Pharmaceutical care of people requiring palliative care

Course information
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Course information

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Contents of Pack

Your pack contains:

- Pharmaceutical care of people requiring palliative care – Course information
- Pharmaceutical care of people requiring palliative care – Course activities
- Set of pharmaceutical care needs assessment tools for palliative care (10)
- NHSScotland - Clinical standards education and advice (Palliative Care) (1 copy)
- Aide Memoire - Quick Guide (1 copy)
- Set of Pain Diary forms (10)
- Universal Pain Assessment Tool (1 copy)
- SIGN guideline 106 Quick Guide
- The DVD with Alison MacRobbie’s presentation (in 16:9 PAL format). This DVD will play in almost any DVD player, and any PC or Mac with DVD playing software.

Acknowledgements

This pack was developed originally in 2006 by key representatives from the Scottish Palliative Care Pharmacists Association (Janet Trundle, Alison MacRobbie, Aileen Scott-Aiton, Helen Moulsdale and Joe Harrison) along with Annamarie McGregor (NHS Director Pharmaceutical Care Model Schemes) and Christine Alford.

The pack has been updated in 2008 by Alison MacRobbie, Aileen Scott-Aiton and Joe Harrison with review by Janet Trundle.

Disclaimer

While every precaution has been taken in the preparation of these materials, neither NES nor external contributors shall have any liability to any person or entity with respect to liability, loss or damage caused or alleged to be caused directly or indirectly by the information therein.
Introduction

Background  Since the launch of The Pharmaceutical Care Model Schemes (PCMS), 1999, NHS Boards have developed community pharmacy palliative care networks. The PCMS Steps Framework, 2003, brought best practice across Scotland together and provided NHS Boards with a framework to consolidate existing palliative care services and develop them further based on local needs. The framework was incorporated into the Scottish Specialists in Pharmaceutical Public Health Palliative Care Needs Assessment Tool Kit. Implementation of the latter is ongoing.

The framework set out to enable practitioners to move through the steps as they gained experience and developed their skills further. The framework is presented as 3 steps:

**Step 1:** Preparing your practice
- Improving access to medicines, education and advice (Resources), integrated care through discharge planning, improving communications and teamwork.

**Step 2:** Safety net
- Targeted pharmaceutical care interventions to help identify sub-optimal pain management e.g. break through pain audit and pain assessment.

**Step 3:** Holistic Review
- Recognition of symptoms or adverse effects e.g. nausea and vomiting, constipation, dry mouth and swallowing difficulties and to introduce care planning (Resources).

The Scottish Intercollegiate Guidelines Network (SIGN) Guideline 106 recommends that all healthcare professionals involved in cancer care should be educated and trained in assessing pain as well as in the principles of its control.

To that end, a pharmaceutical care needs assessment tool has been developed. This tool combines Step 2 and 3 of the framework, with a focus on common symptoms i.e. nausea and vomiting, constipation, dry mouth and pain assessment. Implementation of the tool is the focus of this pack. The tool will help put learning into practice and help pharmacists to identify and meet the pharmaceutical care needs of their patients as they pass through their palliative care journey.
“Not everyone with palliative care needs has access to a Macmillan nurse or doctors or nurses with an expertise in palliative care. Not everyone spends time in a hospice or hospital and people can fall through the net. Community pharmacists are ideally placed to help”.

Specialist Palliative Care Pharmacist

Community Pharmacists  Healthcare practitioners often assume that patients will seek help for their symptoms, however, in practice they do not always do so. Palliative care patients more than most may have a tendency to accept their symptoms as part of their condition. By using the assessment tool to identify symptoms that can be managed, and/or any changes in clinical need sooner rather than later, pharmacists can provide an important safety net for their patients. It is not anticipated that patients will be experiencing all of the symptoms at the same time.

“Due to workload I can generally only visit my clients once a week. I visited one of my clients yesterday, I knew she had started morphine sustained release tablets the previous week and asked her if they had helped to control her pain? She had taken one tablet, felt really sick and did not take any more because she wanted to wait and check with me first. If only she had thought to phone her pharmacist.”

District Nurse

Possibly the easiest marker to use to identify patients, are prescriptions for a strong opioid. As part of the normal clinical check and counselling process, pharmacists can ask the patient or carer if they are experiencing any of the symptoms/adverse effects specified. If they reply yes to any of them the pharmacist can explore the best way to help them using the assessment tool for guidance (see page 13). Alternatively, the assessment tool can be used if the patient or carer asks the pharmacist for advice on symptoms covered by the assessment tool.

Pharmacists can adapt the questions to their own style and the needs of the patient or carer. The questions have been written with direct patient contact in mind, however in practice it might be the carer that the pharmacists are speaking to. It is possible to go through the majority of questions with a carer without breaking patient confidentiality. As the tool focuses on medication and symptoms, knowledge of the specific diagnosis is not essential. The pharmacist will have to judge what is in the best interest of the patient. The assessment tool also functions as a
care plan as it allows pharmacists to document problems, action taken or to be taken and any outcomes.

The aide memoire suggests ways to optimise information provision and drug treatment by summarising key points to help pharmacists support and advise the patient or carer and suggests when it may be appropriate to refer to their GP or nurse (see page 18-31). The key points to consider and actions are also summarised in a ‘Quick guide’ (see page 14-17).

**Aim of Training**
To update pharmacists on the current management of palliative care and explore ways to develop further the pharmaceutical care of this patient group as part of normal working practice in the community setting.

**Objectives**
At the end of the session pharmacists should be able to:
- define the current therapeutic management of palliative care patients
- identify pharmaceutical care issues and respond to symptoms in patient scenarios and identify appropriate management solutions
- explore how to implement the principles of the pharmaceutical care needs assessment tool in practice.

