

Continuing care
for the dying
at home

Out-of-hours palliative care in the community

Dr Keri Thomas
March 2001

Macmillan 
cancer relief

..... *a voice for life*

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Published by Macmillan Cancer Relief

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Registered charity no. 261017

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Foreword

Macmillan Cancer Relief has made an enormous contribution to the provision of specialist cancer care. I am pleased to be associated with this report and the awareness it raises of the need to support people at their most vulnerable – when they are seriously ill.

The Department of Health's *Out of Hours Review* (October 2000) detailed the many deficiencies in existing care for patients outside normal working hours in England, and made more than 20 recommendations. Macmillan Cancer Relief's own report on out-of-hours care relates a number of the deficiencies identified by the Department of Health's report to the specific needs of cancer patients throughout the UK. Even more significantly, it provides practical

guidelines for UK healthcare professionals to ensure patients' wishes regarding their care are always respected, day or night.

This report demonstrates Macmillan Cancer Relief's particular expertise, as a widely recognised and respected cancer care charity, in linking healthcare agencies. It will make a vital and practical contribution to the existing body of knowledge.

A handwritten signature in dark ink, reading 'Mike Richards'.

Professor Mike Richards, CBE

National Cancer Director

Preface

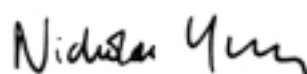
This report, prepared for Macmillan Cancer Relief by Dr Keri Thomas, Macmillan GP Advisor for the Northern region and a Macmillan GP Facilitator working in Calderdale and Kirklees, has grown out of concerns about the unequal availability of 24-hour palliative care cover for people affected by cancer. The report is based on the experiences of many.

The report builds on the *NHS Cancer Plan for England*, launched in September 2000, and also the Department of Health's own review of out-of-hours cover, published in October 2000.

The aim of the report is to suggest ways in which colleagues in the statutory and voluntary sectors might best work together to improve

out-of-hours palliative care for cancer patients. It is intended as a framework for action, with emphasis on practical examples that have been shown to work.

We hope that you will find the report useful, and that it will help to improve outcomes and the quality of life for cancer patients and their carers throughout the UK.



Sir Nicholas Young

Chief Executive

Macmillan Cancer Relief

Executive summary

Background

- Macmillan Cancer Relief has published this report following a wide consultation with commissioners and providers of out-of-hours palliative care along with patient and carer representatives and other specialist agencies.
- It has been produced in response to consistent feedback, particularly from Macmillan GP Facilitators, that out-of-hours care for dying or seriously ill patients in the community is at times inadequate.

Scope and aims of the report

The scope of this report is limited to out-of-hours palliative care services in the community. It aims to

- Summarise the way out-of-hours palliative care is currently delivered
- Demonstrate the need for better out-of-hours palliative care and highlight the inconsistencies in its current provision
- Make recommendations for improving practice in out-of-hours palliative care provision
- Give examples of good practice in out-of-hours care in the community.

The report is aimed at all those responsible for influencing, commissioning and/or providing out-of-hours palliative care services in the community.

Main findings and recommendations

Service provision

- Some palliative care patients in the community are suffering due to an unco-ordinated approach to care provision which has led to inequity of access to generalist and specialist palliative care and gaps in provision of palliative care, especially out-of-hours.
- Improved patient quality of life, carer satisfaction and fewer hospital admissions would follow if provision were better planned and organised at both a strategic and operational level.

Communication

- Communication between those caring for patients during working hours and those working out of hours is often inadequate.
- Transfer of patient information and care to those covering the out-of-hours period is vital to ensure continuity of care.

Patient and carer support

- Adequate support for carers, or provision of full community support where there is no carer, is essential for those patients who wish to remain at home until death.
- Carer education is essential. Healthcare professionals should also involve carers as equal members of the team caring for the patient at home.
- Support can be provided by a combination of statutory, private and voluntary providers but it needs to be proactive and available 24 hours a day to help prevent carer breakdown.

- Palliative care patients' needs can generally be established in advance, which should enable out-of-hours care to be delivered speedily and efficiently through direct referral to the appropriate service that can meet their needs.

Medical support and advice

- There is evidence that symptom control is not always adequately managed by GPs out-of-hours
- Medical advice from a specialist in palliative care may not be readily available locally out-of-hours, which can lead to the patient's symptoms worsening especially over a weekend.

Drugs and equipment

- There are often problems with the ready availability of drugs, particularly controlled drugs due to current regulations, and equipment out-of-hours, which can result in delays in symptom control.

Recommendation 1 Service provision

All commissioners and providers should develop, in collaboration, policies and standards for provision of out-of-hours palliative care, based on local needs assessment, for their seriously ill/dying patients in the community.

These policies, standards and systems should

- be reflected in local plans/strategies (e.g. health improvement programmes), audited by a named local group (e.g. out-of-hours Provider, PCG/T), and assessed as part of the cancer network assessment programme
- also apply to nursing homes and private hospitals. Particular attention should be given to addressing their needs and ensuring a transparently high standard of care in these institutions.

Recommendation 2 Communication

All members of the primary health care team involved in delivering palliative care, in and out of hours, should develop co-ordinated policies to ensure and improve information transfer within and between organisations. Effective information transfer could be facilitated by, for example, a handover form, patient-held records or electronic records.

Recommendation 3 Patient and carer support

Adequate co-ordinated patient and carer support, involving all sectors, should be provided 24 hours a day with patients, carers and on-call services being able to access services via a single telephone call e.g. to NHS Direct. NHS Direct should be able to easily identify calls from palliative care patients and pass them directly to service providers who can meet their needs.

A fully integrated out-of-hours service should be planned by all PCG/Ts as part of their intermediate care provision, possibly co-financed by the statutory (health authorities and social services) and voluntary sectors. This support should include

- 24-hour district nursing provision
- other co-ordinated community support such as Marie Curie Nurses
- a Rapid Response Team to manage crisis situations out of hours.

Recommendation 4

Medical support and advice

The primary health care team and out-of-hours providers should be adequately resourced to ensure that relevant personnel are trained in general palliative care and have access to guidelines and other resources.

24-hour access, by telephone, to an appropriate named provider of specialist palliative care should be readily available.

Recommendation 5

Drugs and equipment

A re-examination of current regulations regarding storage and transportation of controlled drugs is required, along with the development of a national policy which enables out of hours care providers to store and access them easily.

In the absence of patients receiving the medication and equipment they need at the time of consultation (which is the ideal recommended in the Department of Health Review of GP Out-of-Hours Services), a standard should be developed to ensure patients receive prescribed drugs or equipment within 2 hours of the doctor recommending their use.

All doctors and nurses providing care out of hours should have guidance on how to access and use drugs out of hours.

Conclusions

A good palliative care service, in and out of hours, includes

- Good anticipatory care and proactive planning by the primary health care team
- Efficient transfer of information to and from those working in hours and those working out of hours
- Appropriate advice, information and support to patients and their carers from health professionals, who are well informed about their condition, medication and future management needs
- Quick responses to requests for help, with information being passed on to relevant colleagues and revisits initiated when necessary
- Carer support in the form of 24-hour availability of district nurses and access to night-sitters etc
- High quality symptom control with access to specialist palliative care advice when needed
- Easy availability of appropriate drugs and equipment without the need for the carer to leave the patient
- Easy access to and good co-ordination of the provision available, so that all palliative care patients have equity of access to services.

Introduction

This report has been researched and published by Macmillan Cancer Relief in response to consistent feedback, particularly from Macmillan GP Facilitators, that out-of-hours care in the community for palliative care patients is often inadequate. It follows

- a consultation exercise held in April-May 2000, during which views on out-of-hours palliative care services (problems, solutions and examples of good practice) were received from over 50 individuals representing a range of professions and organisations.
- a Palliative Care Forum held in June 2000, attended by representatives from the National Association of GP Co-operatives (NAGPC), Healthcall (the leading deputising service), NHS Direct, Marie Curie, National Council for Hospice and Specialist Palliative Care Services (NCHSPCS), specialist palliative care consultants, Macmillan GP Facilitators/Advisers, district nurses, and a patient/carer representative.
- Further consultation with specialist agencies including the Royal Pharmaceutical Society of Great Britain, the Home Office Drugs Inspectorate, members of the Association of Palliative Medicine and the Out-of-Hours Review Implementation Group.

(See Appendix 4 for list of contributors).

Out-of-hours palliative care in the community is becoming increasingly recognised as an important service in the management of patients at home. Many healthcare professionals feel that palliative care patients (those with cancer or any end-stage illness), are not receiving the best standard of care during the 75% of the week outside normal working hours.

Not only is this report important, it is also extremely timely as it follows a range of relevant Government policy initiatives including the

- NHS Plan (England and Wales, July 2000), and the Scottish NHS Plan (December 2000), which focus on investment in NHS structures and standards
- NHS National Cancer Plan in England and Wales (September 2000), which confirms the need to address out-of-hours palliative care provision. (The Scottish Cancer Plan is due end March 2001)
- Independent review of GP out-of-hours services in England commissioned by the Department of Health (October 2000), which makes 22 recommendations for action by providers of general out-of-hours care and specifically mentions the needs of palliative care patients.

Note

This report is relevant to England, Scotland, Northern Ireland and Wales. Where the term

- Health Authority is used, this includes Health Boards in Scotland
- Primary Care Groups/Trusts (PCGs/Ts) is used this includes Local Health Care Groups (LHCGs) for Wales and Local Healthcare Co-operatives (LHCCs) for Scotland.

Scope and aims of the report

The scope of this report is limited to out-of-hours palliative care services in the community. It provides an analysis of current out-of-hours palliative care provision by summarising the way out-of-hours palliative care is currently delivered, and demonstrating the need for improvements by highlighting the inconsistencies in its current provision. It also makes recommendations for improving out-of-hours palliative care provision and gives examples of good practice, sources

and templates to enable out-of-hours providers and others to develop their own out-of-hours cover in line with the recommendation of this report.

This report is aimed at all those responsible for influencing, commissioning and/or providing out-of-hours palliative care services in the community including health authorities, PCG/Ts, acute trusts, community hospitals, GP co-ops and deputising services.

Current provision

A number of trends have contributed to the often inadequate out-of-hours palliative care provided today. They include

- radical changes in general practice out-of-hours cover over the past 20 years
- changing demographic profiles and expectations of society
- increasing numbers and complexity of palliative care patients
- best-intentioned, but rather uneven, developments in palliative care services across the country.

In addition, poor communication and lack of access to specialist palliative care advice have led to many patients who have wished to remain at home being institutionalised.

The size of the problem

A typical GP (average list size 2000) is likely to see about nine patients with a new diagnosis of cancer per year, and 5-6 patients dying of cancer per year. The average cancer patients:GP ratio (point prevalence) at any one time is estimated to be 30-40 cancer patients per GP. Various estimates have been made about rates of referrals of dying patients (those with cancer and other end-stage illness) to specialist palliative care services. However, it is acknowledged that about 33% of patients die under the care of the PHCT, with about 90% of the final year of life being spent at home. The demand for specialist palliative care is rapidly increasing, with more and more referrals of patients with unresolved problems as a result of

end-stage illnesses. Specialist palliative care units are therefore unable to manage all patients with palliative care needs, the majority being managed by the PHCT, supported by specialist advice when needed.

Recent mapping exercises have revealed great variations in local provision of specialist palliative care services. Some rationalisation is planned as a part of the Supportive Care Strategy (due to be published Q2 2001), which is a part of the NHS National Cancer Plan.

Services provided

During hours (Monday to Friday 9am-5pm) patients may receive help from a number of sources

- their GP and DN
- a Macmillan or other specialist palliative care nursing and medical team
- the local hospice (may have specialist community palliative care team and medical cover)
- Marie Curie services
- their local hospital and A&E department
- specialist tertiary care (e.g. from a Cancer Centre)
- social services or other social care organisations
- a range of other local resources available (e.g. a Rapid Response Team, a Carers Scheme)
- NHS Direct (on-line or by phone).

Out of hours, patients' support is dramatically reduced. They may be able to contact

- their GP (more likely a doctors co-op or deputising service)
- a DN (if 24-hour cover provided)
- Marie Curie services (at restricted times)
- NHS Direct
- A&E Department
- a hospital ward or hospice if known.
- a Carers Scheme or Rapid Response Team in some areas

These lists not only highlight the reduced level of services available out of hours but also, in the absence of good communication, the scope for confusion that exists given the range of people and organisations that can become involved in palliative care provision.

