

End of Life Care in London

Examples of Good Practice

South East London

1. Procedure for the Transportation of Patients with Specialist Palliative Care Needs within the SE Strategic Health Authority

This procedure was written to address the problems that can arise for patients and their families with specialist palliative care needs that require transportation by the London Ambulance Service. It pertains to patients who live in the area covered by the South East London Cancer Network / Strategic Health Authority who often have severe symptoms, such as pain, and are extremely ill and who would be transported by LAS. They are defined as having specialist palliative care needs because they have a life limiting illness and are under the care of a specialist palliative care team.

The procedure has four main objectives:

- a. Ensure that patient transfer is carried out as timely as possible and that the patient is transferred to the appropriate unit.
- b. Involve the patient, family and carers as far as is possible in decisions concerning the transfer.
- c. Ensure the ambulance crew are informed that the person they are transporting has specialist palliative care needs and that they have the necessary information to deal sensitively with the patient's needs should they arise.
- d. Provide clarity around the area of resuscitation status, in order to reduce the possibility of inappropriate intervention.

2. Guy's and St Thomas' Charity, King's College Hospital Charitable Trust and South London and Maudsley Mental Health NHS Trust Charitable Funds End of Life Care Grants Programme

The 3 charities are currently in the process of viewing grant applications to facilitate and support improvements in the care for older people in Lambeth and Southwark in accordance with their preferences about how and where they wish to be cared for as they approach the end of their lives. Specifically:

- a. What can be done to enable people to die at home if they wish where "home" is defined as a domestic residence or care/nursing home? The charities have a particular interest in preventing older people from dying in Accident and Emergency Departments.
- b. What is optimal end of life care for older people with dementia and other degenerative conditions that may have a profound impact on their ability to engage in decision-making about their care? How can they be supported to indicate their wishes about end of life care to the greatest possible extent as their capacity for decision-making decreases?
- c. What extra can be done to implement, in primary care, the Gold Standards Framework and its relationship to hospital and other health facilities for older people?

- d. What can be done to support families, friends and carers so that they can help older people to die at home.
- e. A decision has not yet been made about which projects will be funded, but clearly any successful projects should be watched with interest, as they will involve service redesign.

3. Renal Modernisation Initiative

A project in Lambeth and Southwark, which includes a work stream on end of life care. It has the primary objective of establishing a sustainable renal palliative care service for those in established renal failure with palliative care needs.

The aim of the service is:

- a. To deliver or facilitate the delivery of physical, psychological, emotional, spiritual and social support to patients and carers.
- b. To improve quality of life for individuals and to facilitate open communication enabling patients to make informed choices about their care.
- c. Some of the work completed by the work stream so far has been to establish what services are already available in the hospital and community settings and to learn from the experiences of them and other units in the country who have pioneered work in this field. Strong links with existing palliative care services are being forged and knowledge is being shared across Lambeth and Southwark and renal units around the country.

A conservative care pathway has been developed for use with those who do not wish to commence dialysis therapy - to ensure that their care is optimum and there is seamless delivery regardless of where or by whom they are being cared. Conservative management can now be offered as a real alternative for those for whom dialysis may be deemed to offer limited benefit or prove too heavy a burden.

Symptom control guidelines are being formulated to assist staff to prescribe appropriate treatments for the side effects of kidney failure.

4. S E London Service Redesign and Sustainability Project-End of life care

A piece of analytical work being undertaken by McKinsey and the SHA, that is still in progress, looking at costed clinical service models. Further work is required to improve data quality and to consider aspects of service design in more detail (eg. interrelationships between clinical services, workforce implications, education/training opportunities etc). The initial phase of this project involving McKinsey as an external advisor has now concluded and it is being taken forward under the new London SHA.

Some cost modeling work has been completed, looking at different scenarios, for example, more people dying at home. This work is still in it's early but may be able to inform the strategy.

5. Compass

Compass was a pilot telephone helpline service, launched in October 2005 and closed in December 2006, for people who are dying or living with an illness that may shorten their life and those who care for them. It aims to increase the understanding of, and access to, information appropriate to end of life care. The helpline was a King's Fund funded initiative based at NHS Direct South London and staffed by NHS Direct Health Information Advisors (HIA) at the Beckenham call centre. The helpline was available to the public and professionals living and working in South East London. An evaluation of the helpline undertaken by King's College will be published later in 2007.



North East London:

Care Homes

Pulling together Education providers to deliver high quality and constant training across the End of Life Care sector. Ensuring this training is open the social care sectors well as health and voluntary organisations. Working closely with Further Education colleges, to ensure that the Social and Care Home Staff, have access to Training programmes that will enable them to deliver care, in the setting of the patient's choice. These training programmes should link in with the Education programmes that have been developed by the District Nursing programme and is now being mainstreamed through Higher Education Institutes and delivered locally by local Specialist practitioners. The findings in North East London following this programme were that it is best delivered by specialist practitioners who work locally so that ongoing communication networks can be developed thereby ensuring that education is ongoing and is related to local issues. Links between HEI,s and FEI's via the Hospices could ensure that the Training is both relevant to the local population and the Knowledge of the staff undertaking the programmes. Support for Care homes to develop networks to support each other as they pilot each of the tools within their localities.

