GREATER MANCHESTER AND CHESHIRE
CANCER NETWORK

NETWORK–WIDE GUIDELINES FOR ADVANCED CARE PLANNING FOR END OF LIFE CARE AND BEREAVEMENT

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FORWARD:

The Greater Manchester and Cheshire Cancer Network Supportive and Palliative Care Cross-Cutting Group have developed guidelines for the use of the End of Life Care Tools as follows: Liverpool Care Pathway for the Dying (ICP), Gold Standards Framework (GSF), Preferred Place of Care(PPC) and Bereavement Care, in response to the Action Plan produced by the Cancer Network for implementation of Guidance on Cancer Services; Improving Supportive and Palliative Care for Adults with Cancer. (2004)

The Guideline details are equally applicable both to cancer patients and to others with advanced life limiting illnesses.

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Greater Manchester and Cheshire Cancer Network

GUIDELINES FOR ADVANCED CARE PLANNING FOR END OF LIFE CARE AND BEREAVEMENT CARE

EXECUTIVE SUMMARY

Care of Dying Patients

The care given in hospitals, at home, and in care homes to patients who are dying can be sub-optimal. This may be due to failure of staff recognising or acknowledging impending death, and also due to lack of education, training and best practice in the initial assessment of care, ongoing assessment and care, and care after death. Hospices adhere to a model of excellence of care of dying patients. All patients should have a dignified death, with family and other carers adequately supported during this time in all care settings.

Implementation of the following end of life care tools has been recommended in the Guidance on Cancer Services, Improving Supportive and Palliative Care for Adults with Cancer, National Institute of Clinical Excellence (NICE 2004)[1] to support the improvement of care for all dying patients, and is equally applicable to patients with other advanced life-limiting diseases. NICE Key recommendations[1] are as follows:

Key Recommendations 13 & 14:
'Primary Care Teams should institute the mechanisms to ensure that the needs of patients with advanced cancer are assessed, and that the information is communicated within the team and with other professionals, as appropriate .The Gold Standards Framework (GSF)[2] provides one mechanism for this'.

'In all locations, the particular needs of patients who are dying from cancer should be identified and addressed .The Liverpool Care Pathway for the Dying Patient (LCP)[3] provides one method of achieving this.

'Building on the Best' (Department of Health 2003)[4] has committed to take forward training programmes so that all adult patients near the end of life have access to high-quality palliative care and to live and die in the place of their choice by use of end of life tools . Sharing of best practice over time will result in

- greater choice for patients, irrespective of their diagnosis ,in where they wish to live and die
- decrease in number of emergency admissions of patients who expressly wish to die at home
- decrease In number of older people transferred from a care home to hospital in the last week of life

The LCP and GSF have been adopted by the Greater Manchester & Cheshire Cancer Network to enable staff to deliver best practice in caring for dying patients, which can be evaluated.

In addition, the Preferred Place of Care (PPC) Tool[5] requires implementation across the Cancer Network. All three tools should be linked to guidelines for bereavement care.

Liverpool Care Pathway (LCP)

The NHS Cancer Plan (2000)[6] stated 'The care of all dying patients must improve the level of the best'. The Hospice model of care is now generally regarded as the Gold Standard 'for the dying patient'. A major challenge is the transfer of best practice from hospice setting to other care settings .The Liverpool Care Pathway (LCP) has received recognition as a national lead for service improvement as part of the Cancer Service Collaborative Improvement Partnership. The LCP was developed for use in hospitals, but can be used in other care settings. Use of the LCP is equally applicable to both cancer and non-cancer patients. LCP implementation is led by specialist palliative care services for patients and their families/carers to empower generalist staff to care for the dying at home, in hospital, hosices and in care-homes.

Gold Standards Framework

This tool enables the development of a practice-based system in primary care to improve the organisational quality of care for patients in the last year of life in the community. Evidence-based guidelines and competencies ensure patient-centred best practice and improvement in patient experience of care. The delivery of supportive and palliative care for cancer patients can be extended to patients with any end-stage illness. The main criteria for improvement are:

- Team working and communication;
- Symptom control;
- Care and carer support;
- Staff satisfaction and level of care provided;

which are delivered by the following key standards:

- Communication.
- Co-ordination of care.
- Control of symptoms.
- Continuity of out-of-hours.
- Continued learning.
- Carer support.
- Care of the dying phase.

Although initially developed for use in primary care it can be used in care homes and for all disease groups.

GSF enables those approaching the end of life to be identified, their care needs assessed, and a plan of care with all relevant agencies put in place. The framework focuses on optimising continuation of care, teamwork, advanced planning, including out-of-hours, symptom control, patient, carer and staff support.

Preferred Place of Care

The preferred place of care (PPC) was initially developed and introduced by the Lancashire and South Cumbria Cancer Network (2001) to document and initiate discussions about death and dying with patients and carers as a mechanism to identify and meet their discussed preferences. The Care Plan records:

- Patients' wishes.
- Family circumstances.
- Services which have been accessed.
- Reasons for change in the care.
- Needs assessment documents on care on an ongoing basis.

The PPC has been used in the home and has been piloted in care homes with older people, people with acquired brain injury. Early evaluation suggested that the PPC can have a significant impact on patients receiving care in their preferred place of care at the end of life. The PPC provides a mechanism to audit patient experiences, monitor patients' trajectory of care during the palliative stage of a disease, records patients' and carers' preferences, and highlights deviations from the preferred care plan.