Organisation of GP out-of-hours service delivery

The demand for and delivery of out-of-hours primary care has changed radically over the past 10 years. In the late 1960s a GP, with an average list size, could expect to be called out at night once every six weeks. By the mid-1990s, they could expect to be called out at night once a week. As a result, this form of 24-hour access to the GP has become rare within the past decade. The use of deputising services and GP co-operatives (co-ops) is now widespread which, although positive in terms of providing significant benefits to doctors and their families, improvements in GPs' health status and halting the decline in GP recruitment, has had a negative impact on continuity of patient care.

Since 1992 the number of GP co-ops across the UK has grown from 30 to almost 300. About two-thirds of all GPs use a co-op to look after their patients out of hours. Most of these co-ops are members of the National Association of GP Co-operatives (NAGPC). The vast majority of remaining GPs use a deputising service, such as Healthcall, which is the country's biggest deputising agency (covering up to 18 million people each night).

Other changes in primary care which may have a negative impact on continuity of care, include the advent of NHS Direct, NHS Direct On-line and NHS Walk-in Centres. In the past, the GP was the main point of entry to the health service, but by 2004 it is likely to be NHS Direct. Patients now have more choices, which they may feel afford them quicker and more convenient access to help, and are more important than seeing a doctor they know. The drawbacks, however, include potential

confusion, lack of continuity and variability in quality of care. With these changes, the greatest challenges appear to be in caring for those who are terminally ill and those with mental health problems. This makes co-ordination and quality assurance of services along with accessibility of information, support and drugs more important than ever, in the provision of care for those with life-threatening illness at home.

The needs of patients

Many studies confirm that most people would prefer to die at home, yet in the UK only about a quarter of cancer patients do so, with about half dying in hospital and the remainder dying in a hospice or nursing home. The paradox of terminal illness and people's desire to die at home is that

- most dying people would prefer to remain at home, but the majority die in institutions
- the majority of the final year of life is spent at home but most people are admitted to hospital to die.

The main reason for hospital, hospice or nursing home admission is a combination of carer breakdown, inadequate symptom control and poor communication. There is also evidence that the provision of good care at home is most difficult to achieve for patients who are

- socially/economically deprived
- elderly
- experiencing poor symptom control
- unable to access 24-hour support
- female
- suffering from a chronic illness with an ill-defined terminal stage.

However, the two most important factors on which homecare or inpatient admission depend, appear to be the

- presence, or otherwise of carers who are adequately informed and supported by the PHCT, and
- length of time spent at home or in hospital/hospice before death. Increasing periods of hospitalisation towards the end of life are more likely to lead to an inpatient death.

Home provides familiarity, security, autonomy and reminders of life, which, for many, provide an element of hope and some control over dying. To offer a real choice and enable all cancer patients to stay at home if they wish, will require – in many places – better out-of-hours services and improved continuity of care which in turn will help to prevent crisis admissions. It has been estimated that, with only a limited increase in community care, 50% more cancer patients could be supported to die at home. An estimated 22% of hospital-bed days are taken up by people in the last year of life, but inpatient care is appropriate only for those with more complex problems.

With an increasing trend towards intervention and better treatment, leading to more 'chronic' cancer management, community care can impact greatly on secondary care. Improving care in the community, including out-of-hours care, is not only good for patients but will also reduce the burden on hospitals.

Problems and recommendations

Service provision

GP co-ops/deputising services care for the vast majority of patients in the community out-of-hours. Palliative care patients experiencing difficulties out-of-hours may therefore be visited by a number of different doctors who

- are unfamiliar with their case
- often have limited knowledge of how to deal with different palliative care situations
- have difficulty accessing drugs required.

These visits from strangers can result in patients or carers painfully repeating their story and moving from one course of treatment to another with poor symptom control, leading to

- a need for crisis management with hospice/hospital-based palliative care specialist input
- lack of trust and confidence in primary care, resulting in increasing dependence on specialists whose focus of care is inevitably more commonly hospice/hospital-based rather than home-based.

Hospice/hospital-based specialists in palliative care undoubtedly provide an outstanding service but they are often over-stretched. Many consultants are permanently on call for community patients, to manage the crises that arise as a result of the gaps in service provision and lack of expertise available in primary care.

If palliative care were better delivered and co-ordinated in the community, many crises could be prevented. This would reduce the demand for specialist palliative care provided by hospice/hospital-based staff and enable them to target their efforts towards patients most in need.

Proactive care planning and carer support, along with community-based specialist palliative care,

can help keep patients at home. For this to happen, co-ordination of existing health, social, voluntary and private sector services in the community needs to be improved. Specialist palliative care teams, including those working from hospices funded through charitable donations, could then be used more effectively rather than to plug gaps in general medical and other community health service provision. Those providing services (including the private sector), also need to ensure that the services are properly co-ordinated and developed

- according to identified needs
- with easy access, preferably through one central number e.g. NHS Direct
- in a standardised way across all sectors and in all settings.

Recommendation 1

All commissioners and providers should develop, in collaboration, policies and standards for provision of out-of-hours palliative care, based on local needs assessment, for their seriously ill/dying patients in the community.

These policies, standards and systems should

- be reflected in local plans/strategies (e.g. health improvement programmes), audited by a named local group (e.g. out-of-hours provider, PCG/T), and assessed as part of the cancer network assessment programme
- also apply to nursing homes and private hospitals. Particular attention should be given to addressing their needs and ensuring a transparently high standard of care in these institutions.

Communication

Excellent communication between healthcare professionals and the patient and their carers is essential if important and relevant information is to be passed on to all those involved in palliative care delivery both in and out-of-hours. Few GPs report routinely handing over information on their palliative care patients, particularly to GP co-ops and deputising services. There is also a lack of co-ordination between the PHCT, GPs, GP co-ops and NHS Direct. This leads to care which is often not comprehensive, may be disjointed and leaves the patient, their carer and members of the PHCT confused.

To minimise the risk of confusion and unsatisfactory outcomes of care

- The PHCT should provide the out-of-hours service with relevant information about their palliative care patients including their diagnosis, treatment, management plan (including proactive care) and any particular wishes such as preferred place of death. This information should be regularly updated and available to any visiting out-of-hours care provider. It may help prevent cases being referred to the coroner
- Information about a patient should be easily accessed by and transferred between members of staff within an out-of-hours care provider. There should be a system which enables revisiting, when necessary, which is initiated by the visiting doctor and not dependent on a new call to the out-of-hours service by the patient or carer
- PHCTs should receive updated information about any patients visited by the out-of-hours service, on the next working day
- There should be good co-ordination and transfer of information within practice teams and a checklist of whom to notify after a patient's death
- There needs to be a regular and reliable system of transferring information to any specialist palliative care services involved

- Clear information, both written and verbal should be given to patients and carers. Specific advice on whom to contact and what to do in an emergency should always be given.

Patient example 1

Mr Wilson, a 68 year-old ex-miner with cancer of the lung, expressed a fear of hospitals and the wish to remain at home until he's "carried out in his coffin". He rapidly deteriorated, with increasing breathlessness, weight loss and anxiety and his wife was becoming exhausted and frightened. One Saturday, he coughed up a large amount of blood. The deputising doctor who visited had no knowledge or information about the family. In view of the severity of symptoms and high anxiety, he offered admission, and reluctantly Mr Wilson was taken to the local hospice (which unusually had a vacant bed). He died within 8 hours of admission. Mrs Wilson felt the burden of guilt as well as that of grief and asked the hospice staff whether more could have been done to have kept him at home. They also asked themselves that question.

Recommendation 2

All members of the PCG/Ts and out-of-hours providers involved in delivering palliative care, in and out of hours, should develop co-ordinated policies to ensure and improve information transfer within and between organisations. Effective information transfer could be facilitated by, for example, a handover form, patient-held records or electronic records.

Patient and carer support

For patients who wish to remain at home until death, adequate education and support for carers (or provision of full community support where there is no carer) from healthcare professionals who are well informed about their patient's condition, medication and future needs is essential. Carers are key members of the team caring for the patient at home and must be seen by healthcare professionals as equal team members when planning patient care and management.

However, the physical and emotional demands placed on carers and their need for support must not be underestimated. Preventing carer breakdown is as important as pro-active patient management and support, if patients are to remain at home. Support may be provided by a combination of statutory, private and voluntary providers, but it must be easily accessible, available 24-hours a day for all patients with any end-stage illness and offer a range of health and social services. The DoH-commissioned review of GP services out of hours in England identifies that the needs of palliative care patients can be established in advance. This means that these patients could be appropriately identified on the NHS Direct database so that should they call NHS Direct out of hours, they can be passed directly on to the services that will meet their needs most effectively and efficiently, or advised appropriately.

Patient Example 2

Joan was terrified at the thought of Rodney coming home from the hospice, but felt she had to try to comply with Rodney's wishes to be at home. She received excellent support from her GP & DN, who reassured her that they would be available at the end of the phone, and that if she felt she couldn't cope, more help could be offered. She had a night-sitter once, but usually one of her teenage children sat up through the night with Rodney. After he'd died very peacefully at home, she felt so relieved that she'd been

able to care for him at home that she wondered why she'd ever felt so terrified. Mainly it was a fear of the unknown and of not being able to cope, but with reassurance, information, practical support and the knowledge that help was available if needed together they'd been able to fulfil Rodney's wishes to remain at home for the last two weeks of his life.

Recommendation 3

Adequate co-ordinated patient and carer support, involving all sectors, should be provided 24 hours a day with patients, carers and on-call services being able to access services via a single telephone call e.g. to NHS Direct. NHS Direct should be able to easily identify calls from palliative care patients and pass them directly to service providers who can meet their needs.

Fully integrated out-of-hours services should be planned by all PCG/Ts as part of their intermediate care provision, possibly co-financed by the statutory (health authorities and social services) and voluntary sectors. This support should include:

- 24-hour district nursing provision
- other co-ordinated community support (such as Marie Curie nurses and Carers Schemes)
- a rapid response team to manage crisis situations out-of-hours.

Medical support and advice

Availability of specialist palliative care advice is an essential element of delivering successful palliative care in the community. In any given year, a GP only cares for a small number of palliative care patients, which means that they are often unfamiliar with the most effective treatments available and how to deliver them, leading to inadequate symptom control. Many GPs are also reluctant to ask for advice, particularly as specialist palliative care advice is often not easily available out of hours.

Poor symptom control, for even a short time, can result in crisis hospital/hospice admissions leading to patients and their carers losing confidence in community-based care and the PHCT's ability to manage their complex range of problems. This can make it difficult to discharge a patient back home. It is untrue that symptom control can only be adequately managed in specialist palliative care inpatient units; many 'hospice-at-home' services appear to have reached out successfully from specialist units into the community. However, there is still a need for greater integration of services between primary and secondary/specialist care if specialist palliative care and advice is to be easily accessible by all GPs and patients 24 hours a day. Access to specialist palliative care advice organised at a national level (e.g. via NHS Direct) might be a reasonable alternative to local provision for those in more rural areas.

Education and training of healthcare professionals in palliative care is also important to enable the PHCT to effectively and proactively manage palliative care patients.

Patient Example 3: Mr Bearder

An 84-year-old man with disseminated cancer was readmitted to the local private hospital under the care of a consultant surgeon. Despite increasing doses of diamorphine he remained in severe pain. The staff nurse sought palliative care advice from the local hospices but was unable to get

beyond the Bank Nurse on duty. Problems were compounded by the hospital running out of diamorphine, the patient's friend having to obtain some on the Sunday from a local chemist, while Mr Bearder was still severely agitated and in pain and his family were becoming very distressed. On the Monday morning, after four days of severe pain, the Macmillan nurse came and adjusted his medication, and he settled. He died that night. The charitable trust fund he had founded donated funds to provide palliative care bags and crisis packs to help prevent such a situation recurring.

Recommendation 4

The PHCT and out-of-hours providers should be adequately resourced to ensure that relevant personnel are trained in general palliative care and have access to guidelines and other resources.

24-hour access, by telephone, to an appropriate named provider of specialist palliative care should be readily available.

