



module 261

Community pharmacy and palliative care

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module 261

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Community pharmacy and palliative care

GOALS AND LEARNING OBJECTIVES

This module aims to provide a greater understanding of palliative care and discuss the role community pharmacy can play in this field. It explains the differences between palliative and end-of-life care, and the importance of local networks and treatment pathways for patients and their carers. You will also learn how to identify ways to support patients and carers, and how to develop a support plan in your locality.

KEY FACTS

Nearly 500,000 people in England need palliative care services every year but around a fifth don't receive them

The General Medical Council defines end-of-life care as care for people "approaching the end of life" and likely to die within the ensuing 12 months

People's wishes are not being addressed with end-of-life care, with around 58 per cent of patients dying in hospital when most prefer to die at home

A multidisciplinary team is required to meet the needs of patients in palliative and end-of-life care and to provide personalised co-ordinated care

Approximately 50 per cent of people with cancer experience anxiety and depression around the time of diagnosis and 10 per cent of people in the year following diagnosis have symptoms that require specialist intervention by psychiatric or psychology services

Effective communication is associated with increased levels of satisfaction for patients and may improve clinical outcomes

The needs of individuals requiring palliative and end-of-life care must be treated with both dignity and respect

Boots currently has 2,000 Macmillan information pharmacists providing both clinical and non-clinical support

Introduction & module overview

Around 457,000 people in England require palliative care services every year, but one in five have to go without. Early diagnosis and improvements in treatment are enabling more patients to live for longer after they have been diagnosed with serious illnesses. One result of this is that, by 2030, the number of people living with cancer, for example, is predicted to double and reach 4 million.

People who require palliative and end-of-life care need access to services and support to improve their quality of life. Their families and carers will also have needs. However, commissioning inconsistencies across the country mean that some individuals will have poor or no access to the health and social care services that would address these needs.

Community pharmacies are well placed to provide support. Traditional services, such as supplying medicines and advice to patients, are essential, as is helping to alleviate patients' symptoms, while offering non-clinical advice and signposting or referring where necessary are also invaluable. It is fundamental that community pharmacy is part of any local multidisciplinary team of healthcare, social care and third sector support to ensure patients' needs are met towards the end of life.

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Palliative and end-of-life care

Use of the terms 'palliative care' and 'end-of-life care' can often get muddled. It is important to understand the differences between the two terms so pharmacists can better support patients in these situations.

Palliative care refers to people who are living with a terminal illness where there is no cure, but it can also be used for people who have a complex illness and require their symptoms to be controlled.

NICE defines palliative care as "the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments".

Palliative care includes caring for people who are nearing the end of life. The General Medical Council defines end-of-life care as care for people are likely to die within the next 12 months. This includes people whose death is imminent and those with:

- Progressive, advanced and incurable conditions
- Co-existing conditions with risk of fragility, which means they are expected to die within 12 months
- Existing conditions where a sudden acute crisis in their condition could occur, which results in a risk of dying
- Acute conditions that are life-threatening and caused by sudden catastrophic events.

Any palliative care provided within the last 12 months of life is regarded as end-of-life care but, in some cases, the time frame can be difficult to predict. End-of-life care is an important part of palliative care for those nearing the end of their life as it aims to help them live as well as possible and to die with dignity. Many people receive high quality care, but a considerable number do not. Patients' wishes are sometimes not taken into account, which could be for a number of reasons. For example, around 74 per cent of people would prefer to die at home – but 58 per cent are actually dying in hospital.

Addressing a patient's needs and changing the setting for care at the end of life ultimately provides a substantial cost saving (65 per cent) – money which could be redeployed to provide further services.

Aims of palliative care

Palliative care will improve quality of life for the patient and everyone affected by their illness because it will:

- Treat or manage pain and any other presenting physical symptoms
- Incorporate both the psychological and spiritual aspects of care
- Affirm life and regard dying as a normal process, intending neither to hasten nor postpone death
- Involve a team of people who support the needs of the patient and their family to help them live as actively as possible, cope during the illness and in bereavement.

The National Palliative and End of Life Care Partnership's 'Ambitions for palliative and end of life care: a national framework for action in 2015-20' encompasses the Department of Health's strategy and the NHS Five Year Forward View. The framework sets out the following six ambitions to make the vision of specialist level palliative care a reality:

- Each person is seen as an individual
- Each person gets fair access to services
- Comfort and wellbeing is maximised
- Care is co-ordinated
- All staff are prepared to care
- Each community is prepared to help.

For these to become achievable, the foundations of education and training, evidence and information, 24/7 access, shared records, personalised care planning, service co-design, leadership, supporting/involving family and carers are important.

A multidisciplinary team is required to meet the needs of the end-of-life patient. Depending on the location, a palliative care team can comprise many individuals (see Table 1). Palliative care can be defined as either general and specialist.