Bereavement

Key recommendation 18: Supportive and Palliative Care, NICE Guidance[1] states: 'Provider organisations nominate a lead person to oversee development and implementation of services to specifically focus on the needs of family and carers during the patient's life and in bereavement, and which reflect cultural sensitivity'. Access to different forms of spiritual care can enhance the quality of support offered. The Chief Medical Officer's response[7] to the enquiries at the Bristol Royal Infirmary[8] and the Royal Liverpool Children's Hospital[9] in 2001 recommended that ' all NHS Trust provides support and advice to families at the time of bereavement', and states that 'Providing sensitive, responsive information and support for bereaved families is not an optional extra (Chief Medical Officer 2004)'.
Within Standards for Better Health (2004)[10] the domains of quality for healthcare (NHS, private and voluntary sector) providers states that 'staff treat patients, their relatives and carers with dignity and respect' and 'appropriate consent is obtained when required for all contacts, with patients and for the use of any confidential patient information'.

The Network Bereavement Guidelines recognize and adhere to the principles and guidance for bereavement services published by Dept. of Health, November 2005[11]. A key recommendation for the design and delivery of bereavement service across the Network and locally, recognises the variable provision currently offered by acute Trusts, hospices and primary care. Hence, identification of senior managerial leads within these organisations and working across geographical boundaries is essential to develop high quality, co-ordinated bereavement support which is accessible for families and carers.

References:

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   European Journal for Palliative Care 10:3,113-115, 2003

3. Ellershaw J; Wilkinson S.
   Care of the Dying. Pathway to Excellence.
   Oxford: Oxford University Press. 2003

4. Department of Health (2003)
   Building on the Best: Choice, Responsiveness and Equity in the NHS.
   DOH. London

5. Preferred Place of Care (2001)
   Lancashire and South Cumbria Cancer Network

6. Department of Health (2000)
   The NHS Cancer Plan: Plan for Investment; Plan for Reform
   DOH. London

7. Chief Executive's Bulletin
   Department of Health, 1st April 2004

8. The Report of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary 1984-1995: Learning from Bristol. Department of Health 2001.
   The Royal Liverpool Children's Inquiry Report. Department of Health – Jan 2001

9. Removal, retention and use of human organs and tissue from post-mortem examination. Advice from the Chief Medical Officer. Department of Health, Department for Education Employment, Home Office. January 2001

10. Plans for Better Health
    Department of Health, July 2004

11. When a Patient Dies – Advice on Developing Bereavement Services in the NHS
    Department of Health. November 2005

Gold Standards Framework

Introduction

The Gold Standards Framework (GSF) is a systematic approach which aims to optimise the delivery of care to patients (and their carers) nearing the end of life. GSF was developed from within primary care, for primary care, by Dr Keri Thomas (a GP with special interest in Palliative Care and then Macmillan GP Facilitator). It was first piloted in 2001 in West Yorkshire with 12 practices in Phase 1, then in 2002 with a further 78 practices in 18 areas in Phase 2, supported by Macmillan Cancer Relief and the Cancer Services Collaborative. This was followed in England and Northern Ireland by a national phased implementation programme supported by Macmillan's GSF Programme from Phases 3-6 in 2003-2004. GSF is now supported by the NHS End of Life Care Programme, by a national team in Birmingham with a clinical lead, supported by doctors and nurses, working with the national Programme Director and End of Life Steering Group. The aim of this initiative is to continue spread of GSF and extend the cascade programme through SHA's and Cancer Networks to be able to offer GSF to every Primary Health Care Team.

This generic improvement tool was initially developed for primary care for cancer patients, but is now used for any patient with a life-limiting illness and in other care settings, such as care homes.

Supportive and palliative care towards the end of life will be increasingly needed in future with predicted demographic changes; the ageing population is living longer with serious illness with fewer people available to care for them (WHO 2004)[1]. Overall, most palliative care is provided by generalists, as demand outstrips supply of specialist support. The optimisation of primary and specialist palliative care services will enable full and complementary provision, which will maximize benefits for patients and their carers.

Approximately 90% of the final year of life is spent at home so optimal home care is important no matter where the final place of death is. The majority would prefer to die at home [2]. For many the place of death is determined not by choice, but due to lack of planning or service provision, problems with symptom control or carer support [3]. Use of GSF aims to develop a practice/locally based system to improve the organisation and quality of palliative care for patients and their carers in the last year of life to enable more patients to die in their preferred place of choice. The process of GSF can be summarized by point's 1, 3, 5 and 7 (Appendix 1).

User and Carer Involvement

The GSF as a national initiative has involved patients' groups from an early stage and has been enriched by co-working with Macmillan Cancerlink and other user groups, including that of the Cancer Services Collaborative. Further developments are also planned. For this Network there will be consultation with the Patient User Partnership (PUP) group and locality based palliative care user groups.

What evidence and/or national guidance was used in developing the guidelines?