Mental Health

Working with Mental Health Trusts to start to identify palliative care patients using the Preferred Place of Care Tool.

Ambulance services

Working to roll out the Procedure for the transportation of patients with Palliative care needs. We have identified Two Pilot areas where we can develop the Out of Hours Handover form so this can inform the ambulance service of patients with Palliative care needs and their preferred place of care.

Gold Standards Facilitators

Working with Primary Care Trusts to support the continued employment of GP Macmillan facilitators and Gold Standards Project Managers who can continue to support the development of the Framework locally. Support the development of education to Primary Health Care teams through their regular palliative care meetings and develop bereavement protocols and advanced care planning within local communities.

Out of Hours provision

Supporting Out of Hours communication through rollout of OOH forms through use of Gold Standards Framework and working with Out of Hours providers to ensure that the forms are widely disseminated through Primary Care Trusts. We have completed a mapping across the network of use and usefulness of the locally developed forms.

Drug availability in and Out of Hours

Work with Primary Care Trusts and Palliative Care Services to ensure that Palliative care Drugs are available locally in hours and out of hours. Highlighting the use of pre-emptive prescribing to reduce unplanned admission to hospital due to crisis needs.

Education and Training, Professional, Care Home, Social and carers

Barking and Dagenham PCT funding for the roll out of the LCP within care homes. This initiative could be rolled out across other organisations as a positive way to reduce emergency admissions in the last days of life. We need to acknowledge that there is an added cost to care homes in looking after dying patients and their families and funding may need to be made available.

Critical Care

Working with critical care teams to use the Liverpool Care Pathway for patients that have been diagnosed as dying.

Liverpool care pathway

Work with community teams to use an end of life care pathway. We have 1 PCT which is using the tool in 1 locality and will be using LCP across the trust by February next year. This is supported by education from one of the local Hospices that have already embedded this pathway in their practice. Support local champions to share their experience of use of the tools at regular events within Trusts and at Network events.

Respiratory Services

Working with respiratory teams to develop Preferred Place of Care as a tool to ensure referral onto services that the patients and carers have identified as supportive of their wishes.



North Central London:

GP practices

Auditing previous GSF work across the sector showed that few GP's had taken part in this work and that those who had, were not sustaining the work. To ensure **quality and sustainability** it was agreed to focus on implementation of all levels of GSF (up to level 4) in a select number of practices.

In order to help these practices implement the framework within their **IT infrastructure**, a disc was developed for all practices with assessment forms, monitoring tools, printable home pack...

Carer support

In Barnet PCT an agreement has been made to link GSF practices with Princess Royal Trust Barnet Carers in order for all **carers** of those on the palliative care registers to be offered a referral and **additional support** (telephone line, befriender home service, respite).

In Enfield PCT, the GSF facilitator identified a need for more **night sitting** support. Discussions with Nightingale Community Hospice Trust charity have resulted in the availability of 2 respite nights per patient.

Out of Hours

Following plans to audit Out of Hours handover forms, areas of concern were identified: Lack of appropriate processing of handover forms by provider together with no **palliative care drugs** available. Joint working across PCT and SHA boundaries has resulted in the agreement for necessary drugs to be held by OOH GP's. **Further progress is needed** to implement a remote accessed out of hours handover computerised system.

An OOH '**just in case**' box is being developed by Enfield PCT palliative care steering group with the support of the GSF facilitator. This will enable symptom control in emergency situations.

Further work is planned with London Ambulance Service to improve emergency responses to palliative care patients.

Training

A GSF/LCP/End of life care sector-wide training is in place for district nurses, allied health professionals, social workers and care homes. This has been achieved by joint working with the Cancer Network. The course sees over 100 health professionals every year. Further developments include training for healthcare assistants.

Innovative work:

A psychology student placement has been organised and will progress wider end of life care issues. The placement will cover **mapping level 3 and 4 psychological services** across the 5 PCT's (Joint working group with cancer network) as well as monitoring palliative care **QOF activity** across sector, enabling future recruitment onto GSF project.

Monitoring and evaluation

An After Death Analysis and GSF monitoring form are to be used for all primary care settings. The monitoring form tracks what level of GSF the practices have attained as well as each aspect of holistic care that are operational (e.g: symptom control, psychological, bereavement care). A database is under development which will automatically update this information, ensuring a fast and smart way of monitoring and checking performance.

Suggested way forward

The future needs to build on current achievements. LCP and GSF need to be implemented, embedded and sustained in the majority of care homes and GP practices, as well as intermediate care facilities and district general Hospitals. In order for this to happen, further funding is needed for the end of life care programmes. The funding needs to be increased and extended for a further 3 years. Furthermore, a specific forum is needed to address end of life issues in primary care (e.g: OOH, respite care, training). This forum needs to engage primary care practitioners and join up with commissioning to better influence choice and quality outcomes for end of life.