To get the most out of the training session please read the contents of the course information section before attending.

**Pre-reading**
- **BNF section on Palliative Care**
- **Article: Palliative Care. Pharm J 2000 (Oct 21); 265:603-614**
  Go to [http://pharmj.com](http://pharmj.com).
  Go to ‘back issues’ (left side of home page amongst green boxes). Find 2000 page, then volume 265, and page range containing 603. Navigate to the issue containing that page number and click on the relevant article.

  Go to [http://www.pjonline.com](http://www.pjonline.com)
  You need to register on this site to be able to access full articles; registration is simple. Click on the ‘Library’ tab, then click on the tab ‘Publication Search Options’. Enter 2006 into the ‘year’ box, 276 into the ‘volume’ box and 353 into the ‘page’ box. Press return or the GO button.
Teaching plan

Lecture 55 minutes and 10 minutes discussion.

**Palliative care**
This talk will cover:
• definition and diagnosis
• symptoms
• epidemiology/statistics
• guidance on management
• pharmaceutical care

Comfort break 20 minutes.

Workshops 60 minutes.
Training groups should be divided into groups of between 8 and 12 participants. One facilitator should be assigned to this group which will then be further subdivided into smaller groups of three.
• Cases 1 to 5. The group will identify care issues at the end of each case. Following discussion they should be able to complete the pharmaceutical care needs assessment tool.
*There may not be enough time to do all 5 cases in the session but you can review the remainder in your own time.*

Questions/discussion/answers 10 minutes with the overall group.
Answers should be provided at the end of the session.

Summary 15 minutes.
• Find out what guidelines for palliative care are followed locally and what patient information leaflets are commonly used.
• CPD-action (recording), evaluation and identification of further training needs and using the spare assessment tools to explore how to implement the tool in practice.
• Course assessment.
**Useful reference sources**

**NHS 24 Resource**

NHS 24 is a confidential telephone health advice and referral service integrated with all NHS boards and the Scottish Ambulance Service. NHS 24 has access to the Emergency Care Summary, and Special Notes. The content of both of these, and how they may be useful to a community pharmacist, is explained in the Unscheduled Care folder found in all community pharmacies. There are no doctors available at NHS 24, so if you need to refer a patient to a doctor, please use the numbers provided in the Unscheduled Care folder. If you have any queries about the services NHS 24 provides, or how to deal with a patient in the out of hours period, please contact the NHS 24 pharmacy team at pharmacyenquiries@nhs24.scot.nhs.uk

**Network of Community Pharmacies**

A network of specialist community pharmacies that provides information and advice on the pharmaceutical aspects of palliative care to patients, carers, GPs, nurses and other community pharmacists exists throughout Scotland. These pharmacies stock an agreed list of palliative care medicines. Information about the local service is available via the specialist palliative care pharmacists (page 11-12). ALL pharmacies need to know, including when locums are present, how their local network operates and to actively engage in the network to ensure that patients / carers can promptly access urgently required medicines without having to physically go round pharmacies seeking the medications they need. In some areas, the network includes a taxi protocol for urgent collection and/or delivery of prescriptions or medicines.
Useful websites

- Breast Cancer Care
  www.breastcancercare.org.uk

- Cancer BACUP (now merged with Macmillan Cancer Support)
  www.cancerbacup.org.uk

- Carers: Princes Royal Trust for Carers
  www.carers.org/

- Coalition of Carers Scotland
  www.carers.net

- Directory of Hospice & Palliative Care Services
  www.hospiceinformation.co.uk

- Gold Standards Framework Scotland
  http://www.gsfs.scot.nhs.uk/

- Liverpool Care Pathway for the Dying Patient
  http://www.mcpcil.org.uk/liverpool_care_pathway

- NHS Helpline: Help for Carers
  www.scotland.gov.uk
  (search under Carer or Palliative Care)

- Macmillan Cancer Support
  www.macmillan.org.uk

- Maggies Centre
  www.maggiescentres.org
  (This site has links to other cancer related web sites.)

- Marie Curie Cancer Care
  www.mariecurie.org.uk

- Greater Glasgow and Clyde Palliative Care Information Network
  www.palliativecareggc.org.uk

- Palliative Care Formulary
  (includes syringe compatibility database – you need to register on the site to access this)
  www.palliativedrugs.com
Palliative medicine Handbook (with syringe compatibility section)
www.pallcare.info

Clinical Knowledge Summaries (CKS) (formerly Prodigy guidelines)
www.cks.library.nhs.uk

SIGN (SIGN 106- Control of pain in patients with cancer) revised guideline due November 2008
www.sign.ac.uk

NHS Education for Scotland (Pharmacy) NES
www.nes.scot.nhs.uk/pharmacy/

Cancer (NHS Executive)
www.dh.gov.uk (search term “Palliative Care”)

NHS Quality Improvement Scotland
www.nhshealthquality.org (search term “Palliative Care”)

Scottish Partnership for Palliative Care
www.palliativecarescotland.org.uk
Websites

**SCAN (South East Scotland Cancer Network)**
www.scan.scot.nhs.uk
(Click under Health Care Professional and then link to Palliative Care)
Includes:
- Fife
- Borders Palliative Care Team
- Dumfries and Galloway

**NOSCAN (North of Scotland Cancer Network)**
www.noscan.scot.nhs.uk
(Click on Palliative Care link for Highland guidelines)
Includes:
- Tayside [www.tayside.scot.nhs.uk/nhstayside/intranet](http://www.tayside.scot.nhs.uk/nhstayside/intranet)
- Highland [http://intranet.nhsh.scot.nhs.uk/Organisation/PalliativeCareNetwork/Palliative%20Care%20Information%20Pack/Palliative%20Care%20Information%20Pack.pdf](http://intranet.nhsh.scot.nhs.uk/Organisation/PalliativeCareNetwork/Palliative%20Care%20Information%20Pack/Palliative%20Care%20Information%20Pack.pdf)
- Western Isles
- Shetland
- Orkney
- Grampian [www.show.scot.nhs.uk/nhsgclinicalguidance](http://www.show.scot.nhs.uk/nhsgclinicalguidance)
  (Click on palliative care)

