

Providing good palliative care for patients at home

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Marie Curie Cancer Care

How can optimal pain control be achieved?

What is the role of specialist nurses?

When is care at home not suitable?



PALLIATIVE CARE IS THE PROACTIVE AND HOLISTIC MANAGEMENT OF

patients with significant illness that is unresponsive to curative treatment. The primary care team can play a vital role in palliative care.¹ GPs will see patients at all stages of their illness, from the initial symptoms, through the early stages when although a poor prognosis has been given the patient may feel reasonably well, up to death. The aims for primary care teams are

those set out in the Gold Standards Framework for palliative care (see table 1, p29).²

ASSESSING PATIENTS' NEEDS

A needs assessment should be carried out soon after diagnosis. The precise format will depend on individual circumstances. A joint consultation with the doctor and nurse, either in the practice or at home, is useful both in initial assessment and future care.

Continuity of care is highly valued by patients. In practices that do not have personal lists ideally the patient's usual doctor should coordinate care, with another doctor designated as a backup.

Patients' reactions to receiving a serious diagnosis are complex and variable. Kübler-Ross found certain common patterns including initial denial, anger, bargaining (which includes a belief that medical therapy or lifestyle adjustments may help), depression and finally acceptance.³ In another seminal study, Hinton interviewed patients in the 10 weeks leading up to death and found that while 66% recognised death as a possibility, 26% talked only of recovery.⁴

The ongoing relationship with the patient is a particular strength of

general practice, and members of the primary care team are usually well placed to assess patients' and families' likely reactions and wishes.

A key part of this 'wish-list' is ascertaining where the patient wants to die. Research has shown that three-quarters of patients wish to die at home,⁵ but less than a quarter currently do so.⁶

The QOF indicators are a good starting point for providing palliative care (see table 2, right). Although the QOF recommends 3 monthly meetings to review patients on the register, we hold meetings every month.

In my practice, a concerted focus on developing an integrated nursing team whose members are all skilled in palliative care has led to an increase from 30% of patients who wished to dying at home a decade ago to a current figure of over 50%.⁷ The use of higher-technology healthcare in the home, for example oxygen, may also increase the proportion of patients whose wish to die at home is realised.

LIAISON WITH OTHER AGENCIES

Good inter-professional liaison is essential. Regular practice meetings to review patients should occur. Patient-held continuation cards in which all professionals involved can write notes are invaluable. Most practices use an out-of-hours service and updates on seriously ill patients should be sent there as well as to the nursing services. Arrangements with the local and on-call pharmacist are also important.

Good communication between primary and secondary care

Many patients will be under hospital care and indeed the terminal diagnosis is often confirmed there. This is

Table 2

QOF indicators for palliative care

Records

PC3: The practice has a complete register available of all patients in need of palliative care/support irrespective of age. **3 points**

Ongoing management

PC 2: The practice has regular (at least 3 monthly) multidisciplinary case review meetings where all patients on the palliative care register are discussed. **3 points**

especially true in the case of cancer. The hospital may have a role in palliation even while the patient receives the bulk of care at home, for example, patients with oesophageal or pancreatic cancer may be admitted to have a stent inserted to alleviate dysphagia or jaundice respectively, and lung cancer patients may visit hospital for palliative radiotherapy. Hospitals and GPs should keep each other informed of their involvement.

Specialist nurses

Macmillan nurses have specialist training in palliative care and, while they do not provide hands-on care, they are skilled in counselling, support and symptom control. Marie Curie is another charity that can be contacted via the district or community nurse. Previously focussed on just cancer care, they have diversified to provide broader palliative care and many PCTs have contracts with them. One particular advantage is that they can provide overnight nursing care.

Hospice teams

Hospice-based palliative care teams may also play a role. They are able to provide advice over the phone direct to patients who are being cared for at home or via the primary care team. Looking after a terminally ill patient is daunting for carers and even when home is the preferred place to die they must be reassured that an admission to a hospice or hospital can be arranged. Table 3, above, lists the common situations where terminal care at home is unsuitable.¹ However, many patients can still expect to spend a significant proportion of their final days at home even if death eventually occurs elsewhere.

Table 3

Situations where palliative care at home is unsuitable

- Patient does not wish to be at home
- Poor or absent carer support
- Carers cannot cope
- Distressing symptoms that cannot be managed, e.g. faecal incontinence
- Inadequate symptom control at home
- Acute emergencies, e.g. haematemesis, peritonitis

FACTORS INFLUENCING WHERE DEATH OCCURS

A large meta-analysis of death patterns has evaluated several key factors likely to determine where death occurs.⁸ Broadly speaking, these can be sub-divided into those relating to the illness, the individual and the environment.