- Developed from within primary care for primary care
- Piloted with 12 practices initially in West Yorkshire
- Rolled out in a further 18 areas supported by Macmillan Cancer Relief and the Cancer Services Collaborative
- National phased programme supported by Macmillan's GSF Programme
- NICE Guidance in Supportive and Palliative Care (March 2004)[4] Key Recommendation 13 states, that primary care mechanisms should ensure that needs of patients are identified, assessed and communicated, for example by using the Gold Standards Framework.
- Key part of NHS End of Life Care Initiative (2004) [5]
- Endorsed by the Royal College of General Practitioners

Guideline Detail

It is expected that 16 PCT's within the Greater Manchester and Cheshire Cancer Network will commit to implement GSF.
Executive support from within an organisation is essential for implementation and sustaining use of GSF

Requirements for implementation:

- Commitment of PCT to incorporate GSF in their general palliative care policy to standardise end of life care
- Appoint a facilitator/lead to implement the programme, who will require full administrative and IT support and to enable their personal development and education.
- Implementation of GSF should become embedded in mainstream practice and adopted by the organisation as best practice.

Summary of implementation plan.
(Please refer to appendix 1)

- Develop a project plan
- Identify SHA Lead
- Link to central GSF team
- Inform PCT by forming a steering group or attendance at palliative care strategy groups
- Develop links with Cancer Network, hospice/specialist palliative care teams
- Encourage local momentum that will be the backbone for developing and sustaining best practice in future by identifying local champions
- Develop interest in own area, raise awareness, enlist practices or care homes, visit, encourage and discuss introduction of GSF.
- Register practices or care homes with central team
- Each practice agrees to use GSF for at least 6-12 months, nominates a practice coordinator (e.g. practice manager, district nurse, GP or receptionist – this can be a shared role) and a lead GP

- Practice coordinator sets up supportive care register (using suggested templates provided). Criteria for inclusion are initially cancer patients with a prognosis of 6-

12 months i.e. those eligible for disability living allowance or attendance allowance DS1500, later extended to patients with other end stage illnesses

- Practice coordinators should organise regular primary health care team meetings to discuss relevant patients on the register, assess patient and carer needs, discuss a management plan, preferences for place of care and any anticipated requirements including out of hours issues. The outcome should be improvement in communication which will focus on proactive rather than reactive care
- Practice coordinator downloads resources from the GSF website and develops a system of tasks i.e. sends information/handover form to out of hours provider, agrees assessment tools and provides information to carers
- A 6 monthly Primary Care Practice review meeting should be arranged to review and audit care, develop agreed practice protocols for palliative care
- Offer continuing support to practices; arrange coordinators support meetings to share experiences and develop new ideas.

To ensure sustainability;

- Utilise existing support for example palliative care team, local champions, district nurses
- Incorporate GSF into continuing education programmes for DN's and GP's, i.e. induction programmes, protected learning time
- Develop ownership and ensure GSF becomes accepted as normal practice and incorporate into trust as a Locally Enhanced Service
- Standing agenda item on all strategic groups, e.g. palliative Care Forums, local strategy meetings. Clinical governance
- Ensure links are formed with the Care of the Dying Pathway agenda
- Progress needs to be shared with PCT management, PEC committees and Palliative Care Forums
- Links need to be maintained at a national level with the central GSF team to inform of national agenda events and news
- Ensure GSF becomes part of annual audit programme, to provide evidence of improvements in teamwork, services offered, fewer reported crises and improved support for patients and carers

What aspects will be monitored and measured to assess impact?

- Network GSF implementation will be part of National GSF Audit (Birmingham University) which focuses on; the number of patients dying in their preferred place of choice, evidence of recording and discussion of advanced care planning, improvements in organisation, teamwork and communication, identification of patients, quality of service and avoidance of crises.
- Local audit programmes should focus on gaps in care at review meetings and pool resources to be able to impact on local services
- At local Practice level Significant Event Analysis can be a useful tool to identify and assess quality of palliative care delivered
- Continuous Quality Improvement Programme (CQIP) at a network level could highlight areas, which are not committed to the implementation and where further work needs to be directed.

References:

1 WHO Better Palliative Care for Older People Europe: World Health Organisation 2004

2 Thorpe G (1993) Enabling more dying people to remain at home. BMJ 307 915-8

3 Thomas C Morris SM Clark D. (2004) Place of Death : preferences among cancer patients and their carers.
Society Science and Medicine 58: 2431-2444

4 National Institute for Clinical Excellence (NICE) (2004) Guidance on Cancer Services: Improving
Supportive and Palliative Care for Adults with Cancer. NICE. London

5 Department of Health (2004) Building on the Best: End of Life Care Initiative. DoH. London

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Ellershaw,J and Wilkinson,S (2003) Care of the Dying: A Pathway to Excellence. Oxford University Press. Oxford

Thomas,K (2001) Out of Hours Palliative Care in the Community. Macmillan Cancer Relief. London

Thomas,K (2003) Care for the Dying at Home; Companions on the Journey, Radcliffe Medical Press Abingdon

Useful Websites:

www.goldstandardsframework.co.uk
www.macmillan.org.uk

Summary of Implementation Plan

Appendix 1

The aim of the Gold Standards Framework is to develop a practice/locally based system to improve and optimise the organization and quality of care for patients and their carers in the last year of life. It can be summarized by points 1, 3, 5 and 7.

1. One chance- Aim for the best for all- One 'gold standard' to aspire to for all patients nearing the end of life, whatever the diagnosis, stage or setting.