**WOSCAN (West of Scotland Cancer Network)**
www.show.scot.nhs.uk/woscan
Includes:
- Ayrshire and Arran
- Greater Glasgow and Clyde [www.palliativecareglasgow](http://www.palliativecareglasgow)
- Lanarkshire [www.lcis.org.uk](http://www.lcis.org.uk)
  (Click on Support Services then click – “Living with Cancer” then click “Palliative Care”)
SPCPA members’ contact list for palliative care

**SCAN**

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WOSCAN

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Fax: 01236 748786
linda.johnstone@standrews.lanpct.scot.nhs.uk
### Pharmaceutical Care Needs Assessment
#### Palliative Care

<table>
<thead>
<tr>
<th>Name</th>
<th>Doctor’s name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of birth or CHI no.</td>
<td>Date</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>1</th>
<th>Can you tell me what medical condition(s) you have? Or have you had?</th>
</tr>
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</table>

<table>
<thead>
<tr>
<th>2</th>
<th>What is/are the name(s) of the medication you take for your condition(s) and how do you take it/them?</th>
<th>dose</th>
<th>frequency</th>
<th>indication</th>
</tr>
</thead>
</table>

<table>
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<tr>
<th>3</th>
<th>Do you ever forget or choose not to take your medication? If yes, how often – weekly/monthly?</th>
</tr>
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<tr>
<th>4</th>
<th>Do you know what to do if you have missed a dose of your medication?</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>5</th>
<th>What, if any, side-effects do you experience from your medication?</th>
<th>yes</th>
<th>no</th>
</tr>
</thead>
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<thead>
<tr>
<th>6</th>
<th>Do you feel that your medication is controlling your symptoms or have you noticed any changes since you started taking your medication? Do you know the trigger signs?</th>
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<tr>
<th>7</th>
<th>Do you have a regular check/blood test/review? Can you tell me when that was, and the outcome?</th>
</tr>
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</table>

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<tr>
<th>8</th>
<th>Would you like any information/advice on anything about your condition/medication/health promotion areas?</th>
</tr>
</thead>
</table>

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<tr>
<th>9</th>
<th>Do you smoke? If yes how many cigarettes and for how long? (Ask only if considered appropriate)</th>
<th>yes</th>
<th>no</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Specific questions</th>
<th>yes</th>
<th>no</th>
</tr>
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<table>
<thead>
<tr>
<th>10</th>
<th>Are you experiencing any of the following:</th>
</tr>
</thead>
<tbody>
<tr>
<td>10a.</td>
<td>Nausea or vomiting?</td>
</tr>
<tr>
<td>10b.</td>
<td>Constipation?</td>
</tr>
<tr>
<td>10c.</td>
<td>A dry mouth?</td>
</tr>
<tr>
<td>10d.</td>
<td>A sore mouth?</td>
</tr>
<tr>
<td>10e.</td>
<td>Swallowing difficulties?</td>
</tr>
<tr>
<td>10f.</td>
<td>Any pain?</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>11</th>
<th>If the patient is experiencing pain and no one is involved in assessing it or if there is a delay in reviewing the pain control, then ask the following questions:</th>
</tr>
</thead>
<tbody>
<tr>
<td>11a.</td>
<td>What word(s) would you use to describe your pain?</td>
</tr>
<tr>
<td>11b.</td>
<td>Using the following 0 – 10 pain score describe your worst pain in the last 24 hours, where 0 is no pain and 10 is the worst pain imaginable.</td>
</tr>
<tr>
<td>11c.</td>
<td>Does moving make your pain worse?</td>
</tr>
<tr>
<td>11d.</td>
<td>Is there any time of day when your pain is worse?</td>
</tr>
<tr>
<td>11e.</td>
<td>What is/are the name(s) and strength of your medication that is/are specifically for pain, how do you take it/them, and how many do you take on average/day?</td>
</tr>
<tr>
<td>-</td>
<td>Do they have a breakthrough pain killer?</td>
</tr>
<tr>
<td>-</td>
<td>Is the analgesic breakthrough dose appropriate?</td>
</tr>
<tr>
<td>-</td>
<td>Are they also taking a regular simple analgesic?</td>
</tr>
</tbody>
</table>

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<tr>
<th>12</th>
<th>Do you have any other symptoms or would you like to ask any questions?</th>
</tr>
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<table>
<thead>
<tr>
<th>Issue or action</th>
<th>Note any follow up action required and any outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Understanding</td>
<td>☐ Compliance</td>
</tr>
<tr>
<td>☐ Effectiveness</td>
<td>☐ Health/self help</td>
</tr>
<tr>
<td>☐ Safety</td>
<td>☐ Referral</td>
</tr>
</tbody>
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Aide memoire - Palliative Care
General questions

1. Can you tell me what medical condition(s) you have?
   Or have had?
   This helps to clarify their understanding of their condition(s). Length of diagnosis can be important. People are provided with lots of support and information at initial diagnosis – the amount of information and support received at diagnosis will vary, also they may or may not be attending appropriate clinics. Over time people can forget key information or the messages may change over time.

   **Action**
   Note answer and offer patient general information on conditions.

2. What is/are the name(s) of the medication you take for your condition(s) and how do you take it/them?
   Check with prescription or patient medication records. Confirm that the patient is taking the medication as instructed on the prescription with any appropriate counselling instructions, e.g. swallowed whole.