Drugs and equipment

Members of the PHCT identify lack of pharmacy cover and accessing appropriate medication quickly out of hours as problems. This can be compounded by the following actions NOT being undertaken:

- GPs planning palliative care and pre-prescribing medication which may potentially be needed
- GPs being familiar with the type of drugs they may require and how best to use them
- On-call pharmacists having palliative care drugs available
- Adequate storage of controlled drugs by GP co-ops (with Home Office licence)
- Alternative arrangements to avoid nurses transporting controlled drugs, except in exceptional circumstances (see UKCC guidelines).

Palliative care patients' conditions can deteriorate or change rapidly, requiring urgent treatment and drug intervention if crises are to be avoided. It is important, therefore, that all healthcare professionals involved with palliative care, in and out of hours, have easy access to drugs, including controlled drugs, and a good understanding of which drugs to use and how to prescribe them to best effect.

Anticipating the patient's needs (including possible changes in dosage and drugs used) is essential. This will enable the GP to supply sufficient drugs, kept at the patient's home, to cover out-of-hours periods which will allow the on call doctor to administer drugs at the time of consultation. Drugs may also be prescribed on an 'as required basis', in accordance with local protocols and Local Medical Committee (LMC) agreement, allowing nurses to administer them if necessary. As well as leaving a supply of drugs in the patient's home, this type of approach can also be facilitated through provision of palliative care bags (e.g. Bearder bags), carried by on-call doctors, which contain the drugs that are

commonly required. However, the problems relating to storage of controlled drugs by GP co-ops and transportation by nurses need resolving.

A GP

"Now we have the Bearder bags, I know where to go when I need some buscopan for a patient at 2am and no chemists are open. Previously I would have had to leave the patient with a rattley chest until the next morning."

Recommendation 5

A re-examination of current regulations regarding storage and transportation of controlled drugs is required along with the development of a national policy which enables out-of-hours care providers to store and access them easily.

In the absence of patients receiving the medication and equipment they need at the time of consultation (the ideal recommended in the DoH review of GP out-of-hours services), a standard should be developed to ensure they receive prescribed drugs or equipment within two hours of the doctor recommending their use.

All doctors and nurses providing care out of hours should have guidance on how to access and use drugs out of hours.

Conclusions

Patient Example 4

David was a 49-year-old man with melanoma, who had a wife Sylvia, and four children at home. He refused hospice admission and had expressed the wish to remain at home as long as possible. He was rapidly deteriorating and his main problem was headache due to cerebral secondaries. His GP sent Healthcall a handover form detailing his diagnosis, medication and management plan.

A night-sitter came twice a week, to give the family a break. A mattress was supplied by the hospice and he was moved downstairs. One Saturday the supply of diamorphine ran out and the on-call doctor was able to access more via the on-call pharmacist. On the following Bank Holiday weekend the Rapid Response Team answered a crisis call for carer support from his wife (via the district nurse). On the Sunday his headache was worsening and the visiting doctor requested the advice of the palliative care consultant on-call at the local hospice. She suggested increasing the dexamethasone (a supply of which the GP had previously left in the home) and visited the family on the next working day.

David continued to remain at home surrounded by his family, quite lucid, with his symptoms controlled, until his death two weeks later. The family was grief stricken but had been able to fully participate in his care and felt that all his wishes had been fulfilled. Sylvia said, "It is a great comfort to me now and to the children to know that we had done everything we could to keep David at home with us, and that he died in peace and with dignity at home. I would encourage others to make every effort to keep their loved one at home, if that is their wish and if they can manage. We are very grateful that we received so much help."

Delivering a good out-of-hours palliative care service in the community is a complex task, which could be improved with strategic organisational planning. Co-ordinated, locally relevant and relatively simple changes in service delivery could have a considerable positive impact.

Improving out-of-hours services will not just benefit patients with palliative care needs. It will benefit all patients living in the community who are seriously ill, and provide them with a more realistic chance of remaining at home to die. Better carer education and support will mean that carers are more directly involved in patient care as a member of the homecare team, which can increase carer satisfaction and help them cope with bereavement.

Better palliative care through better anticipation of the patient's needs, better communication and better access to specialist palliative care in the community will ensure there are fewer crises, fewer inappropriate hospital/hospice admissions and more people dying where they choose – at home.

A good palliative care service, in and out of hours, includes

- Good anticipatory care and proactive planning by the PHCT
- Efficient transfer of information to and from those working in hours and those working out of hours
- Appropriate advice, information and support to patients and their carers from health professionals, who are well informed about their condition, medication and future management needs
- Quick responses to requests for help, with information being passed on to relevant colleagues and revisits initiated when necessary

- Carer support in the form of 24-hour availability of district nurses and access to night-sitters etc
- High quality symptom control with access to specialist palliative care advice when needed
- Easy availability of appropriate drugs and equipment without the need for the carer to leave the patient
- Easy access to and good co-ordination of the provision available, so that all palliative care patients have equity of access to services.

There will inevitably be resource implications for community teams which will need examining if improved out-of-hours palliative care is to become a reality, but increased investment in primary and community care will save costs to secondary care.

Next steps

This report reflects Macmillan's contribution and commitment to the NHS Cancer Plan. Macmillan Cancer Relief urges all relevant agencies to use this report to audit and improve their working practice in the delivery of out-of-hours palliative care by including

- All cancer networks, health authorities, PCG/Ts, local medical committees, specialist palliative care units
- The National Association of GP Co-operatives (NAGPC), individual doctors' co-operatives, Healthcall and other out-of-hours providers
- NHS Direct which should look at ways to handle palliative care patients, for example, through improved software algorithms, protocols for management.

Finally, we would urge various policy makers to take action. We support the recent DoH out-of-hours document which reviews the ways in

which care for terminally ill patients can be improved. In addition, we suggest the DoH undertakes

- a review of pharmaceutical regulations regarding storage, transport and dispensing of controlled drugs out of hours
- an assessment of the resource implications of improving community palliative care out of hours
- a review of out-of-hours palliative care provision in 2005 to evaluate progress made
- the development of collaborative agreements for palliative care provision with social services.

We would also suggest that the National Council for Hospice and Specialist Palliative Care Services include consideration of out-of-hours palliative care in the community as part of quality standards of care and performance indicators.

Appendix 1 Examples of good practice

This appendix details some examples of good practice that have been notified to the authors. It is not an exhaustive list. Many specialist palliative care services have developed protocols and guidelines for the management of palliative care patients in the community and it is recommended that in seeking this information the PHCT contacts the local hospice/inpatient unit or specialist in palliative care.

Educational programmes are also run from these units and it is important to use the training that is available for the whole team locally.

Some of these examples may not suit some geographical areas and local resources but it is to be hoped that some of these examples may be used by primary care teams, PCG/Ts, LHCCs, Health Authorities and out-of-hours providers, who are seeking to improve the service offered to palliative care patients in their areas.

The contact addresses and telephone numbers are as accurate as possible at the time of publication. All the examples mentioned have indicated that they are keen to share their expertise with others.

Examples of templates detailed here can only be useful if they are amended to contain locally relevant information on palliative care services available out of hours. There will be local variation (e.g. with drug choice), but discussing these suggestions with the local specialist palliative care service is highly recommended and will lead to greater consistency and continuity of care.

This section is subdivided into five sections to correspond with our recommendations

- Service provision
- Communication
- Patient and carer support
- Medical support
- Drugs and equipment

Corresponding examples and templates are included; the details of contacts and phone numbers quoted should be replaced by locally relevant information in all cases.

Service provision

Checklist for out-of-hours provision

The following checklist will help health authorities, co-operatives, deputising services, PCTs etc ensure that elements of a well-planned and co-ordinated service are in place.

1 Out-of-hours provision for palliative care

- ☐ Co-op
- ☐ Deputising service
- ☐ GP doing own on-call
- ☐ HA Palliative Care Steering Group/HImP
- ☐ Standards
- ☐ Extra resources
- ☐ Other (specify)

2 Communication

- ☐ Handover form/Infifax
- ☐ Patient-held record
- ☐ Electronic patient record
- ☐ Other (specify)

3 Patient/carer support

- ☐ 24-hour district nursing
- ☐ Adequate night-sitters
- ☐ Adequate respite provision
- ☐ Adequate carer support (e.g. carer scheme)
- ☐ Co-working with social services
- ☐ Written information given to patient/carers about contact numbers

- ☐ Written information given to patient/carers about possible symptoms
- ☐ Other (specify)

4 Medical support

- ☐ Access to 24-hour specialist palliative care advice from doctor
- ☐ Access to 24-hour specialist palliative care advice from nurse
- ☐ Guidelines/written advice in crisis pack available out-of-hours
- ☐ Training provided
- ☐ Other (specify)

5 Drugs & equipment

- ☐ Palliative care bags available
- ☐ On-call pharmacists
- ☐ Protocol for drugs left in patient's home
- ☐ Access to palliative care drugs out of hours (usually within 2 hrs of prescribing)
- ☐ Other arrangement (specify)

6 Co-ordination

- ☐ Central strategic planning of out-of-hours provisions
- ☐ Central contact phone numbers
- ☐ Access phone numbers distributed to GP/DNs and publicised
- ☐ Needs assessment/audit undertaken
- ☐ Other (specify)

Calderdale and Kirklees Health Authority out-of-hours protocol

Summary for all GPs and DNs

- **GPs/DNs to complete handover form** and GP to sign for ALL patients with palliative care needs and keep updated regularly. This includes post chemotherapy/radiotherapy, slowly deteriorating end-stage illness but particularly terminal phase patients. Ensure to date form and number (e.g. update no. 3).
- **Fax or send handover form** to PENDOC or Healthcall (numbers on handover form). If no fax, telephone details directly in hours and send form later. NB PENDOC and Healthcall would like to emphasise that faxing handover forms is much easier for them and that they will need faxed signed handover forms eventually for legal reasons. Please use the surgery fax machines and only phone for amendments or as a last resort.
- **Keep handover form in DN notes**/patient-held record in patient's home and/or keep copy in your notes – a copy may be useful for an admission. NHS Direct will be notified on receipt of form by PENDOC/Healthcall.
- **Drugs** - the main message is to think proactively about medication.
 - Supply enough to cover the out-of-hours period allowing for a dose range
 - *Doctor administration* deteriorating patients may need certain drugs not previously used (e.g. hyoscine for secretions, midazolam for agitation) and these should be left in the home. When the on-call doctor assesses the patient, these drugs would be available for use. (They are also in the Bearder bags, but this may be less accessible.)
 - *Nurse administration* of drugs left in the home, prescribed by a doctor with prior authorisation, occasionally occurs at the discretion of the PHCT. ("It is good practice for a visiting doctor to decide on the appropriateness of their use. For practical purposes, these drugs may have been left in the home and the decision to initiate use delegated to a nurse, with authorisation. This practice is left to the discretion of the individual PHCT, but is not recommended by the LMC." Statement by LMC)
- Possible drugs to leave in the home include midazolam, methotrimeprazine, hyoscine butylbromide, diamorphine, oral morphin, haloperidol (for doses/indications see crisis sheet or BNF)
- **Syringe drivers** – if a syringe driver is used from the Bearder bags out of hours, please replace it by the end of the next working day and PENDOC/Healthcall will collect it.
- **After a death**, please inform others (i.e. PENDOC/Healthcall, hospital, hospice, Macmillan nurses, PHCT etc).
- **Private hospitals and nursing homes** should be included in this protocol.
- **To reduce inappropriate hospital admissions** out of hours, consider the 4-point action plan.

Four-point action plan

1 Communication

- Fax the handover form to PENDOC/Healthcall – keep in DN notes/patient-held record and update regularly
- Who else needs to know about this patient e.g. hospice?
- Does the patient/carer know what to do in an emergency?

2 Carer support

- Co-ordinate pre-emptive carer support e.g. night-sitters, respite care
- Written information of anticipated problems and management for patients/carers
- Co-ordinate emergency support e.g. Rapid Response Team (crisis support sheet)

3 Medical support

- Write anticipated management plan on handover form for on-call doctor
- Use crisis packs (crisis symptom guidelines and drug advice) or A-Z Pocketbook of Symptom Control (by Dr P Kaye)
- Call hospice for specialist advice 24 hours

4 Drugs and equipment

- Leave anticipated drugs in the patient's home
- Bearder palliative care bags are kept in PENDOC cars and Healthcall bases, stocked with drugs, syringe driver and crisis pack
- On-call pharmacists, call Healthcall 01484 512211

DNs contact PENDOC directly on 01484 541130/482256 rather than via NHS Direct

Patients and carers can contact PENDOC directly on 01484 482256

NAGPC Guidelines for Excellent Palliative Care within Out-of-Hours Co-operatives

(Developed at Workshop June 99)

*Contact Logie Kelman, Manager,
NAGPC, Regency House, 90-92 Otley Road,
Leeds LS6 4BA*

Tel 0113 278 2381

Fax 0113 278 3674

Website www.nagpc.org.uk

Email manager@nagpc.org.uk

General

Many co-ops have procedures in place for the delivery of care for 'special needs' patients. The out-of-hours movement has received some negative reports of there being little evidence that procedures are in place for the care of the terminally ill.