Many charities have a role to play in palliative care including Macmillan and Marie Curie (see boxes overleaf). Both are registered charitable organisations providing care and support to people with terminal illnesses and their families.



Table 1: Types of palliative care and who is involved

	General palliative care	Specialist palliative care
Team involved	Non-specialists in palliative care include: <ul style="list-style-type: none"> • GPs • Community nurses • Community pharmacists • Social workers and benefits advisers • Care workers • Spiritual care professionals 	Specialist teams include: <ul style="list-style-type: none"> • Palliative medicine physicians • Palliative care specialist nurses such as Macmillan and/or Marie Curie nurses • Palliative care pharmacists • Specialist social workers • Specialist allied health professionals, such as physiotherapists, occupational therapists, dieticians and social workers • Counsellors and therapists
What the team should do	Aim to meet the needs of a person and their family within the limits of their knowledge and competence. They must seek specialist advice or refer the patient to specialist services when necessary	Manage more complex patient care problems that cannot be dealt with by generalist services. Palliative care specialists usually work in teams to provide joined-up care
Aims of care	<ul style="list-style-type: none"> • Information for the person and their family/carers through signposting • Holistic assessment of a person's needs • Co-ordination of care teams at all times including out-of-hours • Provide basic levels of symptom control • Support the addressing of psychological, social, spiritual and practical needs • Sensitive but open communication with all parties 	<ul style="list-style-type: none"> • Provide assessment, advice and care for people with palliative care needs including advanced cancer in all locations • Provide specialist in-patient facilities including hospice beds for people with complex problems that cannot be managed adequately in other settings • Bereavement support services
Setting	Normally in the community	Care may be provided in community, hospice and hospital settings by statutory and/or voluntary organisations

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Focus on: Macmillan**Macmillan provides:**

- Nurses who offer support and information to people with cancer and their families. This is usually advice to the primary care team regarding medicines to treat symptoms such as pain, nausea and vomiting. Self-referral by the patient or their family can occur so they get direct access to the Macmillan nursing team
- Support for other healthcare professionals including pharmacists
- Information and support from diagnosis, through treatment and beyond
- Training courses, such as free courses, workshops and e-learning, for those affected and for others who want to learn more.

On the Macmillan website (macmillan.org.uk) there are resources ranging from news and updates to details of services to support health professionals.

How a patient is treated**Physical symptoms are assessed and managed**

The patient should be reviewed regularly to assess physical needs, including symptoms and treatment goals, and referred if necessary. Symptoms and the impact of symptoms could include issues with everyday life (e.g. sleep disturbances or hypercalcaemia resulting in vomiting). Prescribed medicines should be as simple as possible and there may be medication that is no longer required (e.g. statins).

Assessing and managing psychological needs

Doctors will regularly assess an individual's psychological needs to ensure he or she is coping well. Where the patient or the family/carers have significant levels of psychological distress, prompt referral to specialist psychological care services could be considered through their GP. Where a patient or their carer is distressed while in the pharmacy, for example, they should be offered a place that is quiet, comfortable and private to talk or gather their thoughts.

The following should be considered when talking to individuals or carers:

- Approximately 50 per cent of people with cancer experience anxiety and depression around the time of diagnosis that will normally adversely affect their quality of life
- In the year following diagnosis, 10 per cent of people have symptoms that require specialist intervention by psychiatric or psychology services
- About 50 per cent of people with advanced disease experience anxiety and depression
- Psychological symptoms are often not recognised, so services may not be offered
- Health and social care professionals often lack appropriate assessment skills and may underestimate the benefits of psychological support.

Assessing social needs

Healthcare professionals must assess a patient's needs regularly as some people find it difficult to ask for help. Social care includes emotional support, help with

bathing and dressing, housework and shopping, practical aids such as wheelchairs, caring for dependents and advice on work and/or employment issues.

There may be financial benefits that the person or their carers are eligible for or respite or day care may be needed. Local authorities, the NHS and voluntary organisations provide support – so find out what is available in your locality.

Assessing religious or spiritual needs

Multidisciplinary teams should have access to appropriate spiritual care-givers and should also be aware of local community resources for spiritual care. Spiritual need relates to a person's search for meaning within his or her life, whereas religion is a means of expressing underlying spirituality.

Addressing needs of family and carers

Family members and carers may require support to address specific concerns, fears and anxieties. Ensure that family members and carers are made aware of local sources of information, advice and support to address their own needs. People of different ethnic backgrounds or cultures may have specific preferences regarding family involvement.

Effective communication

Communicating effectively is associated with increased levels of satisfaction for patients and may also improve clinical outcomes. Being sensitive, honest and empathetic with a patient and their family/carers should help these individuals with the difficult and complex decisions they need to make at this emotional time in their lives.