   **Action**
   Note how person takes medication and advise appropriately when discussing symptoms (see Nos 10 & 11).

3. Do you ever forget or choose not to take your medication? If yes, how often-daily/weekly/monthly?

   **Action**
   Clarify which drugs are missed and when.
   Explore the patient’s reasons for choosing not to take their medication. For example patients may not want to take their prescribed opioid as they may think they will become addicted to it or through fear of, or experiencing, adverse effects. Many patients with long-term medical conditions forget to take their medicines as advised. Underline the benefits of the medication and offer any relevant patient information leaflets. Offer support and advice and provide compliance solutions if necessary e.g. linking to meal times and discuss with GP if appropriate. Refer if appropriate.
4. **Do you know what to do if you have missed a dose of your medication?**

Document response. If the patient forgets to take a dose of quick acting (immediate release) morphine/oxycodone prescribed regularly, or a dose of modified release morphine/oxycodone, advise them to take a dose as soon as they remember. They must not take a double dose to make up for the missed one. If the dose of modified release opioid is overdue by several hours or more, suggest that they take a dose of breakthrough pain medication as they need it, until the next dose of regular medication is due, and/or seek advice from a pharmacist or the doctor or nurse looking after them.

**Action**: Offer appropriate verbal advice depending on response and see questions 10 & 11.

5. **What, if any, side effects do you think you are experiencing from your medication?**

Check that any adverse effects can be attributed to their medication. Some people erroneously link symptoms or adverse effects to medication and this can affect their adherence. In palliative care patients, it may be a sign of worsening prognosis. If the person complains of sedation and they are prescribed other sedative drugs or drugs with sedative side effects, this might be an opportunity to discuss whether these can be rationalised with the patient/GP. It is important to prompt for the following signs of opioid toxicity as patients often do not volunteer these signs:

- Subtle agitation
- Seeing shadows at the periphery of the visual field
- Vivid dreams or nightmares
- Confusion
- Myoclonic jerks
- Visual or auditory hallucinations

The presence of opioid toxicity is an indication that the opioid dose is too high for the patient at this particular time and can happen at any dose. Management may include reducing the dose of opioid usually by approximately one third, ensuring adequate hydration, treating the agitation/confusion with haloperidol, slower titration of opioid dose, and, if persistent
unacceptable side effects remain despite appropriate intervention, switching to a different opioid. Check your local formulary/policy for the use of alternative opioids, and seek specialist advice on managing the toxicity.

**Action**
If there is a suspicion that the patient is suffering from opioid toxicity the GP should be contacted immediately.

6. Do you feel that your medication is controlling your symptoms or have you noticed any changes since you started taking your medication? Do you know the trigger signs?

**Document response.**

**Action**
For any of the common palliative care symptoms follow on with Question 10 & 11 to gain further details. For other conditions offer appropriate verbal advice.

7. Do you have a regular check/blood test/review? Can you tell me when that was, and the outcome?

**Document response.**

**Action**
For any of the common palliative care symptoms follow on with Question 10 & 11 to gain further details. For other conditions offer appropriate verbal advice.

8. Would you like any information/advice on anything about your condition / medication?

**Action**
For any of the common palliative care symptoms follow on with Question 10 & 11. For other conditions offer appropriate verbal advice.

9. Do you smoke? If yes, how many cigarettes and for how long.

**Action**
This question is not likely to be appropriate for most palliative care patients but may be important if the patient has COPD or heart failure and uses home oxygen, or is breathless but appears to have a sufficiently long prognosis to potentially benefit from stopping smoking.
Palliative Care specific questions:

10. Are you experiencing any of the following?

10a Nausea or vomiting?

In clinical practice it appears that in opioid naïve patients, 30-60% will develop nausea and/or vomiting when commencing opioid therapy. Tolerance in the majority of patients usually occurs within 5-10 days. Therefore, patients commencing or increasing their dose of opioids should have access to an anti-emetic. A dopamine antagonist such as metoclopramide 10mg, three times daily (which is also prokinetic) or low dose haloperidol 1.5mg at night should be effective.

Nausea and vomiting are present in 15-45% of patients with advanced cancer. Reversible causes include drugs, constipation, anxiety, cough or hypercalcaemia and should be treated where possible. Pharmacological treatment should be based on the likely cause of the nausea and vomiting and the probable neurological pathways and neurotransmitters involved (see article on page 19). The anti-emetic should be prescribed regularly and when required. If an anti-emetic successfully controls vomiting, but nausea persists, suggest trying an increase in dose. A combination of anti-emetics, with different mechanisms of action, may be necessary to achieve symptom control. Input from palliative care specialists may be required at this point.

Action

Patients commencing or increasing their dose of opioid should have access to an anti-emetic. If not, contact their GP and suggest that a ‘one-off’ prescription will usually suffice.

If the patient is vomiting or if oral absorption is in doubt, consider the subcutaneous or rectal route and refer where appropriate.

Long-term anti-emetic use should be reviewed regularly and discontinued if the underlying cause has resolved.

General advice which can be given to patients includes:

- Relax as much as possible as anxiety can make nausea worse.
- Eat little and often.
- The following foods are often well tolerated: Fizzy water, dry biscuits, crackers or toast, ginger flavoured foods e.g. ginger biscuits, sucking boiled sweets or mints, cold foods e.g. sandwiches, and peanuts/crisps.
- Avoid food preparation and cooking smells or unpleasant odours where possible. Try to get some fresh air before mealtimes.
- Brush teeth regularly.
**10b Constipation?**

Constipation is prevalent in 25 – 50% of advanced cancer patients. This can be due to loss of appetite and subsequent decreased food and fluid intake, periods of immobility, medication and disease involvement in the gastrointestinal tract. Constipation can lead to nausea and vomiting, abdominal pain or discomfort, distension, confusion and disorientation.

