on developing local services and resources to do so, including template service specifications is available on the Pharmaceutical Services Negotiating Committee website[30]. » Information should be available to guide the number and location of pharmacies in order to meet the needs of the local population. This information should take into account any other approach used to facilitate medications access and should inform local commissioning intentions where possible.
Medications access from inpatient units, for example hospitals, adult hospices and some children's hospices	» May offer processes for emergency supply where a prescription is available but the medications are not available from the community pharmacy. » Offers the benefit of specialist medications and advice being available outside normal working hours. » Hospitals may have an out of hours, on call pharmacist available to support this process. » A contractual framework should be considered that includes strict procedures and risk assurance methods agreed by a multidisplinary team including pharmacy. » External scrutiny should be invited, for example the Care Quality Commission, General Pharmaceutical Council and the local police controlled drug liaison officer.

6. Disposing of medications when they are finished

-- Robust processes should be in place to remove unwanted medications.

This should be at an appropriate time in order to keep people safe from harm.

-- Pre-emptive prescribing has the potential to lead to unnecessary quantities of medications being in the home.

Having ways to remove these supplies on time will lessen the risks associated with this and allow this valuable prescribing practice to continue safely.

-- Guidelines should include the following information.

- Medications must not be disposed of in general, domestic waste, nor be disposed of through the sewage system.
- Prescribed medications are the property of the dying person and remain so even after their death. This has practical implications when it comes to recording what happens to the medications when they are no longer required and removed from the home.
- Normally the dying person's family or those important to them are responsible for the removal of unwanted medications, including controlled drugs from the home. They should be advised that all medications should be returned to a community pharmacy for disposal. Medications can be legally returned to any community pharmacy for disposal even if they did not originally dispense them. The only exception is for nursing homes that must make their own arrangements for disposal.
- It should not normally be the responsibility of healthcare professionals to dispose of unwanted medications.
- There are circumstances where it may help for healthcare professionals to get involved, for example where those important to the dying person such as family members or carers are unavailable, unable or willing to help or are too distressed. On the other hand, they may see the removal of medications as a part of sorting through things and making sense of events after a death. This can be a healthy part of grieving that should be supported in a safe way wherever possible.
- Healthcare professionals can remove unwanted medications if they suspect inappropriate use or they pose a risk if left in the home. This is important for controlled drugs. Concerns must be reported to the healthcare professional in charge and an incident report completed.
- Where the person's death is referred to the coroner, medication must remain in the home until removal has been authorised, usually within seven days.
- Healthcare professionals can legally be in possession of a person's controlled drugs that are no longer required but only for the purpose of transportation for disposal.
- Medications for disposal must be taken without delay to a community pharmacy. They must not be taken via the healthcare professional's place of work or otherwise remain in their possession or car. Medications should remain out of site during transportation. The healthcare professional must have their identification with them when transporting medications and when handing over to the community pharmacy.
- When controlled drugs are removed from the home by the healthcare professional, the circumstances must be documented in the person's clinical record, including:
  - Name of the family member or carer that requested the removal.
  - Name and quantity of the medication.
  - Name and address of the community pharmacy they are being taken to.
  - Name of the healthcare professional removing the medication from the home.
  - Date this was undertaken.
- Include an example record sheet for the healthcare professional to record the removal, transportation and handover of medications to the community pharmacy.
- Healthcare professionals should receive training on this process which should be repeated on a regular basis.
- The process should be audited on a regular basis and take into account the views of healthcare professionals when considering changes to bring about improvement.

6. Disposing of medications when they are finished

-- Offer written information for those important to the dying person about what to do with medications when they are no longer needed.

This should include:

» Where they can take the medications to be disposed of, how to do this safely and as soon as they feel comfortable to do so.
» How to store the medications safely in the home while making arrangements for their disposal.
» Who else they can ask to dispose of the medications where they feel unable to, and how to go about this.
» How they can get more help if needed.

Where written information is offered, this should be in plain language and should take into account developmental level, learning disabilities, and any specific speech, language and other communication needs.

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About the London Clinical Networks

The London Clinical Networks bring together those who use, provide and commission the service to make improvements in outcomes for complex patient pathways using an integrated, whole system approach.

The Clinical Networks work in partnership with commissioners (including local government), supporting their decision making and strategic planning, by working across the boundaries of commissioner, provider and voluntary organisations as a vehicle for improvement for patients, carers and the public. In this way, the networks will:

- Reduce unwarranted variation in services
- Encourage innovation in how services are provided now and in the future
- Provide clinical advice and leadership to support their decision making and strategic planning.

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