3. Three processes-
   1. Identify patients in need of palliative/supportive care towards the end of life
   2. Assess their needs, symptoms, preferences and any issues important to them
   3. Plan care around patient's needs and preferences, and enable these to be fulfilled and, in particular, to allow patients to live and die where they choose

5. Five goals of GSF-
   1. Patients are as symptom controlled as possible
   2. Patients live and die where they choose
   3. Better advanced care planning, information, less fear, fewer crises/admissions
   4. Carers well supported, enabled, empowered and satisfied
   5. Staff confidence, team-working, satisfaction, communication better

7. Seven key tasks or standards to aim for –the 7C's
   1. C1 Communication
   2. C2 Co-ordination
   3. C3 Control of symptoms
   4. C4 Continuity including out of Hours
   5. C5 Continued learning
   6. C6 Carer support
   7. C7 Care in the dying phase

The Seven C's

C1 Communication

Practices maintain a Supportive Care Register (paper or electronic) to record plan and monitor patient care and as a tool to discuss at regular primary health care team (PHCT) meetings. The aims of the meetings are to improve:

- The flow of information
- Advanced planning/proactive care
- Measurement and audit, to clarify areas for future improvement at patient, practice PCT and network level.

C2 Co-ordination

Each PHCT has a nominated coordinator for palliative care (e.g. District Nurse) to ensure good organization and co-ordination of care in a practice by overseeing the process:

- Maintaining the register

- Organizing PHCT meetings
- Using tools such as checklist for example pain and symptom assessment tools, to cover all areas of care.

C3 Control of symptoms

Each patient has their symptoms, problems and concerns (physical, psychological, social, practical and spiritual) assessed, recorded, discussed and acted upon, according to an agreed process. The focus is more on the patient agenda.

C4 Continuity

Practices will transfer information to the out of hours service for palliative care patients, for example using a handover form and out of hours protocol. Information should also be passed on to other relevant services. Record and minimize the number of professionals involved, for example note the lead GP, lead District Nurse and deputy for each patient.

C5 Continued Learning

The PHCT will be committed to continued learning skills and information relevant to patients seen**:** 'learn as you go'. Using practice-based or external teaching, lectures, videos, and significant event analysis of other tools, the practice and personal development plans and audits/appraisals are implemented. The practice develops a learning and reference resource. Learning is clinical, organizational/strategic and also attitude/approach, for example communication skills.

C6 Carer support

- Emotional support: carers are supported, listened to, kept fully informed and encouraged and educated to play as full a role in the patient's care as they and the patients wish. They are regarded as an integral part of the caring team.
- Practical support: practical hands-on support is supplied where possible, for example night sitter, respite care, equipment
- Bereavement: practices plan support, for example practice bereavement protocol, visits, notes tagged, others informed
- Staff support is inbuilt and nurtured, leading to better teamwork and job satisfaction

C7 Care of the dying

Patients in the last days of life (terminal phase) are cared for appropriately following the Liverpool Care pathway.

The 3 central processes of GSF- all involving improved communication, are to

1. **Identify** and raise awareness of this key group of patients i.e. using a register and hold a regular meeting to discuss, plan and audit their care.
2. **Assess** their main needs, both physical and psychosocial, and that of the carers.
3. **Plan** ahead for problems, including preference for place of care and out of hours issues- move from *reactive* to *proactive* care by anticipation and prevention

The Liverpool Care Pathway (LCP) for the Dying Patient

Introduction

The Liverpool Care Pathway for the dying patient (LCP) has been developed to transfer the hospice model of care into other care settings. It is a multi -professional document, which provides an evidence-based framework for end of life care and addresses physical, psychological, social and spiritual needs. Guidance is provided on different aspects of care including comfort measures, anticipatory prescribing of medicines and discontinuation of inappropriate interventions. Key sections of this document are described by [1]Ellershaw and Wilkinson (2003) and include:

- Identification of patients who are dying
- Initial assessment and care
- Ongoing assessment
- Care of the relatives after death

The National Team (Liverpool Care Pathway Central Team) provide support and guidance to organisations wishing to adopt the LCP; goals remain the same but prompts can be amended according to local need. Four generic versions are currently available via the LCP website and include:

1. Hospital
2. Community
3. Hospice
4. Care Homes

The National Clinical Lead, Dr. John Ellershaw is working with the National Programme Director to continue the spread of the 10-step programme implementation of the LCP (appendix 1) across the SHA' s and Cancer Networks. Future plans include Continuous Quality Improvement Programmes (initially within hospital settings) to allow for national benchmarking of LCP outcome measures.

What evidence and/or national guidance was used in developing the guidelines?

- Liverpool Care Pathway was awarded Beacon Status in the category Palliative Care in September 2000

- Ellershaw and Wilkinson [1] (2003) describe key areas for inclusion in a holistic care pathway document regarding care of the dying patient. This document has been further developed by the Liverpool Care Pathway Central Team and is a fundamental part of the NHS End of Life Programme

- The National Council for Palliative Care[2] (2004) have been instrumental in the production of guidelines for managing the last days of life as well as providing available research evidence.

- Key recommendation 14 of the NICE Guidance [3] (2004) for Supportive and Palliative Care states, “In all locations the particular needs of patients who are dying from

cancer should be identified and addressed. The Liverpool Care Pathway for the Dying Patient provides one mechanism for achieving this".