Aim

The aim of this paper is to give guidance to co-ops to aid in development of local guidelines for the delivery of care to patients requiring palliative care.

There are five areas of importance for excellent palliative care but firstly, each co-op should nominate an interested GP or group of GPs to be responsible for setting up procedures and monitoring them.

Protocols for Care

Co-ops should make sure that members are agreed on how to handle calls for the terminally ill. This should include

- Clear policy on which professional deals initially with the call – e.g. GP, DN or Macmillan nurse.
- Larger co-ops may be able to introduce a dedicated palliative care rapid response team.
- Symptom control protocols – some regions have guidelines for symptom control - these

could be adopted by the co-op and placed in each doctor's bag.

- A list of drugs to be carried should be agreed. Suggested drugs include diamorphine, Oramorph (standard strength and strong), haloperidol, cyclizine, methotrimeprazine, metoclopramide, midazolam, hyoscine hydrochloride and butylbromide, diazepam enema, micralax enema.
- Equipment: syringe drivers need to be available, either held by the co-op or easily obtainable for patients e.g. from DN, hospice etc.

NB Audit and education – Co-ops cannot rely on protocols being adhered to; they need to be audited. Palliative care provides a good setting to demonstrate a commitment to good practice and clinical governance! Educational events on palliative care could be arranged between the co-op, local hospice and post-graduate centre. Subjects could include how to set up a syringe driver; symptom control issues; dealing with emergencies.

Communication

A robust system should be developed for communication.

From GP to co-op concerning all terminally ill patients.

- Many co-ops have found dedicated fax forms to be useful (*see example on page 22*). Information should include name, address and age of patient.
- Name of main carer (and contact number)
- Primary diagnosis
- Secondary spread (complications)
- Present treatment
- Suggested further treatment
- Expected prognosis
- Whether individual GP is available (and contact number)
- District nurse involved

- Whether night-sitter available
- Ward/unit/consultant involved
- Whether and where bed is available in emergency
- It is useful to flag information on computer so that receptionists can notify the GP/nurse taking the call that information regarding the patient is available
- There should be a system (person) for keeping information up to date e.g. monthly housekeeping of the file where fax sheets are stored
- Co-ops could encourage local cancer/palliative care services to adopt patient held records, however these cannot replace direct GP to co-op communication.

Within the co-op, to encourage continuity of care e.g. make previous contact details available if contact occurs again especially within a few days.

From co-op to GP the next morning/after weekend. It is suggested that this should happen for all contacts with the terminally ill or their carers.

Community nursing teams and specialist services

The co-op should have close links with these services, to encourage a multidisciplinary approach.

- Joint protocols need to be developed e.g. DNs can request and expect visit from GP within 1 hour of calling the co-op
- Individual members need to know how to gain access to DN and to be encouraged to discuss individual patients with the DN on call
- Co-ops need to encourage local community trusts to provide 24-hour/7-day DN and night-sitting services
- Co-op should have discussions with local, specialist palliative care providers concerning access to inpatient beds and specialist advice out of hours.

Storage of controlled drugs

Many co-ops have supplies at base. The law on this, however, is complex and far from clear. Immediate access to drugs is needed 24 hours a day, 7 days a week for palliative care. Other solutions include

- Agreement with local chemist to be 'on call' and to stock range of controlled drugs
- Agreement with local hospice/hospital pharmacy to supply drugs to the co-op as needed
- NAGPC and GPC (General Practice Committee) should campaign to change rules on supply and storage of controlled drugs.

Appraisal of practices

Examples include

North West Regional NHS Executive together with Macmillan is running a three-year project to define and disseminate standards for PHCTs in cancer care throughout the patient's journey, including out-of-hours palliative care.

*Contact: Mike Brown,
Regional Management Advisor
Tel 0161 705 3916 or 01925 704000*

Measham Medical Unit has also developed similar key standards across the cancer journey.

*Contact: Drs Orest Mulka and Pawan Randev,
Macmillan GP Facilitators
Tel 01530 270667
Email mmu@tesco.net*

Cardiff GP Co-operative (CADOC) Protocol

A system to ensure that any essential information is available – i.e. all practices fax or phone relevant information to the treatment centre, which then enters the information onto the computer. When the patient contacts CADOC, the records are retrieved with the special information message appearing automatically on the front page.

*Contact: Dr Trevor Thompson
Email elybridge@btconnect.com*

Communication

Direct contact with own GP

It is still common practice in many areas for a patient who is terminally ill or their carers to be given direct communication links with their own GP or DN, at the discretion of the health professional involved. This can be in the form of

- His/her own home number given directly to the patient or carer
- A 'second on call' system, whereby NHS Direct or the out-of-hours provider is alerted to pass the call directly to the GP/DN involved, but with a backstop if this person is unavailable.

In many rural and remote areas this may be the only method of delivering good palliative care out-of-hours. However, this situation is changing fast, and those providing their own on call service will have to maintain the same standards according to criteria laid down by the Department of Health Out of Hours Review Implementation Group, monitored by the PCTs. Also, to allow adequate protected time off, pressure should not be placed on the PHCTs to cover the out-of-hours periods personally.

Handover forms

Handover forms are a proven method of transmitting information from the PHCT to the out-of-hours provider for vulnerable patients (e.g. the terminally ill). They can be paper based or electronic, and there may in future be provision for them to be used and transmitted via NHS Direct. Handover forms can also be used by secondary services (i.e. hospitals or hospices) on the discharge of patients into the community, where, especially for Friday discharges, there may be subsequent out-of-hours problems.

The importance of handover forms cannot be too highly emphasised and can have a vital effect on the home death rate of a practice team because they

- transmit important information such as diagnosis, management plan and medication.
- build in proactive planning; the need for certain drugs (e.g. hyoscine or midazolam) is anticipated, the GP is prompted to prescribe and leave them in the home; or pre-emptive carer support can be booked in advance.

It is essential that the forms are updated regularly, especially before a long holiday, e.g. Bank holidays, Christmas and Easter. If they are updated every two weeks and signed by the GP they become useful additional information for the coroner, and can prevent a death becoming a coroner's case.

The process of their usage can be as follows

- DN completes form and GP checks and signs
- Handover form is faxed to the out-of-hours provider, and NHS Direct notified
- If the patient contacts the out-of-hours provider, the details are transmitted to the consulting doctor
- The original handover form should be placed in DN's notes or patient-held record in the patient's home
- Forms are updated, collected and audited by practices and the co-op.

Three examples of handover forms are

Calderdale & Kirklees Handover Form

(see page 20)

Huntingdon GP Co-operative Handover Form

(see page 21)

National Association of GP co-operatives Palliative Care Infobox

(see page 22)

PALLIATIVE CARE HANDOVER FORM

Information from GP/District Nurse to out-of-hours services for patients with palliative care needs

Please update regularly (Section C) NHS Direct should be notified by the Coop/Deputising Service

Please fax/send to your out of hours service eg Coop AND LEAVE A COPY WITH THE PATIENT.

Name: **PENDOC** Fax No: **(01484) 482169**

Name: **HEALTHCALL** Fax No: **Hudds (01484) 450816 Dews (01132) 424632**

Completed by: ☐ DN ☐ GP ☐ Other (specify) _____ GP Signature _____ DATE _____

GP Name _____

Patient consent to referral ☐

Where to send this form

GP/DN could complete the form, but GP must read and sign
Patient consent details should be checked

SECTION A - PATIENT DETAILS

Name of patient DOB

Address

..... Carer's name

Diagnosis & Date

Complicating conditions If Ca. site of 2nd

Current Hospital treatment eg chemo/RTT Insight

Palliative Care Service/Hospice involved

Hospital Unit/Consultant involved

District Nurse Visiting

Section A - patient details This overview only needs completing once with a brief summary of the condition and treatment

SECTION B - LOCAL DETAILS

Out-of-hours specialist advice from: Kirkwood Hospice (01484) 557900 Overgate Hospice (01422) 379151

Out-of-hours drugs available from: Bearder Bags or on call pharmacist (01484) 512211

Out-of-hours carer support available from: See Crisis Support Sheet

Section B - local details Some local details of whom to contact out-of-hours

SECTION C - UPDATE

DATE:

Current medication

Emergency drugs left in home where appropriate, eg in terminal stage: (name)

Syringe driver available from

Plan for weekend care, eg District Nurse visiting etc

Plan for anticipated problems, eg symptom control/carers support

.....

Before considering admission:-

Please contact GP/hospice/social support team/other (name)

or try

Other issues/further details

Section C - update This should be regularly updated and reviewed. Anticipate leave drugs in home where appropriate.

- 'Before considering admission' builds in proactive care
- GP could be 'second on call' and give phone no. here if they wish
- Other issues e.g. particular requests/? home death /allergies /patient-held record /advanced directive etc

For further information, contact Dr K Thomas, Macmillan GP Facilitator,
Calderdale & Kirklees Health Authority ☎ 01484-466027

updated 11/99

Huntingdon GP Co-operative
HANDOVER FORM FOR HUNTSDOC GPs

Huntsdoc Fax no: _____

1 Patient Name: _____ **Date of Birth:** _____

Address: _____

Phone Number: _____

2 Diagnosis: _____

3 Hospital team involved: _____

Treatment plan: _____ **Clinical details:** _____

Main medication: _____

Patient fully aware? Yes ☐ No ☐

Emergency drugs left at home: _____

4 Do you wish to be kept informed if the patient contacts Huntsdoc? Yes ☐ No ☐

If yes, how can Huntsdoc contact you? _____

5 Has the patient been told to contact Huntsdoc if necessary? Yes ☐ No ☐

Is a district nurse involved? Yes ☐ No ☐

Name of district nurse: _____

6 Please contact the local hospice/palliative care consultant on call via Hinchingsbrook Hospital for advice if needed

Date: _____ **Time:** _____

GP handing over: _____ **Practice:** _____

National Association of GP co-operatives

PALLIATIVE CARE INFOFAX

This information is confidential and must only be used by the co-operative

Patient details

Surname:

First Names:

Telephone Number:

Main carers Name:

Relationship:

Is patient aware of the diagnosis? **Y/N**

District/visiting nurse:

Specialist involved:

Patient's own GP

Practice Name:

Telephone Number:

Date of notification to co-op:

Do you wish to be contacted concerning care? **Y/N**

Patient's Medical Condition:

Diagnosis:

Complicating conditions:

Present treatment (e.g. undergoing chemotherapy):

Main medication (e.g. MST 60 mg bd etc.):

Details of emergency drugs in the home:

Syringe driver, if needed, available from:

Future treatment:

Any weekend/NH visiting plan (e.g. DN visiting on Saturday):

Respite bed? **Y/N** If Yes, where?

Before considering admission, please contact e.g. GP/XX

Hospital or try (e.g. increase medication):

Details on medication care/patient held records: **Y/N**

Any other comments or information relevant to continuity of care:

Senders name:

Signature: Date:

Patient-held records

These can be very effective for improving communication between professionals and patients. Cancer Networks/Supportive Care Networks are responsible for their development.

Examples include

Measham Medical Unit (Beacon Award for Cancer Services)

*Contact: Drs Orest Mulka and Pawan Randev,
Macmillan GP Facilitators
Tel 01530 270667
Email mmu@tesco.net*

Marie Curie Centre, Newcastle

Patient-held records have been piloted here, initiated by a Cancer Unit on behalf of the community trust. The pilot found the records to be of value to co-operatives out of hours.

*Contact: Drs Kath Mannix and Lindsay Crack
Tel 0191 256 5702
Email kmannix@newcastlecentre.mariecurie.org.uk*

Lisburn, Northern Ireland

Patient-held records were developed as part of a palliative care clinical project in a commissioning pilot.