Illness-related factors

Low functional status and a long illness were associated with death at home,⁸ whereas the presence of non-solid tumours (such as haematological malignancy) was associated with death in hospital.⁹

Individual factors

Favourable socio-economic conditions are associated with an increased likelihood of dying at home,¹⁰ as are an expressed preference for doing so,⁵ clinical support from nurses,¹¹ and congruity of opinion between patients, carers and clinicians.¹²

Environmental factors

Death at home is more likely to occur with intensive support at home, both from the family as well as clinicians.⁵ Patients living in rural areas are also more likely to die at home, though they find access to all healthcare more difficult. It is likely, however, that community-based care is relatively more accessible to them than hospital care.¹³

SYMPTOM CONTROL

The therapeutic options for the common symptoms in palliative care are discussed below. The list of symptoms is not exhaustive, and reference can be made to the section on prescribing in palliative care in the BNF.¹⁴

Table 1

Goals of the Gold Standards Framework

To provide high quality care for people in the final months of life in the community such that:

1. Symptoms are controlled as well as possible
2. Place of care: patients are able to live well and die well where they choose
3. Security and support: there is better advanced care planning and information, such that patients feel less fear, and have fewer crises/admissions to hospital
4. Carers are given support and information and feel empowered
5. Staff confidence, communication and working are improved

Table 4

Common misconceptions about the role of opiates

Opiates are often underused in terminally ill patients because of the following concerns:

They are addictive

Rarely a problem if taken for sound medical reasons as opposed to recreational use. Pain appears to act as a 'physiological antagonist' to addiction.

They cause respiratory suppression

True, but less so in the presence of pain and hardly relevant in the dying patient, where this may be beneficial.

They are only useful in cancer

No. Distressing symptoms in non-malignant illness, especially cardiorespiratory disease, end-stage renal failure and neurodegenerative disease may be helped by opiates despite relative lack of pain.

Pain

Analgesia is more effective when given regularly. Mild-to-moderate pain may be managed with paracetamol or mild opioids such as co-codamol or co-dydramol. Tramadol is a useful alternative. When pain is more severe, opiates should be used, and morphine is the mainstay. This can be initially given as an oral solution, typical starting doses are 10-20mg up to qds. It has the advantage of rapid onset. Furthermore, the daily consumption of oral morphine can be used to help calculate the optimal dose of the drug in tablet form. The oral solution can then be used as a top up for breakthrough pain. Morphine can also be used rectally as suppositories.

An alternative to morphine is fentanyl given as a transdermal patch which is changed every 72 hours. Individual patches have their strengths labelled by micrograms per hour (25, 50, 75 and 100); each '25' equates to around 90mg of morphine and oral morphine can be useful for breakthrough pain.

Opiates are the mainstay of analgesia in significant pain and their euphoriant effect and dissociation from distress make them useful in terminal non-malignant disease even if pain is not a key feature, for example, distressing dyspnoea in end-stage CCF or COPD. Reluctance to use opiates sufficiently is a frequent reason why patients are managed sub-optimally, and both patients and health professionals may harbour

misconceptions about this class of drug that ought to be dispelled. These are listed in table 4, left.

The following types of pain require specific management:¹⁵

● **Bone pain.** Bone is a frequent site for metastases, and NSAIDs may be helpful, e.g. diclofenac 50 mg up to tds, or ibuprofen 400mg tds

● **Neuropathic pain.** Neuropathic pain, for example in Pancoast's syndrome when lung cancer invades the brachial plexus, may be helped by a tricyclic antidepressant (e.g. amitriptyline) or gabapentin. Nerve blocks and transcutaneous electrical nerve stimulation (TENS) may have value for pain in localised areas.

● **Muscle spasm.** Diazepam or baclofen may be used.

● **Gastrointestinal pain.** Bowel colic caused by partial obstruction may be alleviated by loperamide or hyoscine hydrobromide; the latter may be given sublingually.

Nausea and vomiting

Both nausea and vomiting are extremely common in cancer, and may be due to the direct effects of the tumour or the side-effects of radiotherapy or drugs, particularly opiates. It is good practice to use antiemetics routinely for the first 5 days with opiates and thereafter on a prn basis dictated by the symptoms. Prochlorperazine up to 5mg tds, metoclopramide 10mg up to tds, haloperidol 1.5 mg od, or cyclizine 50 mg up to tds may be used.

Constipation

Opioid analgesia often causes constipation so patients should be offered regular laxatives. Lactulose, co-danthramer or senna are suitable options.

Breathlessness

This is a very common symptom as the potential causes are numerous and often co-exist: the patient may have terminal cardiorespiratory disease, a primary lung tumour or pulmonary metastases, or a contributory systemic problem such as anaemia. Simply moving air around, for example using a fan, helps subjectively despite defying scientific principles. Oxygen can be safely given at home as long as nobody in the household smokes in the vicinity of the cylinder, and if continuous use is required a concentrator is more suitable. The usual oxygen cylinder is size f (1,360 litres). For ambulant patients a

portable (size dd) cylinder may be used when they venture outdoors. Diazepam and dexamethasone may also be used to relieve anxiety, as can opiates even in the absence of pain.

Excessive respiratory secretion

Excessive respiratory secretion (the 'death rattle') is best managed with hyoscine hydrobromide given by sc injection at a dose of 400-600mg 4-8 hourly.