- Whilst the above guidance is cancer specific, the Departments of Health's [4]"Building on the Best …" (2003) advocates the extension of the boundaries of palliative care provision by making care opportunities currently available only to cancer patients accessible to all patients, regardless of diagnosis.

- Dissemination of the LCP to more than 100 Centres across the UK including Hospital, Community, Hospice (taken from Liverpool Care Pathway Website)

Guideline Detail

Key recommendations for successful implementation and sustaining use of the LCP

(1) Executive support from within an organisation is essential for implementation and sustainability. This should entail:

  (a) Commitment of resources both human and fiscal.
  (b) Organisational commitment to include LCP training within each organisation's induction and Annual Mandatory training programmes.
  (c) Inclusion of Pathway audit in each organisation's governance programme.

(2) The executive team should also identify a nominated person to lead the implementation process. The lead will:

  - Report directly to (member of) Trust or Hospice Senior Management Team
  - Provide quarterly updates
  - Chair Steering Group for implementation of LCP
  - Possess strong negotiating and influencing skills
  - Have a thorough understanding of the LCP.

(3) Involvement and support of the Specialist Palliative Care Team is essential both as a resource during implementation and to ensure sustainability of the use of the LCP.

(4) The nominated lead will identify a Facilitator/Clinical Lead who will:

  - Report directly to nominated lead
  - Provide monthly updates to nominated lead
  - Take an active lead within the LCP steering group
  - Attend core training
  - Be clinically credible – Palliative Care experience desirable having the ability to work autonomously

(5) The nominated lead will establish a steering group, which will have representation as

follows: -

(a) Chaired by the Trust/PCT/Hospice lead, minimal representation should be as follows:

- **HOSPITAL –** LCP Facilitator/Clinical Lead, Clinical Nurse Specialist Palliative Care , Clinical Governance, Ward Manager, Lead Nurse for Palliative Care, Medical representation (Consultant in Palliative Medicine)

- **COMMUNITY** – LCP Facilitator/Clinical Lead, Clinical Nurse Specialist Palliative Care, Clinical Governance, Medical representation (Consultant in Palliative Medicine or GP), Lead for District Nurses.

- **HOSPICE** – LCP Facilitator/Clinical Lead, Clinical Nurse Specialist Palliative Care, Clinical Governance, Medical representation (Consultant in Palliative Medicine).

Other representation, which may be useful

- GSF Lead or Facilitator
- Clinical Audit
- Medical Records
- Pastoral
- Pharmacy

If LCP facilitators/Clinical Lead are working across acute and community, the Steering Group should be joint.

(b) The purpose of the Steering Group will be to:

- Agree a local model of LCP documentation reflecting that of the Liverpool model.
- Provide ongoing monitoring of the documentation and annual review.
- Provide a forum for the provision of practical support, advice and guidance to the LCP facilitators/Clinical Leads
- Facilitate effective communication between the LCP facilitators/Clinical Leads and stakeholders.
- Monitor implementation of the LCP Facilitator's work plan through quarterly progress reports

(6) The Facilitator/Clinical Lead will identify and develop Pathway Champions who will:

- Have demonstrable interest in end of life care
- Participate in local LCP champion group
- Attend local core training

(7) Follow the 10-step education strategy suggested by the Central Liverpool Care Pathway Team (see appendix 1)

(8) Link with the LCP Group for Greater Manchester and Cheshire Cancer Network

What aspects will be monitored and measured to assess impact?

- Undertake baseline audit of care of dying prior to use of LCP.

- In the implementation phase it will be the responsibilities of the facilitator to ensure that systems are in place to monitor the use of the LCP across each organisation.

- Inclusion of pathway audit in the organisation's annual audit programme is essential to monitor the standard of documentation and variance recording. Audit and Variance Analysis are vital aspects of the LCP cycle.

- Linkage with the End of Life Care Cancer Network Group and participation in National Continuous Quality Improvement Programme will also ensure the sustainability of the Tool.

- Specialist palliative care services should maintain ownership of the care pathway from the start in order to be part of the process of developing a long term strategy for sustainability

References

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3 National Institute for Clinical Excellence (2004) Improving Supportive and Palliative Care for Adults with Cancer. NICE

4 Department of Health (2003) Building on the Best. Choice, Responsiveness and Equity in the NHS. Department of Health (December)

5 Department of Health (2003) End of Life Care Initiative
Department of Health (2003)

6 Liverpool Care Pathway Website (2005). http:// www.lcp-mariecurie.org.uk

Appendix 1

10 Step Education Programme – to facilitate the implementation of the LCP project by an advisory specialist palliative care team (adapted from Ellershaw & Wilkinson 2003)

MONTH 1

Step 1 Establish the project

- Executive and MDT endorsement of the LCP Project
- Pilot site identified for introduction of the LCP i.e. a ward area/unit/department or directorate/GP practice

Step 2 Development of documentation

- MDT meet to discuss LCP and amend prompts according to local need. NB Goals remain the same
- Supporting documentation written/identified

Step 3 Retrospective audit of current documentation

- Optional base review (recommended)

MONTH 2-5

Step 4 Induction – education programme

- Implement intensive education programme over a 6 week period to include all members of the MDT
- Ensure an LCP resource folder is available to the MDT