*Contact: Dr Mark Palmer, Lisburn Health Centre,
Lisburn, N Ireland BT28 1LU
Tel 0289 2603088*

Advance Directives (Living Wills)

Although not legally binding, advance directives can be very valuable in decision making if the patient were unable to give verbal consent.

*Contact: Samantha Reddin,
Terrence Higgins Trust Lighthouse,
52-54 Grays Inn Road, London WC1X 8JU
Tel 020 7831 0330 (HIV and AIDS Charity)*

Patient and carer support

Homelink, Hartlepool Hospice

This service provides night-sitters and social and nursing care

- DN refers patient to service (but remains key worker)
- supplements existing services 24 hours a day on short-term basis
- service reviewed every two weeks.

A volunteer befriender service is also available to provide respite for carers during the day.

*Contact: Homelink Co-ordinator,
Hartlepool and District Hospice,
13 Hutton Avenue, Hartlepool TS26 9PW
Tel 01429 288993*

Rapid Response Teams (generic)

There are many examples of generic rapid response teams with the remit to provide patient or carer support in the patient's home during a crisis.

The team can help avoid hospital admission and support discharge for patients who are medically suitable for care in the community and have been assessed by the district nurses/liaison nurses (district nurses working in acute sector).

The services are accessible 24 hours a day, 7 days a week and are delivered by generic support workers who provide social, nursing and domestic care. Care is normally available for up to 5 days but can be extended.

The team works in close liaison with social services, housing departments, mobile alarm/warden services, physiotherapy, specialist palliative care services and occupational therapy.

Examples include

Newcastle Rapid Response Team

Originated as an adult medical service, which has developed and expanded to cover a wider patient population, including palliative care for cancer and non-cancer patients. Now funded by the Health Authority.

*Contact: Anne Giblin,
Intermediary Care Development Co-ordinator,
2nd Floor, Physio Block, Newcastle General
Hospital, Westgate NE5 4LP
Tel 0191 256 3033*

Kirklees Rapid Response Team, Huddersfield & Dewsbury

Joint funded by the Health Authority and Local Authority to facilitate discharge from hospital (or

A&E Dept) and prevent inappropriate hospital admissions.

*Contact: Pam Ward, The Homestead, Hurst
Knowle, Almondbury, Huddersfield HD5 8SG
Tel 01484 347865*

Rapid Response Teams (for palliative care patients)

Example

Rapid Response Team, Inverness

Teams of nurses from the local hospice can provide palliative care in a patient's home at short notice. There is obviously a limit to distance from the hospice, and time that they can be involved (usually 48 hours). This service has enabled some patients to either go home to die from the hospice or hospital and has prevented some admissions.

*Contact: Highland Hospice, Ness House,
1 Bishop's Road, Inverness IV3 5SB
Tel 01463 243132
Email highlandhospice@cali.co.uk*

Carer Support Services

Example

Calderdale and Kirklees HA (see pages 25 and 26)



CRISIS SUPPORT

To prevent admission and to enable patients to remain at home if they and their carers wish there are 4 important factors:

1. Communication
2. Carer support
3. Medical support - advice from doctors and nurses
4. Drug and equipment availability

1. Communication

- 1.1 Use the *Handover Form*, which has patient's details and ideas for proactive care (copy should be in District Nurse notes and with Coop/Healthcall)
- 1.2 Use *Patient Held Record* if available
- 1.3 Make sure the patient and carers *understand* what you tell them and know what might happen and where to go for help
- 1.4 *Inform* anyone else who needs to know ie DN, GP, deputising colleagues, Macmillan Nurses, hospice etc

2. SEE OVERLEAF

3. Medical Support

Use CRISIS SYMPTOM sheets, A-Z pocketbook, YCO symptom management book or other guidelines

Specialist Palliative Care Advice

24 hour telephone medical/nursing advice is available in matters relating to specialist palliative care from the on-call doctor/nurse at the hospices: Telephone:

Kirkwood Hospice 01484-557900

Overgate Hospice 01422-379151

Please **DO** use this service as an advice line if you run into any problems - a doctor/nurse is on call at all times and are more than happy to be of help.

4. Drugs and Equipment

- (i) **PALLIATIVE CARE DRUGS** - available in *Bearder Palliative Care Bags*. Drugs include, parenteral cyclizine, diamorphine, haloperidol, hyoscine, methotrimeprazine, metoclopramide, midazolam, diclofenac dexamethasone and rectal diazepam.

OR For list of *Out of Hours on-call pharmacists* call Healthcall on 01484-512211 or contact your local pharmacist.

- (ii) **EQUIPMENT** (commode, nebulisers etc) access out of hours Huddersfield/Dewsbury : 01484-300712

Emergency store at Huddersfield Royal Infirmary via head porter (access through District Nurse)

Calderdale : Access through District Nurses or Emergency Duty Team

2. Carer Support Services

	HUDDERSFIELD	DEWSBURY	CALDERDALE
24 hour District Nursing	01484-344335 01484-344335 evenings	01924-512000 ext 3682 evenings 17.30 - 22.00 01924-512033 nights 22.00 - 8.00 Mob: 07720 463083	01484-347057 (from 19.6.00) Mob: 01422 363208
Rapid Response Team	01484-347865	01924-325660 - 8.00 - 22.00 07720-463041 - 22.00 - 8.00	N/A
Marie Curie Nurselink	0845 6000269	0845 6000269	0845 6000269
Crossroads/Calderdale Carers	01484-516049	01924-442760	01422-364455
GP Led Bed Scheme	01484-347865	GPs contact homes direct	N/A
Social Services - Emergency Duty Team	01924-326489	01924-326489	01422-365101
Home Nursing (home care/night sitters)	N/A	01924-464547	01422-321282
Others:			
Goldsborough	01484-400005	01924-360011	N/A
BUPA	N/A	01924-360011	N/A
Medicare	N/A	N/A	01422-254194
NHS DIRECT	0845-4647	0845-4647	0845-4647
PENDOC direct line for GPs/DNs	01484-541130	01484-541130	01484-541130
PENDOC direct line for patients	01484-342256	01484-342256	01484-342256

Medical support and advice

Many local specialist palliative care services have developed their own local guidelines, contact sheets and symptom control guides.

Examples include

Cambridge and Huntingdon Palliative Care Resource Folder

This has been developed by the Pharmaceutical Policies in Palliative Care Group, and is given to all GPs and DNs in Cambridge and Huntingdon areas. It gives up-to-date advice on symptom management with appropriate advice lines to specialists in palliative care. It is now available electronically.

*Contact: Palliative Care Secretary, Papworth Hospital, Papworth Everard, Cambridge CB3 8RE
Tel 01480 830541*

The Thorpe Hall Guide to Palliative Care

Sue Ryder Care, Thorpe Hall, Peterborough, provides guidance for local GPs, PHCTs and district hospital palliative care teams.

*Contact: Sue Ryder Care, Thorpe Hall, Longthorpe, Peterborough PE3 6LW
Tel 01733 330060*

St Nicholas' Hospice, Bury St Edmunds, Suffolk

The team has produced Clinical Guidelines and Guidelines and Policy for Syringe Drivers, which together provide medical support to teams delivering palliative care in the community.

*Contact: St Nicholas Hospice, Macmillan Way, Hardwick Lane, Bury St Edmunds, Suffolk, IP33 2QY
Tel 01284 766133*

Liverpool Care Pathway for the Dying Patient

This pathway has been developed in Liverpool to improve Palliative Care especially in the final 48 hours of life and has recently received an NHS Beacon Award. It has been adapted for use in hospitals, hospices and community primary care teams, including nursing homes; training is essential. Further details about the pathway, further education and training, are contained in the NHS Beacon Resource Handbook.

*Contact: Dr John Ellershaw, Medical Director, Marie Curie Centre, Speke Road, Woolton, Liverpool L25 8QA
Tel 0151 8011400
Email jellershaw@mariecurie.org.uk*

Symptom control sheets, Sefton Health Authority (see pages 28 & 29)

Palliative Care Packs, Calderdale & Kirklees Health Authority

These resource packs are given to each GP with local information, reference books (e.g. A-Z Pocketbook of Symptom Control by Dr Peter Kaye; Yorkshire Cancer Network symptom management book) and relevant leaflets.

*Contact: Dr Keri Thomas, Macmillan GP Facilitator, Calderdale & Kirklees Health Authority, St Lukes House, Crosland Moor, Huddersfield HD4 5RH
Tel 01484 466027
Email kerithomas@doctors.org.uk*

or

*Dr Mary Kiely, Consultant in Palliative Medicine, Huddersfield NHS Trust
Tel 01484 347005*

SPECIALIST PALLIATIVE CARE SERVICES

Sefton Macmillan Nurses
(referrals 9am - 5pm, Mon - Fri)
Church Street Clinic, Southport
Tel: 01704 547471 ext 3726
Thornton Clinic, Bretlands Road
Tel: 0151-932 0169

NB: There is no on-call service:
Contact District Nurses out of hours.

Queenscourt Hospice, Southport
Dr K Groves - Medical Director
Tel: 01704 544645

Aintree Hospitals Palliative Care Team
Dr G Corcoran - Macmillan Consultant in
Palliative Medicine
Tel: 0151-529 4396

**Liverpool Marie Curie Centre and
Royal Liverpool Hospital**
Dr J Eilershaw - Consultant in Palliative
Medicine
Tel: 0151-428 1395

For sitting services contact can be made with
Marie Curie Nursing Service or Crossroads: via
District Nurses.

FURTHER REFERENCES

Since September 1994 the BNF has included a
section on prescribing in Terminal Care. See
also Care of the Dying Document produced by
(ex) Mersey Regional Drug Information Service.

BEREAVEMENT

Has your surgery a policy for follow up?
Know your local groups.

5

SEFTON HEALTH

CARE OF THE DYING AT HOME

Successful care requires:

- adequate information for families and carers
- good communication between professionals

DISTRICT NURSE SERVICE AT NIGHT AND WEEKENDS

Southport & Formby: Tel: 01704 531978
(Mobile via Hospital Switchboard:
01704 547471)

South Sefton:

Nights (16.45 - 8.00am) Tel: 0151-949 0517
Daytime on Saturday, Sunday and
Bank Holidays:

Bootle Tel: 0151 933 7543
Litherland Tel: 0151-928 8255
Crosby Tel: 0151-931 2074
Liverpool Tel: 0151-486 3572

- Do the Deputising Service/Associate GP know about an expected death?
- Remember to carry the appropriate parenteral medication in your medical bag. (see page 6)

Do the family know who to contact in the event of death?

1

DOSE RANGE OF DRUGS COMMONLY USED IN CARE OF THE DYING

Diamorphine SC dose per day = 1/3 total oral
Morphine dose per day (see calculation page 4).
Use 2-4 hourly dose for breakthrough pain.

Cyclizine

stat: 50mg po/sc

regular: po - 25-50mg TDS.

sc - up to 150mg over 24 hours by
continuous infusion.

Haloperidol

stat: 1.5mg po/sc

regular: 1.5-10mg/24 hours either po or
continuous sc infusion.

Methotrimeprazine

stat: 25mg po/sc

regular: 25-150mg/24 hours either po or
continuous sc infusion.

Midazolam

stat: 5mg sc

regular: 10-60mg/24 hours by
continuous sc infusion.

Hyoscine Hydrobromide

stat: 400mcg sc

regular: 400-2400mcg/24 hours by
continuous sc infusion.

Hyoscine Butylbromide (Buscopan)

stat: 20mg po/sc 8 hourly

regular: 20-60mg/24 hours po/sc 8
hourly.

NOTE: Prochlorperazine, Chlorpromazine and Diazepam are
not suitable for use in syringe-drivers. (Consider use of rectal
Diazepam).

Available out of hours at Fazakerley A & E Dept. on
presentation of a prescription. Southport - all drugs stocked
by several local pharmacies, contact via police. In case of
difficulty contact on-call pharmacist at District General
Hospital.

NB: Unlicensed use of drugs is common in Palliative Care.
There is a wide experience of usage in hospices and
specialist palliative care services.