Restlessness and confusion

These symptoms may be caused by the direct effects of the tumour, medication side-effects or hypoxia. Haloperidol is a suitable choice but if more sedation is desirable chlorpromazine is preferable.

Insomnia

This may be treated with any recognised hypnotic such as temazepam; the risk of dependence is irrelevant in this clinical setting.

Pruritus

Itching is common, often caused by obstructive jaundice (e.g. in hepato-biliary disease) or uraemia (in end-stage renal failure) and emollients may help. Colestyramine can be useful and so can sedative antihistamines, e.g. promethazine.

Convulsions

This is a risk in patients with secondary tumours or uraemia. Standard anticonvulsants such as phenytoin, carbamazepine or sodium valproate usually suffice. When oral treatment is no longer feasible rectal diazepam or sc phenobarbital may be used. In raised intracranial pressure due to cerebral oedema dexamethasone at a dose of up to 16mg daily may be given.

Anorexia

Anorexia may be helped by corticosteroids e.g. prednisolone 15-30mg daily or dexamethasone 2-4 mg daily. The euphoriant side-effects of steroids may also improve the patient's mood.

Depression

Depression is common with any significant physical illness. Drug treatment should be offered as in any setting. Tricyclics, while generally less favoured than SSRIs may confer some advantages in terminally ill patients

key points

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Three-quarters of patients wish to die at home,

but less than a quarter currently do so. A concerted effort in primary care can increase the chances of a terminally ill patient fulfilling this wish. In my practice, a focus on developing an integrated nursing team whose members are all skilled in palliative care has led to an increase from 30% of patients who wished to dying at home a decade ago to a current figure of over 50%.

Good inter-professional liaison is essential.

Regular practice meetings to review patients should occur. Patient-held continuation cards in which all professionals involved can write notes are invaluable. Liaison between the primary care team, patient, relatives and carers, outside agencies and secondary care is essential to the success of domiciliary palliative care.

Practice nursing teams are pivotal in providing support

and care for patients. Macmillan nurses have specialist training in palliative care and, while they do not provide hands-on care, they are skilled in counselling, support and symptom control. Marie Curie have diversified to provide broader palliative care and many PCTs have contracts with them. One particular advantage is that they can provide overnight nursing care.

Analgesia is more effective when given regularly.

Common symptoms such as pain, nausea, vomiting, constipation and breathlessness can usually be managed with medication at home. Interventions such as home oxygen and the syringe driver are underused in primary care and, if applied more frequently, could lead to better symptom relief in the home setting.

Hospice-based palliative care teams may also play a role.

They are able to provide advice over the phone direct to patients who are being cared for at home or via the primary care team. Looking after a terminally ill patient is daunting for carers and even when home is the preferred place to die they must be reassured that an admission to a hospice or hospital can be arranged. Many patients can still expect to spend a significant proportion of their final days at home even if death eventually occurs elsewhere.

because of their sedative properties and beneficial effects in slowing nerve conduction. However, antimuscarinic effects such as dry mouth, visual blurring, constipation and urinary retention may exacerbate other common problems so the choice depends on individual circumstances.

NUTRITIONAL SUPPORT

Terminally ill patients are often malnourished, through a combination of the metabolic challenge of the disease leading to a catabolic state with negative nitrogen balance, and anorexia leading to reduced intake. Oral nutritional supplements, that provide a high calorific intake per unit volume, are available in several flavours.

OTHER MEDICAL PROBLEMS

Patients are likely to have other chronic illnesses that may be unrelated to their terminal illness, but may be modified by the latter. Whether or not medication is continued is a matter of clinical commonsense. For example, withdrawing thyroxine from a hypothyroid patient would be unhelpful, while stopping a statin would be a welcome reduction in the medication burden of a dying patient.

THE SYRINGE DRIVER

The parenteral route for delivering medication becomes necessary when oral treatment is no longer feasible. In practice this happens because of nausea, vomiting, bowel obstruction, extreme weakness or when the comatose stage is reached. Diamorphine is the preferred analgesic because of its high solubility. It is also the most potent analgesic, with each mg approximately equivalent to 3mg of morphine. Nausea and vomiting may be managed by haloperidol or methotrimeprazine, both of which can also help sedate the patient although the benzodiazepine midazolam may be necessary with significant distress. The latter is also suitable for treating convulsions.

CONCLUSION

Three-quarters of people wish to die at home though currently only a quarter of deaths occur in this setting. Primary care has the potential to deliver high-quality domiciliary palliative care that could potentially increase the proportion of the

population realising their wish. The main tenets to successful management are close liaison between the patient, their carers and other agencies, and effective use of the therapeutic armamentarium for symptomatic relief.

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Useful information

Macmillan Cancer Support
020 7840 7840
www.macmillan.org.uk

Marie Curie Cancer Care
Marie Curie now provides palliative care for all terminally ill patients not just those with cancer. The website has a section for healthcare professionals.
www.mariecurie.org.uk