Communication with professionals within a multidisciplinary team and other service providers caring for the person is also key to ensure true integration and continuity of care. Effective communication is necessary and enables professionals to exchange information, plan interventions and share responsibility for the person's care.

It is important that the person and their family/carers have all the information they need so they can be involved in any decision-making. Both written and verbal information is useful for some patients and may be needed at different stages. The patient should have a care plan that is referenced, reviewed and updated regularly to document key issues and preferences, hopes and wishes.

Evidence-based techniques for communicating effectively with patients and family/carers include using:

- Open ended questions and 'wish' statements
- Verbal and non-verbal expressions of empathy
- Praise and asking the individual's permission to discuss certain topics
- 'Hope for the best' phraseology to align with hopes and wishes.

The care of the individual by health and social care professionals should be based on locally agreed protocols and guidelines, delivered within the context of a managed system or pathway.

What can community pharmacists offer?

The needs of individuals must be addressed and patients empowered to tailor their own journey, with education and information supporting them in their decision-making. Community pharmacy teams are at the forefront of healthcare and can provide a great support mechanism, both for the individuals affected and the wider multidisciplinary team caring for them.

It is important to be mindful of the needs of patients and their family/carers at this emotional time. Offering a repeat prescription collection and delivery service may be all that is required by some individuals, as they might have accessibility issues and want to be with their loved ones for as much of the time as possible.

**Reflection exercise 1**

When providing advice to a patient who has recently been diagnosed with cancer, consider the following:

- **Where should the advice be given and what sort of support could you offer?**
- **Who would you signpost to for advice on matters such as finance, counselling and local support networks?**
- **How would you phrase your advice?**

**Next month's CPD module...**

Schizophrenia: management in primary care and developments in practice

Learning scenario 1

Sally Potter, who is 28 years old, asks to speak to you, so you take her into the consultation room. She tells you that her grandmother has just been given a diagnosis of terminal cancer. The family are distraught and don't know what to do. She wants to take control of the situation as she already cares for her mother, who has COPD. She knows she will need to care for her grandmother as her father works and her mother is reliant on her.

What advice would you offer Sally?

- Tell her that it is very difficult for a granddaughter to be involved and she should give her father some information leaflets
- Suggest Sally brings her grandmother and her parents to the pharmacy so you can discuss next steps
- Signpost Sally to one of the voluntary organisations as they have lots of support and can even pay home visits to look after her grandmother
- Listen to Sally's concerns showing empathy and sensitivity at this emotional time. Provide information about the condition, local care pathways, charities and local organisations and the numbers of key contacts

Offering a medicines use review or a conversation about their medicines is a good way of ensuring the patient is taking his/her medicines correctly. Pharmacists can play an active role in discussions that:

- Address the patient's understanding of what the medicine is for and how it should be used, as well as any issues or concerns
- Provide sufficient information that is totally dependent on the wishes of the patient
- Support patients, their family/carers with medicines or other areas that require support.

Following the review it may be apparent that the patient needs, say, a monitored dosage system to help them with their medicine-taking and allay fears regarding the timings of the dosage schedule. Patients should also be reminded that the pharmacy can dispose of unwanted medicines and that emergency supplies of certain medicines can be obtained without the need for a prescription.

Focus on: Marie Curie

Marie Curie Cancer Care provides:

- Nurses who care for terminally ill people and give them the choice of dying at home supported by their families. They provide 24-hour hands-on care at home. To access one of the nursing team for this free-of-charge service, a patient should be referred to their GP or district nurse
 - Support with financial matters such as benefits and entitlements, everyday money matters and sorting out tax
 - Advice on how to live with a terminal illness, how to cope with feelings and how to talk about their diagnosis with family and friends
 - Advice on caring for someone with a terminal illness, getting support, day-to-day caring and preparing for the end of life
 - Information for bereaved family and friends, including coping with grief, practical/legal/financial matters and organising a funeral.
- On the Marie Curie website (mariecurie.org.uk) there is a section for healthcare professionals in addition to a palliative care knowledge zone.

Learning scenario 2

Rob Jones, a 68-year-old retired gentleman, has recently seen the palliative care team with his wife and been told she is now receiving end-of-life care. He is tired and emotionally drained and finds his wife's medication confusing at times due to caring for her throughout the day and night.

What advice would you offer Mr Jones?

- Inform him that he can contact Marie Curie directly, who will arrange for a nurse to care for his wife through the day or night
- Tell him to book a holiday as his wife can go into a hospice for a while
- Address the issues he is having with the medicines and provide practical support or aids to help him. Refer him to the palliative care team to address the care plan and suggest considering some respite care
- Try and encourage him to get a family member or carer to take over giving his wife her medicines

▶ Answers on page vi



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This module is also online at pharmacymagazine.co.uk



It is important that family and carers understand the importance of keeping healthy themselves so they can care for the individual concerned. Flu vaccination services or health screening (e.g. NHS health checks) may be advisable and are easily accessible within a community pharmacy setting.