MILESTONES PRINT SERVICES 0151-529 3937

(M&G 6297)

6

<p>MEDICATION FOR COMMON SYMPTOMS IN THE DYING PATIENT (see page 6 for dosages)</p> <p>PAIN Usually progress to strong opiates (ie. morphine or diamorphine) via analgesic ladder* Remember NSAIDs useful in bone pain, orally or rectally. Caution in impaired renal/liver function, lower dosage may be required. Clotting factors may be deranged in liver failure/metastases – risk of bleeding.</p> <p>COLIC Consider Hyoscine Butylbromide (Buscopan) with or without opiates.</p> <p>NAUSEA & VOMITING Regular anti-emetics eg. Cyclizine or Haloperidol.</p> <p>BREATHLESSNESS Consider opiates or benzodiazepines eg. Diazepam, Midazolam.</p> <p>ANXIETY & RESTLESSNESS Diazepam, Midazolam or opiates. Is the patient in urinary retention or constipated?</p> <p>AGITATED DELIRIUM Use sedative and antipsychotic drugs eg. Haloperidol, Methotrimeprazine.</p> <p>EXCESS CHEST SECRETIONS Use Hyoscine hydrobromide.</p> <p>PROCESS</p> <ol style="list-style-type: none">1. Review current medication.2. Anticipate need for other medication to be available.3. Consider route of administration.4. Ensure appropriate prescription chart is complete. <p>*Care of the Dying document.</p>	<p>ANALGESIA</p> <ul style="list-style-type: none">• Use immediate release Morphine to titrate dosage against pain.• When pain controlled convert to Slow Release Morphine tablets regularly every 12 hours.• Consider Slow Release Morphine Suspension if unable to swallow tablets.• Use immediate release Morphine tablets or liquid for breakthrough and incident pain. <p>Is the pain sensitive to Morphine?</p> <p>Consider seeking specialist advice regarding use of adjunct drugs for pain control, eg. steroids, anticonvulsants, antispasmodics, bisphosphonates, non-drug interventions.</p> <p>INDICATIONS FOR USING A SYRINGE-DRIVER</p> <ol style="list-style-type: none">1. Altered conscious level in dying patient2. Persistent nausea and vomiting eg. bowel obstruction.3. Inability to swallow oral medication. <p>NB: If syringe driver has stopped (eg. battery failure) and the patient is in pain, consider giving a stat dose as well as recommencing the syringe driver.</p> <p>For evenings and weekends: Syringe-drivers are available via local District Nursing Services or Fazakerley A & E Department.</p>	<p>CONVERSION OF ORAL MORPHINE TO SUBCUTANEOUS DIAMORPHINE</p> <p>Calculate the total daily dose of regular morphine and prn morphine taken over 24 hours.</p> <p>Divide total daily dose by 3 to give subcutaneous diamorphine dose over 24 hours via syringe-driver.</p> <p>eg. MST 60mg bd & Oramorph 10mg x 3 doses = 150mg/day</p> <p>Total daily dose oral morphine = 150mg</p> <table><tr><td>3</td><td>3</td></tr></table> <p>= 50mg/24 hours SC diamorphine</p> <p>REMEMBER POTENTIALLY REVERSIBLE CAUSES OF DISTRESS</p> <ul style="list-style-type: none">• Constipation• Retention of urine• Infection• Hypercalcaemia• Gastric dilatation• Fear <p>DISPOSAL OF DRUGS</p> <p>All unused drugs should be returned to a pharmacy for disposal.</p>	3	3
3	3			

2

3

4

Crisis Packs, Calderdale and Kirklees Health Authority (see pages 31 and 32)

These packs comprise a Crisis Support sheet and a Crisis Symptom sheet and are a useful reference sheet for GPs to keep in their bags. They form part of their out-of-hours protocol.

Contact: Dr Keri Thomas, Macmillan GP Facilitator, Calderdale and Kirklees Health Authority, St Lukes House, Crosland Moor, Huddersfield HD4 5RH
Tel 01484 466027
Email kerithomas@doctors.org.uk

or

Dr Mary Kiely, Consultant in Palliative Medicine, Huddersfield NHS Trust
Tel 01484 347005

West Cumbria Hospice at Home

This service provides

- nursing care in patients' homes
- day-care facilities at Cockermouth and Whitehaven
- a lymphoedema service at West Cumberland Hospital
- GP advice and domiciliary visits available from the local specialist in palliative care.

Contact: West Cumbria Hospice at Home, Workington Infirmary, Infirmary Road, Workington CA14 2UN
Tel 01900 602244 ext 2025

Home Care and Carers Palliative Care, Southampton

This scheme works in close partnership with PHCT to provide support at any level from telephone advice through to specialist palliative care in the community. Resources include Palliative Care Guide and Handbook. This and other actions help achieve a home death rate approaching 50%.

Contact: Dr Richard Hillier, Consultant in Palliative Medicine, Countess Mountbatten House, Southampton University NHS Trust, West End, Southampton SO30 3JB
Tel 023 8047 7414
Fax 023 8047 3501
Email richard.hillier@suht.swest.nhs.uk

Out-of-hours Palliative Care District Nursing Service, Sunderland

Two nurses are available every night providing pain management, symptom control and support to patients and carers, enabling those in the terminal stages of illness to stay at home. This NHS Beacon Service is funded by Sunderland Health Authority.

Contact: Mrs Jackie Murray, Primary Care Manager, St Benedict's Hospice, Priority Health Care, Wearside, Newcastle Road, Sunderland SR5 1NB
Tel 0191 516 6300

Education, Training and Staff Development Project, Southampton

This project develops creative, relevant and sustainable education programmes for undergraduates and postgraduates of all professional backgrounds. They include

- GP/DN extended course in palliative care
- palliative care interest groups (ongoing, outreach meetings in the community)
- Countess Mountbatten House Teaching Network - staff development of all disciplines to increase teaching capacity in the community and elsewhere.

Contact: Dr Bee Wee, Countess Mountbatten House, Southampton University NHS Trust, West End, Southampton SO30 3JB
Tel 023 8047 7414
Fax 023 8047 3501
Email b.wee@suht.swest.nhs.uk



CRISIS SYMPTOM SHEET

Emergency symptom control

- Is the patient unable to swallow?) If yes to any of these parenteral
- Is the patient vomiting?) drugs will be necessary
- Is the patient semi/unconscious?) (SCI-subcutaneous infusion)

PAIN

ASSESSMENT

(A) Pain due to pre-existing factors, already opioid responsive:

- convert oral morphine sulphate to subcutaneous diamorphine at ratio of 3:1

REMEMBER breakthrough doses!

eg MST 60 mg bd + oramorph 20 mg prn x 3 = 180 mg morphine/24 hours

⇒ 60 mg diamorphine/24 hours SCI

REMEMBER to prescribe breakthrough doses equivalent to 1/6 of the 24 hour dose

Anti-emetics not routinely needed unless nauseated

(B) New pain—assess as normal clinical practice:

- Bony pain—consider NSAID: ketorolac 10-30 mg stat SC
ketorolac 60-90 mg/24 hours SCI
or diclofenac 100 mg pr

- Bowel colic/distension

- hyoscine butylbromide 20 mg stat SC
- hyoscine butylbromide 60-120 mg/24 hours SCI

- Liver capsule pain

- regular opioid 4 hourly by mouth or by SCI (low dose if opioid naive)
- consider NSAID
- consider steroid—dexamethasone 4-8 mg daily

NAUSEA & VOMITING

Parenteral drugs likely to be essential ie, SCI

ASSESSMENT

Drug history:

NSAIDs, opioids, antibiotics, chemotherapy

Large volume vomits: ? gastric outlet obstruction - large liver, gastric tumour

Constipation:

perform rectal examination - consider high level constipation

Intestinal obstruction:

distension is frequently absent, ask about colic
listen for obstructive bowel sounds obstruction may be only partial

Infection:

exclude UTI/RTI

Hypercalcaemia:

patient may be drowsy/constipated/thirsty
is active management appropriate?

Uraemia:

Features of ↑ICP: ? brain metastases

Radiotherapy:

especially if gut included in field

Anxiety may superimpose on any of the above

ANTI-EMETICS

Prokinetic: metoclopramide 10-20 mg stat SC,
60-90 mg/24 hours SCI
useful in outlet obstruction/partial obstruction
NB - if increased colic, discontinue

Antihistamines: cyclizine 25-50 mg stat SC 100-150 mg/24 hours SCI
useful in obstruction, movement related nausea and ↓ICP

Dopamine antagonists:

haloperidol 2.5-5 mg stat SC

5-10 mg/24 hours SCI

useful in "chemical nausea" (drugs, hypercalcaemia) and
also in obstruction

methotrimeprazine 12.5 - 25 mg stat SC
25 - 100 mg/24 hours SCI VERY sedative and hypotensive
at higher doses

ALL THE ABOVE ARE COMPATIBLE WITH DIAMORPHINE

k0848

Dr Mary Kiely, Huddersfield - Nov '99

<h1>CRISIS SYMPTOM SHEET</h1> <h2>AGITATION / RESTLESSNESS</h2> <p>May occur as a preterminal event (in final hours or days of life) 10% of agitated patients may require complete sedation</p>	<h1>DYSPNOEA</h1> <p>Subjective difficulty in breathing (different from tachypnoea or hyperventilation) associated with high levels of anxiety and fear</p>
<p>ASSESSMENT</p> <p>Consider treatable causes:</p> <ul style="list-style-type: none"> ■ urinary retention ■ faecal impaction ■ increased pain <p>Myoclonus/twitching: uraemia/hypertcalcaemia/opioid toxicity (active management of first two may be inappropriate in opioid toxicity may have pinpoint pupils also) Reduce opioids by 30–50% Midazolam 5 mg stat SC 20–100 mg/24 hours SCI Visual hallucinations: haloperidol 2.5–5 mg stat SC 5–10 mg/24 hours SCI</p> <p>“Death rattle”:</p> <ul style="list-style-type: none"> ■ reposition patient – head slightly down ■ hyoscine butylbromide 20 mg stat SC 60–90 mg/24 hours SCI ■ midazolam 20–50 mg/24 hours SCI <p>Spiritual needs: address as appropriate – patients may need permission from family “to let go”</p>	<p>ASSESSMENT</p> <p>Consider reversible causes:</p> <ul style="list-style-type: none"> ■ bronchopneumonia ■ anaemia ■ pleural effusion ■ heart failure/COPD ■ pulmonary emboli ■ SVCO <p>Treat reversible causes as appropriate to patient’s general condition</p> <p>PALLIATIVE MEASURES</p> <p>Opioids</p> <ul style="list-style-type: none"> - morphine sulphate prn, 5–10 mg if opioid naïve - increase analgesic dose by 30–50% if on regular opioid - no evidence that nebulised opioids better than systemic - consider diamorphine SCI (see conversion factors earlier) <p>Benzodiazepines</p> <ul style="list-style-type: none"> - diazepam 1–2 mg bd - lorazepam 0.5–1 mg prn - midazolam 2.5–5 mg prn SC, 5–10 mg/24 hours SCI <p>Nebulized saline prn</p> <p>Facial cooling/fan. Oxygen is of doubtful significance unless hypoxic</p> <p>Explanation, reassurance, and involving family and carers in simple relaxation techniques can all help</p>

Training for out-of-hours doctors

Example

Calderdale and Kirklees

Led by

- Dr Mary Kiely, Consultant Palliative Medicine, Huddersfield NHS Trust
- Dr Susan Salt, Consultant Palliative Medicine, Calderdale NHS Trust
- Dr Keri Thomas, Macmillan GP Facilitator, Calderdale and Kirklees HA
- Dr Mark Davies, GP and Medical Director of PENDOC

Training sessions include

- Overview of importance of out-of-hours palliative care, development of HA out-of-hours protocol and use of handover forms
- Emergencies in palliative care and crisis information pack
- Drugs in Bearder palliative care bags, their usage and syringe drivers
- Discussion of scenarios covering diagnosis and management options, preventing automatic admission and encouraging use of guidelines, crisis pack, and on-call specialist advice.

*Contact: Dr Keri Thomas,
Macmillan GP Facilitator, Calderdale and Kirklees
Health Authority, St Lukes House,
Crosland Moor, Huddersfield HD4 5RH
Tel 01484 466027
Email kerithomas@doctors.org.uk*

Warwick Integrated Service Directorate for Palliative Care

This brings all providers together in one forum, including NHS Specialist staff, GP and hospice representatives etc. The outcome is a unified service where a patient known to one doctor/nurse or the healthcare worker can get help and advice from any part of the service. Over time, equal access to care any time of day or night will be available for all patients, relatives and GPs.