The aim of treatment is the comfortable passage of faeces without rectal intervention. An understanding of the patient’s normal, accepted bowel habit is essential before recommending treatment. Prophylactic laxatives should be prescribed regularly (not when required) for almost all patients who receive medication that causes constipation and titrated according to response before changing to an alternative agent. (Note if they have an ileostomy, laxatives are not likely to be needed).

Patients prescribed an opioid require both a stool softening and a stimulant agent. Co-danthramer is a combination laxative (stimulant/softener), which is licensed for use in terminally ill patients. A combination of bisacodyl and docusate sodium is another option. Movicol® may be used for severe constipation unresponsive to the above options. However, the volume of fluid required for administration may be inappropriate for patients with a poor fluid intake and a stimulant may still be required as well.

**Action**

If the person is prescribed an opioid, confirm if they are prescribed and taking the appropriate stimulant/softener combination each day.

General advice which can be given to patients includes:

- Drink plenty of fluids, approximately 6-8 cups every day if possible (water, tea, juice, milk).
- Eat prunes at breakfast or prune juice, other fruit juices, plums or rhubarb.
- Take small, regular meals.
- Encourage them to eat a high fibre cereal (porridge, weetabix, bran flakes etc) if they can manage it. (This will require them to take extra fluids). This would be inappropriate if appetite is poor, they aren’t drinking enough fluids or have been told they may be at risk of bowel obstruction.
- Keeping as physically active as possible.
10c A dry mouth?
The use of non-palliative care drugs, which can cause dry mouth, especially those with anti-cholinergic side effects, should be rationalised if possible.

**Action**
Discuss rationalising with GP if appropriate.
If dry mouth is a problem, recommend:
- Regular sips of water or unsweetened drinks or sucking ice.
- Chew sugar free chewing gum.
- Use an atomised water spray.
- Use a saliva spray/gel e.g. Oralbalance® (no clear evidence, but some patients find them helpful). Glandosane® aerosol spray should be avoided in patients with their own teeth (very acidic: can destroy teeth enamel). AS Saliva Orthana®, which has a more neutral pH, is preferred.

10d A sore mouth?
Try and identify cause (e.g. presence of candidiasis, mouth ulcers) and treat appropriately. If it is due to mucositis, benzydamine hydrochloride 0.15% oral rinse can be used every 3 hours. This can also be diluted 1:1 with water, if stinging occurs. Refer to dentist if necessary e.g. if pain is related to dentures or teeth.

**Action**
Take the appropriate action, referring when necessary.

10e Are you experiencing swallowing difficulties?
If the difficulty is with solid dose forms, consider alternative oral formulations. Note, however, that patients may find the taste and smell of some liquid formulations sickly. Consider alternative routes e.g. subcutaneous, topical or rectal.

**Action**
Contact the GP to discuss other options and if required advise on dose conversions or seek specialist advice.
Are you experiencing any pain?

Approximately 70 - 80% of cancer patients in Scotland experience pain. Pain is more than a physiological phenomenon and tolerance varies greatly between patients. There are a large number of factors contributing to a patient’s experience of pain, for example, level of anxiety, mood, cultural influences, fears, fatigue, and changes to any of these factors will influence the pain picture. Underlying pathologies such as depression or anxiety may also be present and need to be addressed.

The principles of treatment outlined in the World Health Organisation (WHO) Cancer Pain Relief programme should be followed.

- Step 1  Mild pain
  Paracetamol 1g qds and/or NSAID
  +/- adjuvant

- Step 2  Mild to moderate pain
  Opioid e.g. codeine, dihydrocodeine
  + paracetamol and/or NSAID
  +/- adjuvant

- Step 3  Moderate to severe pain
  Opioid e.g morphine, diamorphine
  + paracetamol and/or NSAID
  +/- adjuvant

Inadequate pain assessment has been shown to be a barrier to the effective management of pain. Approximately 88% of patients can obtain satisfactory relief from pain when the WHO analgesic ladder is adhered to.

Analgesics should be selected depending upon the outcome of the initial pain assessment. The dose can then be titrated as a result of ongoing regular reassessment of response. Opioid doses should be increased by 30-50% (no more than 30% in older people or at high doses), or according to breakthrough doses used (add up all the regular and breakthrough doses taken in previous 24 hours to calculate the new total 24 hour dose). Primary analgesia should always be adjusted as the pain severity alters. If the pain severity increases and is not controlled
on a given step, treatment should move upwards to the next step of the ladder. Patients should not be prescribed another analgesic of the same potency.

Monitoring the effect of adding an opioid or changing a dose is often poorly managed in the community setting. In circumstances where there appears to be no plan in place to follow up/review these patients, the pharmacist should liaise directly with the GP or nurse to arrange follow-up.

The National Patient Safety Agency has issued advice in response to patients receiving unsafe doses of opioids, sometimes with serious consequences. It details the responsibilities of practitioners involved in prescribing, dispensing and administration of opioids to ensure, in anything other than acute emergencies, that the dose, frequency, formulation and/or dose increase are appropriate for an individual patient. You should familiarise yourself with this guidance intended to improve patient safety. NPSA Rapid Response Alert NPSA/2008/RRR05 reducing Dosing Errors with Opioid Medicines 4July 2008


Action

If they are presenting for the first time with a prescription for an opioid, the Education and Advice Standards (see Resources) apply – ensure that someone is following them up – confirm anti-emetic and laxative are co-prescribed. Check that the dose, formulation, frequency are appropriate for the patient. If you are not familiar with the opioid prescribed, you should seek appropriate advice e.g contact local specialist palliative care pharmacist (page 11 and 12)

If they are in pain assess the patient’s current prescription/PMR in relation to the World Health Organisation (WHO) analgesic ladder.
If the opioid dose is being increased, you should endeavour to confirm that the increment is safe for the patient – normally this is no greater than 30-50% (30% in older people or at high doses). Seek specialist advice if necessary. Warn the patient/carer that sedation may occur and advise of the risks of driving or operating machinery. Confirm that they have a supply of anti-emetic and advise that they may require an increase in their laxative dose.