Step 5 Implementation – education programme

- Implement the LCP
- Provide educational support to staff when patients are cared for on the LCP

Step 6 Reflective Practice

- Review the LCP each time it has been completed and discuss the outcomes of care and completion of the LCP with the MDT on an individual patient basis

Step 7 Evaluation and training needs analysis

- Evaluate and analyse the LCP – feedback aggregate patient data to MDT
- Identify specific training or resource needs

Step 8 Maintenance – education programme

- Regular update teaching sessions according to identified training needs
- Introduce at least two nurses (registered general nurses grade D–G) from the pilot site to the Palliative Care Team Network Nurse programme

MONTH 10-12

Step 9 Training the teachers

- The network nurses depending on prior skill and knowledge are trained to take on the ongoing education role in their own area with the support of the Palliative Care Team: For new staff and ongoing support for their team

Step 10 Programme on ongoing feedback from analysis of the LCP

- Establish a framework of analysis to feedback to staff on a regular basis and to inform the clinical governance agenda

Preferred Place of Care Guidelines

Overview

The Preferred Place of Care (PPC)[1] Tool is a document which was designed to facilitate patient choice in end of life care. It identifies services being accessed by patients with palliative care needs, changes that occur in care planning, and the reasons why the changes occurred. PPC was originally developed in 2001 as a tool to contribute to the evaluation of a Community Education programme for palliative care which was introduced in response to the NHS Cancer Plan (2000)[2]. The aim is to aid evaluation of the nursing contribution in improving patient and carer choice in the place of care when an individual is receiving palliative care in the community. Since PPC was introduced into practice in community settings its potential benefit for use across a wide range of care groups and in all care settings has been recognised.

The PPC provides a mechanism for identifying patients' preferences about where they receive care and any particular issues they have about their care. In many instances an individual patient's choice of place of care is not only influenced by services available in the locality but may be affected if there is a change in the patient's condition, family situation or availability of Health Care Professional providing care when the condition changes.

Key aims of PPC:

- Assess needs and resources for patients who wish to die at home.
- Enables discussions about death and dying with patients and carers which identifies and facilitates meeting their expressed preferences.
- PPC assists in identification of resource deficits and development of cross-agency provision

Patients and carers are invited to comment on their experiences of care and hence views on service development

What evidence and/or national guidance was used in developing the guidelines

The governments command paper **Building on the Best: Choice, Responsiveness and Equity in the NHS (2003)**[3] commits the Department of Health (DOH) to take forward training programmes so all adult patients nearing the end of life will have access to high quality specialist palliative care to be able to live and die in their place of choice. The document states as follows:

"There is already work in hand to develop specialist palliative care services for cancer, as well as training programmes for district nurses. We wish to offer all adult patients nearing the end of life, regardless of their diagnosis, the same access to high quality palliative care so that they can choose if they wish to die at home. We will be taking forward training programmes for primary care teams and staff across a range of settings including hospital wards, care homes and nursing homes, working in partnership with Macmillan Cancer Relief, Marie Curie Cancer Care and other groups to draw on their expertise. This will widen the pool of staff who are experienced in the needs of people nearing the end of life and able to offer appropriate support in a range of settings of the patient's choice."

On 26 December 2003, the Secretary of State for Health announced the introduction of a £12 million investment over three years to improve care for people coming to the end of their lives. This follows the commitment in Building on the Best[2] to take forward training programmes so all adult patients nearing the end of life will have access to high quality specialist palliative care to be able to live and die in the place of their choice. It was intended that this investment will specifically help support the implementation of the:

- Gold Standards Framework;
- Liverpool Care Pathway for the Dying, and;
- **Preferred Place of Care** tools.

Within this the ***Preferred Place of Care*** is described as a tool which:
Enables doctors, nurses and others to discuss with patients and carers, their preferences around end of life care so that they are able to make informed choices. The tool also invites the patient and carer to comment on their experience of care, thereby including users in the development of service provision.

The NICE Improving Supportive and Palliative Care for Adults with Cancer Guidance (2004)[4] further states:
"People who are dying from cancer and their families have particular needs, these should be identified and addressed by those providing their care, whether it be in the patient's own home or in a hospital, care home or hospice. For example, people's preferences about their place of care and death should be supported, where possible."

The National Service Framework for Renal Services[5] Part Two: Chronic Kidney Disease, Acute Renal Failure and End of Life Care also states:
"Part one of this NSF identified the importance of information and choice for people with renal disease; this will include an assessment of prognosis. This quality requirement concerns those who decide not to undergo dialysis treatment, those who choose to withdraw from dialysis after a period of treatment, and those who are coming to the end of their lives while continuing dialysis. Their right to make choices, and to have a say in where they wish to die, is supported by the Government's Command Paper Building on the Best: Choice, Responsiveness and Equity in the NHS. The Gold Standards Framework, the Liverpool Care Pathway for the dying patient and the Preferred Place of Care document are tools which can be used to improve end of life care."

Guideline Detail

1. Executive support from within an organisation is essential for implementation and sustainability.

2. The PPC document is a patient held record and should follow the patient through their care trajectory.As the document is mainly aimed at palliative patients, the criteria should be:
   Patients who:
   - Are claiming benefit under special rules
   - Have input from a Specialist Palliative Care Nurse
   - Are deemed to be in the advanced or terminal stages of disease
3. The PPC plan will be initiated in the patient's home, in a hospice or in a hospital.