Community pharmacy palliative care services

There are many examples of services being commissioned from community pharmacy to address some of the medication aspects of palliative care in their locality. Such a service would normally provide access to a specified list of the most frequently needed palliative care medicines, which can be supplied during normal pharmacy hours and out-of-hours on a rota arrangement. The aim of such services is to improve patient access to palliative care medicines in order to stop any delay in administration, which may cause harm or even lead to hospital admission.

The service also gives community pharmacies the opportunity to provide information and advice to patients and families/carers and to refer to specialist centres, support groups or other health and social care professionals where appropriate.

Some areas have introduced 'just in case' boxes, which are available from community pharmacies to address anticipatory prescribing. These boxes contain a small supply of prescribed medicines commonly required for relief of symptoms in the last few days of life and are kept in the patient's home. The community pharmacist will assemble these boxes according to the patient's needs.

Working together

Macmillan is supporting a palliative care service offered by 71 pharmacies within the Greater Glasgow and Clyde area. The pharmacies not only stock specific core medicines, but also provide advice and useful contact numbers and support other pharmacies within their localities. NHS 24 can arrange the dispensing of out-of-hours urgent prescriptions from participating pharmacies.

This Community Pharmacy Palliative Care Network has a resource folder, endorsed by the RPS, which contains all the information needed to support pharmacists and individuals. It is available to all pharmacies within the area and details palliative care guidelines, contact numbers, information on specialist medicines, plus other information for patients and carers.

Answers: learning scenario 1

- Tell her that it is very difficult for a granddaughter to be involved and she should give her father some information leaflets**
INCORRECT. All family members can be involved with care where the patient is in agreement. Empowerment with information will help with decision-making
- Suggest Sally brings her grandmother and her parents to the pharmacy so you can discuss next steps**
INCORRECT. Unless you have much experience in this area and are fully integrated as one of the multidisciplinary team, this may not be the best option
- Signpost Sally to one of the voluntary organisations as they have lots of support and can even pay home visits to look after her grandmother**
INCORRECT. Although charities can provide care locally, this in isolation will not fully support the needs of the patient
- Listen to Sally's concerns showing empathy and sensitivity at this emotional time. Provide information about the condition, local care pathways, charities and local organisations and the numbers of key contacts**
CORRECT. Understanding the support available locally and the relevant care pathways is essential for best care of this patient

Reflection exercise 2

Working in collaboration to provide support for patients receiving palliative care can benefit the patient and promote the benefits of community pharmacy. To do this consider:

- Identifying the stakeholders involved in the provision of palliative care in your locality
- Understanding the local treatment pathways and support networks
- How you can integrate with these networks to support the patient.

Information pharmacists

Macmillan funds specialist pharmacists, who work as part of multidisciplinary teams to improve the experiences and outcomes of people affected by cancer. Services include addressing polypharmacy and any issues patients have with their prescribed medicines (e.g. adherence, side-effects or contraindications).

The service provides not only multiple access points for support but also links into local services such as support groups, bereavement and financial advice services, and other referral points where necessary.

Boots Macmillan information pharmacists (BMIP) have received extra training to support the needs of people affected by cancer. Being part of their local Macmillan team, these pharmacists provide both clinical and non-clinical support to cancer patients. Boots UK currently has around 2,000 BMIPs, supported by 300 Boots Macmillan beauty advisers, who are trained to advise patients on caring for their skin, hair and nails during cancer treatment.

Conclusion

Although there might seem to be a lack of commissioning opportunities for pharmacists to support local palliative care pathways, the sector should take the lead in helping to set up projects with engaged commissioners and voluntary organisations to drive the patient agenda forward in this area. Integration across care settings and being part of a multidisciplinary team is crucial to community pharmacy in palliative and end-of-life care, highlighting its true benefits and utilising the skills and knowledge of this dynamic workforce.

Answers: learning scenario 2

- Inform Mr Jones that he can contact Marie Curie directly who will arrange for a nurse to care for his wife through the day or night**
INCORRECT. Mr Jones can be offered this service but it needs to be accessed through the GP or district nurse
- Tell Mr Jones to book a holiday as his wife can go into a hospice for a while**
INCORRECT. This may be a really insensitive thing to say. He might need some time out and needs to look after himself but must be supported in his decision-making, ensuring his wife is cared for too
- Address the issues Mr Jones is having with the medicines and provide practical support or aids to help him. Refer him to the palliative care team to address the care plan and suggest considering some respite care**
CORRECT. The needs of the carer need to be addressed as much as the patient and a holistic view should be adopted
- Try and encourage him to get a family member or carer to take over giving his wife her medicines**
INCORRECT. If he normally copes, practical support or aids may be helpful. He should, however, consider asking for additional support if needed



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