For an increase in dose or change in pain relief medication, confirm that someone e.g. General Practitioner, District Nurse, Community Palliative Care Nurse, Macmillan Nurse will review how effective the change has been within the next 48 hours. If there is no plan encourage the patient/carer to contact the GP/nurse if the pain is not controlled within the next 48 hours (72 hours if over the weekend).

If the person is in pain despite regular opioid use confirm if anyone (as above) is involved in regularly assessing/managing their pain and when their next review is planned. If no other healthcare professional is involved, or there is likely to be a delay before an assessment by another healthcare professional, offer to perform an initial pain assessment before referring or contacting the GP with points to consider.

Questions 11a-e are a simple pain assessment and will help you to identify factors that may be contributing to poor pain management.

11. If the patient is experiencing pain and no one is involved in assessing it or if there is a delay in reviewing the pain control, then ask the following questions:

11a What word(s) you would use to describe your pain?
Pain can be described as nociceptive, neuropathic or of mixed origin.

Nociceptive pain The vast majority of pain in cancer patients is nociceptive, and occurs as a result of activation of nociceptors. Nociceptive pain is called ‘somatic’ when it is produced by
damage to structural tissues, such as skin, bone, muscle or joint. Pain of somatic origin is usually well localised and constant. Nociceptive pain is known as visceral pain when it is produced by an injury to thoracic or abdominal organs. Visceral pain is diffuse and poorly localised and may be referred to skin sites remote from the site of the lesion. Nociceptive pain usually responds well to simple analgesics and opioids.

**Neuropathic pain**  Neuropathic pain is a consequence of damage to the peripheral and/or central nervous system. In cancer patients, neuropathic pain most commonly occurs as a consequence of tumour compression or infiltration of peripheral nerves, nerve roots, or the spinal cord. In addition, surgical trauma, radiation-induced injury, or chemotherapy treatments may also result in this type of pain. Neuropathic pain is regarded as only partially opioid responsive and may be effectively treated with adjuvant analgesics such as anticonvulsants and antidepressants (often an unlicensed indication). Pain in an area of abnormal or absent sensation is always neuropathic.

**Mixed pain**  Nociceptive plus neuropathic pain

**Neuropathic descriptors**
- pins and needles or tingling
- shooting
- burning
- sharp or stabbing
- electric shock
- numbness
- skin strange to touch

**Nociceptive descriptors**
- aching
- stabbing
- dull
- tender
- cramping
- pressure-like

**Action**
Consider if there is a neuropathic component of their pain? Confirm if they are taking adjuvant therapy at the appropriate dose? If not discuss with GP/nurse.
11b Using the following 0-10 pain score describe your worst pain in the last 24 hours, where 0 is no pain and 10 is the worst pain imaginable.

Pain scales can be used to determine the severity of pain and to assess effectiveness of treatment interventions. This will be a very helpful baseline for you and the patient to work from if you recommend any changes as you can compare scores at follow up.

<table>
<thead>
<tr>
<th>Score</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 = no pain</td>
<td>No action required, continue to monitor for pain escalation.</td>
</tr>
<tr>
<td>1-3 = mild pain</td>
<td>No action required, continue to monitor for pain escalation.</td>
</tr>
<tr>
<td>4-5 = moderate pain</td>
<td>Continue to assess pain. If persistent refer to GP for review of analgesia.</td>
</tr>
<tr>
<td>6-10 = severe pain</td>
<td>Persistent severe pain, which distresses the patient. Refer to GP urgently for review of analgesia.</td>
</tr>
</tbody>
</table>

Note the pain score in the detail column. Some patients may find it helpful to use the Universal Pain Assessment Tool (a copy is included in this information pack) to assess their pain.

Action  
Note pain score

11c Does moving make your pain worse?

Is the patient describing movement-related pain or pain which comes on suddenly at rest? If pain is well controlled at rest, and only worsened by movement, an increase in the dose of regular (modified-release) opioid is not required or appropriate.

Action  
Check that the patient has a suitable prn analgesic and is taking it before movement. For bone pain, contact GP and ask them to consider NSAIDs if not contra-indicated (consider a Proton Pump Inhibitor if the patient is at risk of gastrointestinal side-effects or if they are already taking steroids).
11d  Is there a time of day when your pain is worse?
Consider dosing times of modified release preparations and formulations and aim for pain free at night as the first step e.g. Immediate release NSAID might be better than modified release as it offers more flexible dosing and quicker effectiveness.

Action
If the person is not sure offer a pain diary and ask them to score at different times of the day and return it to you.

11e  What is (are) the name(s) and strength of your medication that is (are) specifically for pain, how do you take it (them), and how many do you take on average per day?
Check with prescription/patient medication records. Confirm that the patient is using the medication as instructed, at the appropriate time and in the appropriate way. Note if there is a difference and offer appropriate advice. Poor pain control may be due to non-compliance or sub-optimal treatment. If prescribed modified release preparations e.g. MST Continus® or OxyContin® ensure the patient understands these are long-acting and should be taken at regular twelve hour intervals and swallowed whole. Confusion between OxyNorm® and OxyContin® due to the similarity of names is a source of prescribing, dispensing and administration errors. A patient safety information card which may assist patient counselling is available from Medical Information at Napp (ref UK/OX-06022), although it refers to ‘every 4-6 hours’ for administration of OxyNorm® in accordance with the SPC whereas common usage is ‘as required for breakthrough’.