North West London:

Implementation of Liverpool Care Pathway at Chelsea and Westminster NHS Healthcare Trust

Outline

- 63 patients have been cared for on pathway to date
- 10 ward areas using the LCP guidance
- Clinical staff in all areas have received training including; nursing, medical and allied health professionals
- Funding for the facilitator post supported by the Friends of Chelsea and Westminster hospital and Kensington and Chelsea PCT.

How the changes were made

- -Intensive educational programme
- -Pilot site identified
- -Robust project plan
- -Awareness of conflicting priorities within ward areas
- -Thorough preparation of clinical areas with ongoing support from facilitator in preliminary stages.
- -Post implementation audit – demonstrating improvements in documented care delivered.

Hospice at Home at St. John's Hospice, St Johns Wood

Outline

Increasing numbers of patients supported and dying at home as a direct result of providing well trained and motivated health care assistants. Very positive feedback from patients, carers and families through annual evaluation. Have been able to demonstrate that Hospice at Home has been able to facilitate

urgent and speedy discharges from hospital for patients wishing to die at home. 34 patients referred for terminal care during 05/06 – 27 were able to die at home.

How the changes were made

St John's Hospice at Home has existed in various formats over the last 8 years. Historically this service has been exclusive to the patients managed by the nurse specialists at St John's who visit patients in Westminster. The care was provided by various agencies with mixed success. Problems encountered included lack of continuity of care, little control over quality of staff/standard of care given and poor communication from agency managers.

In October 2003 the whole scheme was reviewed and the following plans made:

- 4 health care assistants with community experience would be recruited onto the hospice bank system to provide the care, rather than registered Nurses. This decision was made because of current 24 hour cover by District Nursing teams.
- In order to retain the staff, regular work of 10 hours per week would be guaranteed on the hospice unit as supernumery staff if no Hospice at Home work was available
- A Hospice at Home co-ordinator would be appointed with administrative support to initially set up and then manage the scheme

Palliative support for patients with advanced heart failure within Harrow PCT

Outline

Service was established using current provision and via enthusiasm and dedication of the community palliative care team. Links with community palliative care team has lead to the following improvements for heart failure patients and their carers:

- Patients and carers now have a choice as to where they would like to be cared for at the end of life.
- Community HF nurses are now able to go into NWP and facilitate an early discharge for those deemed palliative by ensuring that the medical team responsible for the patient is aware that appropriate MDT support is available in the community to care for and support the patients and carers.
- Tools have been developed to assist the community heart failure nurses in referring appropriately and in a timely fashion to the palliative care team.
- Developed half a pathway for heart failure patients requiring palliative care.
- Access to hospice care is also available if it is not possible to facilitate a home death for whatever reasons in addition respite available to those struggling at home.
- Access to day care and complimentary therapy to improve quality of life
- Improved symptom control and psychological support for those with advanced heart failure.
- HF nurses have acquired a better understanding of community based services and what social services care packages are available with limited financial resources.

Changes were made through:

- Close collaborative working with all members of the multidisciplinary team
- Shadowing and learning from the community palliative care team
- HF nurses visited the hospice and day care
- Joint visits with MDTs , utilising each other others expertise
- HF nurses conducted teaching session for palliative care team
- HF nurses attended teaching sessions organised by palliative care team
- Attending national conferences and reflecting afterwards with the community palliative care team as to what we might like to use to enhance clinical practice.
- Learning through clinical incident reviews- MDT meetings to reflect on what went wrong and how we can do better
- Incorporating a palliative checklist within the heart failure assessment tool



South West London

Collaborative Work

- Support group for GSF champions from PCTs, GPs, Care homes, hospices
 - Joint training (ethics & communications skills)
 - Sharing resources
 - Sharing good practice
 - Joint evaluations (carer questionnaire)
- Support group for LCP champions from acute trusts, hospices, care homes, community hospital (from autumn 2006)
 - Joint training
 - Mentorship
 - Sharing resources/good practice
 - Benchmarking. See below under evaluation.
- Newsletter. A two page newsletter with information and contact details of the projects and training events is distributed electronically three times/year to a wide range of stakeholders.

Evaluation

- Uniform spreadsheet for auditing LCP across all the sectors (acute, hospice and care homes) in year two.
- Evaluation of available carer questionnaire / telephone interview schedules to establish some baseline feedback on services
- Audit of contacts with other services by care homes implementing GSF/LCP
- Staff survey pre and post implementation of LCP being developed

Education – Training

- Multi professional ethics-communication skills workshops
- Local training for LCP facilitators

Care homes

- LCP and GSF projects in care homes
- Raising awareness of potential GSFCH in London and seeking eligible staff representatives

Related projects

- Funding from King's Fund for 3 year project to improve end of life care for patients with learning disabilities across SW London
- Leaflets compiled by SWLCN on "What to do after a death at home" to be modified and used across London
- Network-wide syringe-driver guidelines implemented May 2006, now to be audited and guidelines reviewed
- As part of the pan-London EoLC group, seeking to work with LAS, to implement policy to improve information pathways to decrease inappropriate acute admissions or treatments