*Contact: Dr Chantal Meystre
Tel 01926 419920
Fax 01926 492453
Email cn@isdcd.fsnet.co.uk*

Grampian Doctors On-call Co-operative

A recent audit to review the management of 38 individual palliative care patients at this co-op has shown that 65.8% of the patients were managed appropriately. As a result Dr David Carroll has been asked to develop guidelines for the management of a wide range of symptoms encountered in palliative care. Laminated copies will be sent to each co-op member and placed in drug bags, out-of-hours centres and GP co-op cars.

*Contact: Dr David Carroll, Roxburghe House,
Milltimber, Aberdeen AB13 0HR
Tel 01224 681818*

Drugs and equipment

see also *Appendix 2 – Provision of drugs*

It is essential that health professionals involved in out-of-hours palliative care can access drugs and equipment as needed. All doctors should have all the required drugs with them at the time of consultation. However, this is likely to require a change of current regulations, and so other provisional arrangements must be made. Different areas' arrangements are often dependent on the demography and geography of the area. Often, a combination of solutions (including handover forms, palliative care bags and on-call pharmacists) can help address out-of-hours cover.

Examples include

Handover forms

The use of handover forms leads to improved anticipation of drug needs and more likelihood of them being pre-prescribed and left in the patient's home. This may either be ensuring there is an adequate supply to cover the weekend, having ready other drugs which may be needed for the visiting on-call doctor to administer or (at the discretion of the PHCT) enabling DNs to administer, with written authorisation.

*Contact: Dr Keri Thomas or Sheridan Teal
(Pharmaceutical Advisor), Calderdale & Kirklees
Health Authority
Tel 01484 466000*

Palliative care bags

These bags contain the drugs and equipment needed in out-of-hours situations (e.g. syringe driver)

Examples

'Bearder Bags'

In Calderdale and Kirklees Health Authority. These specially assembled bags (sponsored by a local charitable trust in memory of Mr John Bearder), contain syringe drivers, crisis packs with guidelines and contact details, palliative care drugs and syringes, needles etc. They are held in the co-op cars or Healthcall bases.

*Contact: Dr Keri Thomas or Sheridan Teal
(Pharmaceutical Advisor), Calderdale & Kirklees
Health Authority
Tel 01484 466000*

Suffolk Doctors On-call, Newmarket

Have designed palliative care packs in their cars for use if needed by the co-op doctor.

*Contact: Dr Jeremy Webb,
Suffolk Doctors On-call, Orchard House Surgery,
Newmarket, Suffolk
Tel 01638 663771*

Lincoln

Provision through charitable funds of palliative care bags for GP co-ops and promotion of local development and initiation of handover form. Controlled drugs are accessed from local hospice, and community pharmacists are involved. They propose to fund all drugs supplied by the co-op out of hours, including palliative care drugs, by top slicing of PCG/PCT drug budgets.

*Contact: Dr Mark Fallon,
Macmillan GP Facilitator, Swallowbeck Surgery,
320 Hykeham Road, Lincoln, LN6 8BW
Tel 01522 681400*

On-call pharmacists and pharmacy rotas

Examples

Calderdale and Kirklees Health Authority

enables those pharmacists who take part in the on-call rota to be stocked with an agreed supply of palliative care drugs, replaced annually (at a cost of less than £100 per pharmacist). They can be accessed by a central phone number.

*Contact: Dr Keri Thomas or Sheridan Teal
(Pharmaceutical Advisor), Calderdale and Kirklees Health Authority
Tel 01484 466000*

Fife/Glasgow/Grampian pharmacy rotas

Specific pharmacists in different rural areas are designated palliative care pharmacies which stock the necessary drugs. There is a rota for out-of-hours cover where a pharmacist can be called to dispense urgent prescriptions. Similar arrangements exist in other areas. The rota is often known to the local police station.

Contacts

*Fife: Dr Bob Grant, Macmillan GP Facilitator, Fife Cancer Service, Old College (top floor), Victoria Hospital, Hayfield Road, Kirkcaldy, Fife, KY2 5AH
Tel 01592 643355 ext 8461*

*Glasgow: Macmillan Administration Secretary, Greater Glasgow Health Board, Dalien House, 350 St Vincent Street, Glasgow, G3 8YZ
Tel 0141 201 4930
Email ElizabethMcCormack@gghb.scot.nhs.uk*

*Grampian: Dr David Carroll, GP Facilitator in Palliative Medicine for Grampian, Roxburghe House, Milltimber, Aberdeen, AB13 0HR
Tel 01224 681818 ext 55650*

Out-of-hours drugs, Lisburn, Northern Ireland

A pharmaceutical company has sponsored a wallet for each GP containing required out-of-

hours drugs, which fits into each doctor's bag. An equipment box is also available.

*Contact: Dr Mark Palmer, Lisburn Health Centre, Northern Ireland
Tel 0289 2603088*

Palliative care boxes

Camdoc Palliative Care Box

Cambridge GP co-op has a palliative care box based at the OOH Primary Care centre at the Chesterton Hospital in Cambridge. This was set up by Dr Stephen Barclay (Health Service Research Training Fellow, University of Cambridge and previous Macmillan GP Facilitator) almost five years ago. All GPs working for the Cambridge GP co-op have access to its contents, which include two syringe drivers, diamorphine and other palliative care drugs. DNs requiring palliative care drugs for community patients access the box through the duty GP.

*Contact: Stephen Barclay,
Camdoc (Cambridge GP co-operative),
Chesterton Hospital, Union Lane, Chesterton,
Cambridge CB4 1PT
Tel 01223 329767
Fax 01223 506128*

District Nurse Office, Huntingdon

A carefully worked out protocol has been developed, with adherence to UKCC and local pharmaceutical regulations, whereby the DN can obtain a named prescribed drug, from the box, deliver it to the patient and administer it. The drug is prescribed by the on-call GP at Huntingdon GP Co-op after assessing the patient's condition. This has been used 33 times in one year, avoiding long delays in obtaining drugs from distant pharmacies.

*Contact: Head of Nursing, Huntingdonshire Primary Care Trust, The Priory, Priory Road, St Ives, Cambs, PE28 4BB
Tel 01480 308222*

For children – Palliative Care Drug Box, Belfast

Devised by Paediatric Macmillan Nurses and Hospital Pharmacist in Royal Belfast Hospital for Sick Children, this box is specifically for children entering palliative care stage and is placed in the home after discussion with GP and family. It contains drugs, a syringe driver and palliative care guidelines. Its use is currently being audited.

*Contact: Marissa McFarlane,
Paediatric Macmillan Nurse,
Royal Belfast Hospital for Sick Children.
Tel 0289 0240503 ext 3595/2402*

Policies, guidelines, surveys

Syringe driver policy

Examples

*Contact: Highland Hospice, 1 Bishop's Road,
Inverness, IV3 5SB
Tel 01463 243132*

*St Nicholas Hospice, Macmillan Way, Hardwick
Lane, Bury St Edmunds, Suffolk, IP33 2QY
Tel 01284 766133*

Local pharmaceutical supplies – the pharmacist's viewpoint

A recent survey of Local Pharmaceutical Committees in England and Wales (Hardman C and Almedzai S, Sheffield Palliative Care Studies Group, Personal Communication), enquired how many pharmacies guaranteed to stock a range of drugs essential to palliative care in the community. From a 76% response rate, 46% of these had such a service, 16% offered an informal service and 10% were planning or revising one. In addition, 28% of those guaranteeing to stock essential drugs had funding from their Health Authority.

*Contact: Colin Hardman
Email colin.hardman@ulh.nhs.uk*

Community Pharmacy Palliative Care Report – Hull

The Local Pharmaceutical Committee along with Hull Pharmacists' Association have run a project for 25 patients to link palliative care patients more directly with specific pharmacists, who then are well informed of the patient's medication, and can support and advise on interaction, mode of delivery, availability etc. They can also be stocked with supplies for use in emergencies. This has had the benefit of more personal supervision of drugs, less wasted medicines, better recording and transmitting of information via a patient-held care file, an agreed formulary being developed and improved patient and carer satisfaction.

*Contact: Mrs Hilary Edmondson
Tel 01482 502882
Email Hils@marina.karoo.co.uk*

Appendix 2 Provision of drugs

The task of ensuring an adequate supply of palliative care drugs out of hours can be difficult. This Appendix provides a review of some solutions.

The DoH Out-of-hours Review (October 2000) recommends the idea of a 'one-stop' approach to supplying medicines out-of-hours to include the particular needs of terminally ill patients. Two recommendations relating to the supply of medicines are

DoH Out-of-hours Review: Recommendation Nineteen

Other than in exceptional circumstances, patients should be able to receive the medication they need at the same time and in the same place as the out-of-hours consultation.

DoH Out-of-hours Review: Recommendation Twenty

The existing remuneration and contractual arrangements for out-of-hours providers and pharmaceutical services should be reviewed and, where appropriate, modified to allow for the provision of all appropriate medicines in the manner set out in Recommendation Nineteen.

(Ref Out-of-hours Review page 43-44)

This is reinforced by 'Pharmacy in the Future - Implementing the NHS Plan' (September 2000), which recommends that health authorities should be required to review local arrangements, in partnership with NHS Direct, PCTs, local pharmacies and patient representatives so that wherever possible patients are able to obtain medicines at the same time as the consultation. A further recommendation is that arrangements for dispensing other drugs urgently out of hours are well co-ordinated, reliable and readily accessible.

Important factors in considering the adequate supply of medication out of hours are

- anticipation of need
- on-call pharmacists
- palliative care bags
- controlled drugs.

Anticipation of need

The key message is to encourage GPs to think proactively about medication

- Sufficient supplies of drugs – to cover the out-of-hours period (possibly allowing for an increased dose range)
- Doctor administration - deteriorating patients may need certain drugs not previously used (e.g. hyoscine, midazolam). These could be left in the patient's home, readily available for use by the on-call doctor
- Nurse administration of drugs left in the home (prescribed by a doctor, with a prior signed authorisation form) occasionally occurs at the discretion of the PHCT. This would be according to local protocols and with LMC agreement. Some use a standard supply of four drugs in the home e.g. diamorphine, midazolam, hyoscine and haloperidol.

On-call pharmacists

To ensure access at all times, on-call pharmacists, pre-stocked with a list of palliative care drugs, may be available on a voluntary on-call basis or may be organised into a rota. Writing 'urgent' on a script means that an emergency dispensing claim can be made by the

pharmacist. The local police usually have a list of pharmacists who can be contacted to dispense urgent medications out-of-hours.

A recent survey of Local Pharmaceutical Committees in England and Wales (Hardman C and Almedzai S, Sheffield Palliative Care Studies Group, personal communication), showed that, of the 76% who responded, 46% had such a service, 16% offered an informal service and 10% were planning or revising one. In addition, 28% of those guaranteeing to stock essential drugs had funding from their health authority.

Note: As a last resort access from hospital or hospice has at times been available but this is currently incorrect, as they are not regarded as legitimate dispensers to community patients.

Palliative care bags

Despite difficulties with controlled drugs, there is considerable benefit from assembling a list of non-controlled drugs used in out-of-hours palliative care initially, and then making special arrangements for the opioids. These bags are held by a co-op, deputising agency, practice, hospice etc. They allow the 'one-stop' approach – i.e. the visiting doctor prescribes certain drugs and administers them at the time.

Palliative care bags ('Bearder bags') should include

- Palliative care drugs (*see list below*)
- Palliative care equipment – including syringe driver, catheter, needles, gloves, Sterets, Tegaderm
- Crisis pack - crisis symptom guidelines for key symptoms (pain, breathlessness, agitation and vomiting); crisis support sheet, key contact details (phone and mobile numbers and times of access), instructions to set up syringe driver

Controlled drugs

Controlled drugs commonly used in palliative care are

- Schedule II drugs
diamorphine and morphine (CD regulations apply)
- Schedule IV drugs
midazolam, diazepam

(usually all that is required is evidence of locked containers for these, to prevent abuse).

There are several considerable problems with the logistics of diamorphine usage, but such obstacles should not be insurmountable. The main problems are detailed overleaf.