Action
Consider the following:
Do they have a breakthrough pain killer?
Every patient on a modified release opioid should have access to breakthrough analgesia, in the form of an immediate release preparation. Check they know which preparation they have for breakthrough. Ensure the patient is aware that breakthrough analgesia can be taken if they experience pain in between taking their regular 12 hourly long-acting opioid. After taking a dose of breakthrough analgesia the patient should wait 30 minutes and if they still have pain, they should take another dose. If they regularly need more than two extra doses of breakthrough analgesia in a day, they may require the dose of their long-acting
preparation to be increased (unless the breakthrough doses are being taken for movement-related pain – see question 11c).

Is the analgesic breakthrough dose appropriate?
Breakthrough analgesia should normally be prescribed at one sixth of the total regular daily morphine/oxycodone dose. However, occasionally palliative care specialists use higher doses in some patients.

Are they also taking a regular simple analgesic?
The WHO analgesic ladder states that patients taking an opioid for pain should also be prescribed regular paracetamol (1g four times daily) and/or NSAID. Explain to the patient that paracetamol taken regularly is much more effective than on a prn basis.

Review their current pain management in light of the answers given and take the appropriate action, this may involve advising the patient to take their current medication in a more effective way or contacting the patient’s GP/nurse to review the current management.

12. Do you have any other symptoms or would you like to ask any questions?
The symptoms discussed above are the commonest ones which patients are likely to have, and which community pharmacists can help to manage. A patient may, however, have other symptoms, which you can help to identify e.g. cough, breathlessness and refer to another appropriate member of the healthcare team.

Action
Refer to local guidelines for guidance on other symptoms, or seek advice from palliative care specialists or refer to GP/nurse.

Issue and action
At the end of the assessment, review the answers to the questions and tick the box that most accurately describes issue(s) or problem(s) identified, note any follow up required and any outcome of your intervention. The action taken may involve providing information, clarifying points, providing compliance solutions, undertaking a review of their medication in light of the information available and/or referring any effectiveness or safety issues to their GP/nurse with recommendations based on what the patient/carer has reported to you.
Pharmaceutical care of people requiring palliative care

Alison MacRobbie
Palliative/Community Care Pharmacist
NHS Highland

Outline

- Commonly used medicines
- Pain Assessment
- Anticipating Needs
- End of Life Issues

What do we mean by palliative care?

“The active total care of patients whose disease is not responsive to curative treatment. Control of pain and other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.”

WHO guidelines: Cancer Pain Relief 2nd ed 1996

What does this mean in practice?

The rule of 90%
- 90% of palliative care patients receive 90% of their care at home.
- 90% of the care is provided by informal carers

D Doyle 2005
Opportunity for Pharmacists to Contribute

- Medicines can contribute greatly to patient outcome
  - timely access is a national priority
  - correct use to be safe and effective e.g. opioids
  - anticipating side-effects e.g. constipation

Communally Pharmacy – Model Schemes for Pharmaceutical Care MEL (1999) 78


Underpinning Care

- Excellent communication
  - with patients/carers
  - inter-professional
  - intra-professional
  - across traditional boundaries

Gold Standards Framework in Primary Care
Managed Clinical Networks for Palliative Care
Care Home Standards for Palliative Care

Impact for the Patient

- Knowing the professionals providing care
- An increasing team looking after them
- How good is the communication between the team?
- Knowing who to contact, how to contact them both in and out of hours
- Invasion of their personal space

Impact for the carer

- Getting to know the team and how to work within the system
- Having to learn quickly ‘on the job’.
- A changing situation
- Learning what’s important and what’s not
- Knowing where to get your support from
- Finding an advocate
- Confidentiality
Impact for the Pharmacist

- Maintaining continuity of medicines/supplies – frequent changes, compliance, routes of administration
- Good communication with patient/carer/healthcare team
- Holding appropriate supplies in anticipation of needs - in hours/out of hours
- A source of information, support and advice
- Confidentiality

A changing picture

* Changing physiology
  - fluctuating electrolyte and urine chemistry
  - fluctuating blood counts e.g. albumin, haemoglobin
  - kidney function
  - liver function (ascites)
  - skin condition

A changing picture cont.

* Impact of tumour
  - site
  - size
  - spread (metastases)
  - impact on surrounding structures and their functionality
  - paraneoplastic effects

Clinical Monitoring - what can the carer/patient do?

- Assisting patients/carers to know what to look out for as medicine side effects
- To let you know if there are difficulties taking the medicines
- To let you know if they have any concerns about taking their medicines
- To let you know about changing symptoms
Common Symptoms

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Common medicines</th>
<th>Non-pharmacological options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>Opioids, NSAIDs, Adjuvants</td>
<td>Acupuncture, Spiritual, Psychological</td>
</tr>
<tr>
<td>Nausea &amp; Vomiting</td>
<td>Metoclopramide, Cyclizine, Haloperidol, Levomepromazine</td>
<td>Acupuncture, Sea-bands</td>
</tr>
<tr>
<td>Constipation</td>
<td>Co-danthramer, Movicol, Senna + docusate</td>
<td>Diet, Fluid Intake, Mobility</td>
</tr>
</tbody>
</table>

Common Symptoms cont.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Common Medicines</th>
<th>Non-pharmacological options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathlessness</td>
<td>Anxiolytics, Oxygen</td>
<td>Positioning, Breathing exercises, Acupuncture, Relaxation</td>
</tr>
<tr>
<td>Anxiety</td>
<td>Benzodiazepines</td>
<td>Relaxation</td>
</tr>
<tr>
<td>Agitation/delirium</td>
<td>Haloperidol</td>
<td></td>
</tr>
</tbody>
</table>