4. The PPC can be initiated by:

- A Nurse, Allied Health Professional, Medical Practitioner, Counsellor or Social Worker in a range of settings including hospitals, care homes, hospice or community.
    - The document should be completed with the patient to ensure the patient's needs and emotional state are reflected.
    - The original pilot study undertaken by Lancashire and South Cumbria Cancer Services Network found that some health professionals find it difficult to initiate or respond to difficult questions relating to end of life care.

5. It is essential that practitioners are competent in communicating effectively with patients and their carers.

What aspects will be monitored and measured to assess impact

1. Systems for distributing and monitoring initiation of PPCs need to be developed and implemented. Awareness of the PPC process needs to be raised across all care settings and across care disciplines, including Hospitals, Hospices, Community, Care Homes and Out of Hours Service Providers as patients may travel through each of these settings during their end of life care.

2. Practitioners need to be confident in their competence to engage in potentially "difficult" conversations. Practitioners may need to undergo enhanced or advanced communication skills training before they are equipped to initiate the PPC confidently with patients.

3. When an organization commits to implementing the PPC then they must facilitate such training for their staff as appropriate.

4. It may be necessary to have a number of "champions" to provide support to less experienced colleagues.

5. A database system for analysis of data produced from the PPCs should be established in order to audit the use of the PPC by the organisation. Also, to further audit the effectiveness of the PPC document and whether the outcome of patient choice of place of care was met.

6. Further information and downloadable copies in PDF format of the PPC document, poster and leaflet be obtained from the Lancashire and South Cumbria web site: www.cancerlancashire.org.uk/ppc.html

References:

1. Preferred Place of Care (2001). Lancashire and South Cumbria Cancer Network
2. Department of Health NHS Cancer Plan (2000). DOH. London
3. Department of Health (2003) Building on the Best: Choice, Responsiveness and Equity in the NHS. DOH. London
4. The National Institute for Clinical Excellence (2004) Improving Supportive and Palliative Care for Adults with Cancer Guidance. NICE. London
5. Department of Health (2005) The National Service Framework for Renal Services Part Two. DOH. London

Guidelines to inform the development of Bereavement Services

Introduction

Bereavement can be defined as 'the situation of anyone who has lost a person to whom they are attached' Grief is 'the psychological and emotional reaction to bereavement (C Murray- Parkes 2001). [1] It cannot be emphasised enough that grief is a natural response to human loss. The majority of people find sufficient resources to respond and adapt to the life transition, but some find it too difficult and traumatic without additional support. According to Murray- Parkes the majority of people 87-90% will have an unproblematic mourning period, 7-10% will need additional psychological support other than information (Standards for Bereavement Care 2001) [2] and 2-4% will require specific psychiatric/psychological therapy to cope with a serious mental health problem related to loss by death (Standards for Bereavement Care 2001) [2] Murray Parkes's research (1975) [3] identified parameters of determinants of grief to try predict how a person would respond to a loss The most important determinants include

- Who the person was and the nature of the attachment to the deceased.
- The mode of death (Sudden/Accidental)
- Historical antecedents (Previous experience/Mental Health history)
- Concurrent stressors (Other changes occurring from the death For example financial difficulties)
- Social Variables (Culture/Religion)
- Personal Variables (Age/Sex/Highly dependent.)

Risk assessment can be undertaken to identify those at risk. Murray-Parkes reports that the best risk indicator is to identify those who we have a gut instinct about their bereavement risk. Types of intervention required include information giving, bereavement group, self-help groups, 1-1 counselling, memorial services, befriending groups, telephone support and written follow up.

Evidence of National Guidance used in development of the guidelines:

Key recommendation 18 in the Supportive & Palliative Care NICE guidance [4] states:
'Provider organisations should nominate a lead person to oversee the development and implementation of services that specifically focus on the needs of families and carers during the patient's life and in bereavement and which reflect cultural sensitivities.'

The NICE Guidance [4] also recommends a three-component model of bereavement.

Component I: all bereaved people should be offered information about grief and how to access the support services.
Component II: a proportion will require additional support.
Component III: a small proportion will require specialist intervention including mental health and psychological support.

The Department of Health Survey on Bereavement Services (Summer 2001) [5] found that every NHS Acute Trust was providing support to people in some form but the extent varied considerably. Many of the Bereavement options in the Acute Settings are administrative posts dealing with Death Certificates. Recommendations of the Kennedy

Report (The inquiry in the management of care of children receiving complex heart surgery at the Bristol Royal Infirmary 2001) [6] place responsibility on Acute Trusts to review their support services for carers and staff.

'Hospitals must have an integrated system of support and counselling for patients, carers and staff, by well trained professionals with links to systems outside. Such a system is crucial to care, not an add on.'

The Royal Liverpool Children's Inquiry (2001)[7] sets out a multitude of recommendations including the provision of Bereavement Advisors to address the issues raised by the Alder Hey Inquiry. Department of Health Making a Difference (1999) [8] raised key points about the changing context of care, recognising that advice and support was an increasingly important part of the professional role.

Standards for Bereavement Care [2] in the UK were developed in consultation with providers or bereavement support across the breadth of the UK.