Suggested list of drugs in palliative care bags

Non-controlled drugs	Controlled drugs
Midazolam	Diamorphine 10 mg 30 mg 100 mg vial (CD)
Haloperidol	
Cyclizine	
Hyoscine butylbromide (buscopan)/hydrobromide	
Methotrimeprazine (levomepromazine)	
Rectal diazepam	
Other options	Other options
Dexamethasone (for acute spinal cord compression/liver capsule pain) orally/vial	Oral morphine solution
Metoclopramide 10 mg	Rectal morphine suppository
Glycopyrronium bromide	
Diclofenac	

Storage of controlled drugs

To comply with Home Office regulations, controlled drugs must be stored in a locked cupboard, with a system for logging usage. The establishment must have a legitimate reason for holding the drugs on the premises (e.g. a hospice, general practice surgery, hospital), and if not, (e.g. a co-op or Healthcall base) it must have a Home Office Licence, and undergo the appropriate police inspection, routine checks and storage procedures. The licence cost is approximately £160 per controlled drug per year (£80 to purchase, £80 to be a supplier). Home office representatives may be happy to perform advisory visits. Licensing of co-op or dispensing practices could be a way of satisfying current legislation, but some have solved the problem by having a base in an A&E department of a hospital, or other licensed premises.

Note In the light of the Harold Shipman enquiry and debate, it is essential that all doctors can account specifically for all controlled drugs in their possession, and accurately record their usage. Records are likely to be regularly scrutinised.

For advice on specific details of controlled drugs, or to apply for a Home Office Licence, contact the Home Office Drugs Inspectorate Regional Officer at the Regional Offices

North and Scotland: 0113 242 9941

Bristol: 0117 929 3714 or: 0117 927 6736

London: 020 7273 3530 or: 020 7273 3888

Information on any aspect of drug therapy can be obtained free of charge from Regional and District Information Services (phone numbers are listed in the *British National Formulary (BNF)*). There is also a useful section on palliative care prescribing in the BNF.

Prescribing of controlled drugs

Morphine and diamorphine are invaluable in the care of palliative care patients. Morphine is usually given orally as a 4-hourly dose initially, a slow release preparation (e.g. MST etc.) or as required extra analgesia (e.g. Oramorph). Diamorphine is the more commonly prescribed

opioid for parenteral use i.e. in a syringe driver. It is vitally important to ensure a good supply of these excellent analgesics to ensure full symptom control.

Currently, retrospective prescribing to restock is illegal (that is, the system of a GP administering an ampoule of a controlled drug to a named patient and then writing a prescription which restocks their supplies with another ampoule, is actually invalid)

The correct procedure is to administer the drug, from a stocked supply, and then send the prescription to the Prescription Pricing Authority (PPA) for reimbursement. All transfers of Controlled Drugs should be recorded in the CD book. Supplies are then re-ordered as stock.

Scheme for dispensing diamorphine injection from stock

- Practice buys drugs from stockist and records in CD book
- Ampoule transferred to emergency bag having been recorded as transferred to GP in CD book
- Drug administered
- Prescription written for drug administered and/or doctor records patient details in second CD Register kept in emergency bag
- Prescription returned to PPA for reimbursement, together with all other prescriptions for personally administered drugs
- Practice reimbursed
- Replacements ordered from stockists as needed.

Transport of controlled drugs

If controlled drugs are held in a locked container at the co-op base and not carried by the visiting doctor, a nurse could be asked to obtain the drugs to set up a syringe driver. Current UKCC legislation allows nurses to transport controlled drugs only on a named-patient basis and only under exceptional circumstances. Carers have occasionally been asked to obtain drugs for the

patient, which is an unacceptable situation, requiring them to leave the patient's bedside. Pending a change of legislation, it may be advisable for the visiting doctor to carry his own supply of controlled drugs or palliative care bag (The DoH Out-of-hours Review recommends that medications are given at the time of consultation.)

Leaving drugs in the home

If the GP anticipates parenteral diamorphine usage, it is suggested that a supply is left in the home to cover the out-of-hours period, e.g. a weekend, and possibly including an increased dose if appropriate. Some doctors have felt nervous about leaving a supply in a patient's home, but no abuse has been reported in our experience, and the benefits of maintaining an adequate supply for pain relief have to be measured against this potential risk. A locked box could be supplied.

Setting up of a syringe driver

Locally agreed criteria should determine whether a syringe driver is appropriate for each patient e.g. is the patient vomiting, semi conscious or unable to swallow? Syringe drivers are not always indicated with deteriorating symptoms, and it is not always appropriate for the out-of-hours doctor to make this decision. However symptoms must be dealt with adequately.

Whether on-call doctors need to be familiar with the actual setting up of a syringe driver is debatable, as infrequent usage of this skill may lead to mistakes and a lack of confidence. However, certain district nurses are much more familiar with the practicalities of this and are more frequently called upon to set up syringe drivers, reinforced by protocols and specific training. A visiting on-call doctor should however be familiar with appropriate drugs to use, dosage, drug compatibility and combinations.

Example

One approach, as discussed with local specialist palliative care consultants would be as follows.

Diamorphine in a syringe driver will take about 4 hours to reach steady analgesic state. In the event of a call to a distressed patient in pain, a dose of diamorphine 5 mg stat sc, with or without midazolam 5 mg stat sc will usually bring the symptoms under control. It is recommended that the doctor waits 15 minutes or so to assess the result. If the patient is still in pain, a further sc dose of 5 mg diamorphine with or without midazolam should be administered. Once the patient is pain free, this allows 4 hours for the syringe driver to be set up (if appropriate, usually by the DN), thus providing maintained pain relief.

(discussed at out-of-hours training session for co-op doctors in Huddersfield October 2000)

Appendix 3 Further references/sources

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Useful reference books

Suggestions for useful texts:

Palliative Care Formulary
Dr Robert Twycross et al Pub:
Radcliffe Medical Press 1998

A-Z of Palliative Medicine
Dr Peter Kaye EPL Publications 31 Dec 1992
(ISBN 0951989502)

ABC of Palliative Care
Fallon, M (Ed) Pub: BMJ 1998

A-Z Pocketbook of Symptom Management.
Dr Peter Kaye. EPL Publications (41 Park Avenue
North, Northampton NN3 2HT)

*Yorkshire Cancer Network symptom
management book*.
Publisher: Yorkshire Cancer Network Palliative
Care Group Tel 0113 206 6316

Useful internet sites

Suggestions for useful websites:

www.hospice-spc-council.org.uk

The National Council for Hospice and Specialist Palliative Care Services. The website provides details about the Council and its work, information about palliative care along with news and links to other relevant websites.

www.palliative-medicine.org.uk

The Association for Palliative Medicine of Great Britain and Ireland has this site for advice on educational opportunities and information on palliative care issues.

www.palliativedrugs.com

Produced by Drs Robert Twycross, Andrew Wilcock and Andrew Dickman, this site provides essential, comprehensive and independent information for health professionals about the use of drugs in palliative care. There is a useful section on the giving of multiple drugs via syringe drivers. For more details/queries contact Dr Andrew Wilcock on 0115 962 7778 or email andrew.wilcock@nottingham.ac.uk.

Glossary

APM Association of Palliative Medicine

Beacon Services individual examples of best practice within primary and secondary care services regarded as worthy of being propagated throughout the NHS. Beacon services receive funding to allow them to disseminate best practice by hosting open days, organising secondments and seminars to pass on information about their approach.

Bearder bags Palliative care bags provided through a donation from the Bearder Foundation (founded by a cancer patient), for patients in Halifax, Huddersfield and Dewsbury, West Yorks.

CADOC Cardiff GP co-operative

CAMDOC Cambridgeshire GP co-operative

DN District nurse

GPC General Practice Committee

GP co-op General practice co-operative

Healthcall Medical Services A major provider of out-of-hours service to GPs in the UK. Working with GP practices and PCG/Ts, they provide a service to over 15 million people.

HImP Health Improvement Programme

Hospice at Home Service A service providing a full range of palliative care (including hands-on nursing) in a patient's own home, thus enabling choice to die at home should the patient and family so wish.

HUNTSDOC Huntingdonshire GP co-operative

LHCCs Local Health Care Co-Operatives

LHGs Local Health Groups

LMC Local Medical Committee

LPC Local Pharmaceutical Committee

Macmillan GP Facilitator A post that aims to improve the quality of cancer and palliative care

by providing protected time for experienced GPs to work in an educational capacity with primary care teams and others involved in cancer care to enhance and extend existing professional skills.

NAGPC National Association of GP Co-operatives

NCHSPCS National Council for Hospice and Specialist Palliative Care Services – a representative and co-ordinating body for all those working in hospice and specialist palliative care.

NHS Direct A 24-hour nurse-led telephone advice and information service. It is part of the National Health Service, providing round-the-clock access to information and advice about health, illness and health services.

NHS Direct Online NHS Direct Online provides a gateway to high-quality and authoritative health information on the Internet. It is supported by the 24-hour nurse-led helpline NHS Direct.

NHS Walk-in Centres Nurse-led centres providing primary care services to the public 7 days a week, generally open from early morning to late evening. Core services are available; specific services will also be determined by the needs of the people accessing the service and by the local HImP.

Oramorph Long-acting morphine tablet

PENDOC GP co-operative covering Calderdale & Kirklees Health Authority.

Postholder Individual appointed to a Macmillan Cancer Relief-funded post. Macmillan postholders are not employed by the charity but by the NHS or other organisation, and so are integrated into all NHS activity from the outset.

PPA Prescription Pricing Authority
www.ppa.org.uk

PCG Primary Care Group

PHCT Primary Health Care Team

PCT Primary Care Trust

PAM Professions allied to medicine – health professionals from a wide range of non-medical and non-nursing disciplines such as physiotherapy, occupational therapy, speech and language therapy and dietetics.

RCP Royal College of Physicians

RCGP Royal College of General Practitioners

RCCH Royal College of Child Health

RCS Royal College of Surgeons

RPSGB Royal Pharmaceutical Society of Great Britain

UKCC United Kingdom Central Council for Nurses, Midwives and Health Visitors – the regulatory body for nursing in the UK
Contact: 23 Portland Place, London W1N 4JT.
Tel 020 7637 7181
Fax 020 7436 2924
www.ukcc.org.uk

Appendix 4 Contributors and acknowledgements

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Acknowledgements

Macmillan would like to thank the many people consulted including the following for their help and contributions to this report.

- all the members of the Forum mentioned
- Macmillan GP Advisors: Dr David Millar, Dr Ivan Cox, Dr Gill Harding, Dr Greg Tanner
- all Macmillan GP Facilitators, including Ian Poole, David Lyons, Pawan Randev, Kavi Sharma, Paul Cormie, Bob Grant
- Calderdale & Kirklees Health Authority members of the Out-of-hours Palliative Care Strategy Group – Mark Davies, Andrew Deacon (Medical Directors, PENDOC) and Tim Hewson, Sheridan Teal (Pharmaceutical Advisor), Mike Johnson (Medical Advisor), Chris Veal (Medical Director), Mary Kiely and Susan Salt (Consultants in Palliative Medicine, Huddersfield and Halifax), Cherry Hunter (Community Health Council), Liz Howarth (Strategic Performance Development Manager)
- Macmillan Regional Service Development Managers and Nurses involved in initial consultation, especially Faye Scullion
- Roger Odd, Royal Pharmaceutical Society of Great Britain
- Colin Hardman (Pharmacist) and Hazel Sommerville (Pharmacist)
- Jane Bradburn (Cancer Voices)
- Dr Mike Vaughan and members of the NHS Direct, West Yorkshire Palliative Care Strategy Group
- Drs Andrew Daley, George Dublan, Mike Hughes, Rob Lane, Liz Higgins, Mike Stockton, Paresh Gajjar, Emma Payne, Mary Kiely and Susan Salt
- Logie Kelman (National Association of GP Co-operatives)
- Peter Tebbit, National Council for Hospice and Specialist Palliative Care Services, London
- Prof Ilora Finlay and those undertaking University of Wales, Cardiff Diploma in Palliative Medicine 1999/2000 who responded to the consultation exercise
- Margaret Gibbs, Pharmacist, St Christopher's Hospice, London
- Home Office Drugs Inspectorate, Northern and Scotland
- UKCC Professional Advisory Service
- Macmillan Cancer Relief, UK Office – Juliet Bouverie, Trina Loram, Peta Cottee, Dame Gill Oliver, Dr Jane Maher, Kaye Irvine and many others
- and multitudinous thanks to Alexis Duval for her great fortitude and perseverance with typing and distribution

Macmillan Cancer Relief works with the NHS and others to provide people who have cancer, and their families, with expert nursing and medical care, and with emotional and practical support, from the point of diagnosis onwards, in order that they may carry on living their lives despite cancer.

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