Common Symptoms contd.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Common Medicines</th>
<th>Non-pharmacological options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oral care - infections</td>
<td>Saliva substitutes, Fluconazole</td>
<td>Sips of water, Pro-biotic yoghurts</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Methylphenidate</td>
<td>Energy conserving measures</td>
</tr>
<tr>
<td>Cachexia</td>
<td>Steroids (effects wear off after 3-4 weeks)</td>
<td>Pro-sure</td>
</tr>
</tbody>
</table>

Some Statistics

- Pain occurs in 50 - 70% of patients
- 88% of patients should have adequate pain control using the WHO analgesic ladder
- Cachexia occurs in 36 - 65% of patients (varies with tumour)
- Dyspnoea rises from 20-50% to 65-80% of patients as death approaches
- Nausea & vomiting - 15 - 45% occurrence
- Constipation occurs in 30 - 50% of patients - approximately 80% will require laxatives
Issues for carers/patients - Pain

- Overestimated by carers/underestimated by healthcare professionals
- Changing nature
- Not all pains are the cancer e.g. toothache
- Contributes to fatigue, forgetfulness, grumpiness
- Multiple therapies - what is for what?

Issues for Pharmacists - Pain

- Assessment - care plan and follow-up
- Patient understanding, expectation, opioid myths
- Therapeutic duplications
- Monitoring toxicity
- Information, advice and counselling (PILs)
- Communication with other healthcare professionals

WHO analgesic ladder

Pain Assessment

- Pain is more than a physiological phenomenon and tolerance varies greatly between patients
  - physical effects/manifestations of pain
  - functional effects
  - psychosocial factors
  - spiritual aspects
How to assess pain

- Full history
  - site and number of pains
  - severity of pain
  - spread, timing, description (quality)
  - factors that aggravate the pain and those that relieve it

How to assess pain contd.

- Aetiology of pain
  - Pain caused by cancer, by treatment, associated with cancer related debility eg ulcer, unrelated
  - Type of pain
  - Analgesic drug history
  - Presence of clinically significant psychological disorder

How to assess pain contd.

- Physical assessment
  - May not be possible in the pharmacy

- Investigations
  - Where essential to the management of the condition only

When to assess pain?

- Pain may well be the first presenting symptom
- Regular assessment and monitoring the effect of analgesia cannot be overemphasised
- Timing of reassessment depends on individual circumstances
  - Difficulty in control
  - Sudden exacerbation of pain
  - Issues for out-of-hours care
Difficulties in assessing pain

- Multidimensional and subjective nature of pain
- Interpretation of descriptions is inconsistent
- Anxiety or depression
- Communication difficulties
  - Language/ ethnicity/ hearing impairment/ reduced level of consciousness/ reduced cognition

Issues for carers/ patients – N & V

- Distress
- Carer burden of patient not eating or drinking/ managing food smells/ extra washing
- Patient unable to take medicines – aggravation of other symptoms eg pain, constipation etc.

Issues for Pharmacists – N & V

- Assessment
- Choice of therapy/length of therapy
- Alternative routes of medicines administration - ? Unlicensed, syringe drivers, issues for out-of-hours
- Dehydration – fluids requirement, increasing constipation, potential for drug toxicity
- Communication and information

Issues for carers/ patients - Constipation

- Prevention is better than sure
- Tend not to associate with reason for symptoms eg. Pain, discomfort, nausea & vomiting, confusion and restlessness
- Patient goes off food
Issues for Pharmacists - Constipation

- Prophylaxis when opioids prescribed (include step 2 opioids)
- Recognition
- Overflow diarrhoea
- Appropriate choice of therapy
- Counselling and advice

Issues for patients/carers – Breathlessness

- Distress
- Simple measures to assist – to have something they can do
- If on oxygen
  - Barrier to communication if on oxygen
  - Lots of stuff if on oxygen
  - Delivery system

Issues for Pharmacists - Breathlessness

- Information and advice
- If on oxygen
  - Continuity of supplies and equipment
  - Support and information
  - Anticipation for out-of-hours

Issues for patients/carers – Oral care

- Dryness – difficulty eating, pain, cracking of skin, infection
- Halitosis – distress
- Dentition – care of false teeth
- Altered taste
Issues for Pharmacists – Oral care

- Fluconazole for thrush – drug interaction
- Good mouth care advice – remember to ask if teeth are false
- Side-effects of drugs leading to dry mouth
- Use of saliva substitutes

End of life care

- Recognition
  - Patient is bedridden
  - Decreasing or fluctuating level of consciousness
  - Able only to tolerate sips of fluid
  - No longer able to take oral medication

End of life care

- Agreement of goals of treatment
  - Current medication is assessed and non-essential medication discontinued
  - "as required" medication is written up
  - Inappropriate interventions are discontinued
  - Needs multidisciplinary involvement
  - Liverpool Care Pathway for the Dying – J Ellershaw

General information

- Contact information
- Medication supplies
- Speed of change
- Exemption categories for prescriptions
Summary of the Pharmacists role

- Medication is appropriate dose, route, duration
- Use of assessment tools/symptom diaries
- Communicate identification of symptom changes e.g. early identification of increasing or changing pain
- Assist with compliance
- Ensure continuity of medicine supplies
- Advice for patients/carers/healthcare professionals

Key questions

- Is anyone helping you assess/manage your pain just now?
- How would you describe your pain?
- Describe your worst pain in the last 24hrs (0 – 10 pain scale)
- What symptoms/side-effects have you experienced since you started your medication?
- Do you ever forget or choose not to take your medication?
- Is there anything that is unclear or any questions that you'd like to ask?