National Cancer Plan[9] endorses bereavement support and education. Mental Health National Service Framework[10] advocates a well co-ordinated, accessible service involving all service users and carers.

Guideline Detail:

Key Recommendations for the design of Bereavement Services

The following form key recommendations in addressing the provision of bereavement services. It is recognised that Trusts, Hospices, and Primary Care Trusts already demonstrate differing provisions. These recommendations therefore set a standard to be aimed for.
" Providing Sensitive, responsive information and support for bereaved families is not an optional extra." (Chief Medical Officer 2005) [11]

1. Executive support from within an organisation is essential. This should include:

    - Identification of Trust Executive Lead with responsibility for Bereavement Services
    - Commitment of resources both human and financial
    - Ensuring there is a written policy ratified by the Trust Board covering all services relating to death and bereavement**.** This policy should describe a core service which is inclusive and can accommodate the range and equity of access for needs of users
    - Include death & bereavement in all appropriate Care Pathways.
    - Provision of training, support and supervision for all staff appropriate to identified needs.

2. Appointment of a Bereavement Service Co-ordinator/Advisor, to ensure appropriate co-ordination and consistency between all services. (Department of Health 2005) [12]

    - To 'Champion' Bereavement issues.
    - Lead and encourage cross boundary working practices including voluntary agencies, internal and external stakeholders

- Undertake assessment of needs and baseline review of services already available, both statutory and voluntary.
- Undertake option appraisal to determine appropriate service models
- Involvement of voluntary sector and volunteer workers.

Bereavement Service Co-ordinator would lead on:

- Policy Development/Strategic Planning
- Standard Setting.
- Administration of a death.
- On-going provision of support for the bereaved. Including
    - Assessment & Referral
    - Information giving
    - Practical advice/Support
    - Counselling/Befriending support.

3. Providers of support to bereaved people in the UK must respect the confidentiality and privacy of those who use their service. Within the organisations there must be a confidentiality policy in place. Confidentiality is not absolute. In exceptional circumstances, it may be necessary to share information about a bereaved client with a third party. Bereaved clients need to be made aware of the limits to confidentiality before support begins.

4. Personal information should be kept securely and in line with legal requirements, such as the Data Protection Act 1998 [13] and the Caldicott Report (1997) [14]

5. Providers of support to bereaved people should:

    - Recognise that particular groups in society are discriminated against
    - Work actively to combat discrimination
    - Be sensitive to social, cultural and spiritual beliefs

    Each professional service should facilitate a process which ensures appropriate personnel are immediately informed a person has died.
    Within each locality, co-ordination of use of Gold Standards Framework, the Preferred Place of Care, Liverpool Care Pathway and Bereavement Care should occur.

6. Initial support following a bereavement should be provided by the clinical team involved in caring for the dying patient and supporting the family/carer This should be done within a maximum of 4 days after the death. At this contact all bereaved families/carers should receive an information booklet about grief and bereavement and services available in that locality.
    Written material should be sensitive to their cultural values and religious beliefs.

    The family/Carer should be given contact details of a named (local) Bereavement Service Co-ordinator/Advisor, to access future information and support should this be required.

7. Referral and assessment criteria for the 3 levels of support [4] are essential. The Bereavement Service Co-ordinator will be responsible for assessing what level of support is required. Bereaved relatives/carers will be referred on to the appropriate specialist bereavement service if required

Every effort should be made to conduct discussions and/or counselling in a private sympathetic environment away from interruptions. The purpose of the support being offered should be clearly explained.

8. Commissioners and providers should ensure
    - All staff are educated and trained appropriately to consolidate, develop, maintain and enhance their knowledge and skills in bereavement support, loss and grief.
    - All staff receive appropriate levels of supervision and support relevant to their involvement in working with bereaved people

9. Feedback from service users should be actively encouraged.

What aspects should be monitored and measured to assess impact:

- Number of people accessing the service and at which level
- Number of bereaved families/carers who receive information booklets
- Carer/Family involvement feedback.
- Staff Audit. On the impact of delivering the service (to identify training/support issues)
- Training programmes in place for all providers of bereavement support

References:

1 Murray- Parkes C. Bereavement Oxford Textbook on Palliative Medicine (2001)

2 Bereavement Care Standards.UK Project. National Bereavement Consortium.(2001)

3. Murray -Parkes C. Bereavement. Studies of Grief in Adult Life. (1975)

4 Supportive & Palliative Care for Adults with Cancer NICE guidance (March 2004)

5 Survey on Bereavement Services. Department of Health (2001)

6 The Report of the Public Inquiry into Children's Heart Surgery at the Bristol Royal Infirmary 1984-1995: Learning from Bristol. Department of Health 2001.

7 The Royal Liverpool Children's Inquiry Report. Department of Health (2001)

8 Making a Difference. Department of Health (1999)

9 Department of Health (2000)
The NHS Cancer Plan: Plan for Investment; Plan for Reform
DOH London

10 National Service Framework for Mental Health. (1999)

11 Chief Medical Officer. CMO Update. (May 2005)

12 When a patient dies – Advice on developing Bereavement Services in the NHS Department of Health (June 2005)

13 Data Protection Act. (1998)

14. Caldicott Report. (1997)

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<u>Website addresses</u>

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