



'The Palliative Care Toolkit'

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(The palliative care education sheet from Michael Sobell House)

Welcome to the fourth edition of the palliative care tool kit from Michael Sobell House. This bi monthly education sheet delivers to you palliative care information and tips that you can use in your day-to-day practice. This month we are looking at outreach hospice care – what patients do you have who may benefit?

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Bereaved carers' views of a hospice at home service. Exley C, Tyrer F (2005) Int J Palliat Nurs;11(5):242-6.

In recent years, there has been an increase in specialist palliative care services in the home. Despite this, there have been relatively few published evaluations of such care. This qualitative study used semistructured interviews to explore bereaved carers' views and experiences of a hospice at home (HAH) service in the East Midlands, UK. Eleven interviews were conducted and analysis followed the framework approach. RESULTS: Carers' views were divided into four themes: caring for someone at home; formal care provided by HAH; access to out-of-hours care; and provision of specialist equipment. CONCLUSIONS: Bereaved carers generally gave very positive accounts on care delivered by the HAH service. Shortcomings identified were the provision of out-of-hours care and the untimely supply and removal of specialist equipment. It is suggested that bereaved carers provide useful insights for qualitative evaluations of end-of-life services delivered in the home.

Beyond hospice care: a survey of community outreach programs. Petersen S. Am J Hosp Palliat Care. 1992 Jan-Feb;9(1):15-22.

In an editorial by David Lescohier (The American Journal of Hospice & Palliative Care), the tough dilemma faced by many hospices today is our acceptance into the mainstream of the medical delivery system. Hospitals have found that offering specialized adjunct programs has helped them maintain an edge in a competitive environment. Part I of this article contains the results of a national survey which explored the differences in the hospices that are pursuing outreach programs and the direction of those programs. Part II provides results and discussion of the benefits, obstacles and problems in several types of outreach: counselling, schools, pre-hospice and day care.

Preferred Place of Care

Claire Young and Margaret Gandon – MSH Outreach Team leaders

The NHS Cancer Plan (DoH 2000) acknowledges that support for patients living at home with advanced cancer is sometimes poorly coordinated and may not be available 24 hours a day. Moreover, it acknowledged that cancer patients should be able to live and die in the place of their choice wherever possible. Approximately 50 per cent of terminally ill patients wish to die in their home (Dunlop et al 1998). Studies from Sweden and Australia show a similar trend with only 12 – 14% of cancer patients dying in their own home (Storey et al 2003)

Two of the stated aims of the Michael Sobell House (MSH) Outreach Service are to enable patients to die at home, and to prevent emergency admissions to A & E departments. Recently the Team have been involved with three admissions from home It has been useful to reflect on some of the issues around these patients' circumstances.

Support Prior to Admission - Mrs Y was referred to the Outreach team for respite support for her main carer. She was booked in for a MSH respite admission. During the Outreach team visits before admission she became increasingly confused at home and we subsequently admitted her to a local hospital. Kaye (1994) identifies the "ABCD" of symptoms difficult to control at home of **A**nxiety, **B**leeding, **C**onfusion and **D**iarrhoea (in a patient who is bed bound). Mrs Y was diagnosed with an infection, started antibiotics and transferred to MSH where she later died. This demonstrated that planned respite admissions sometimes become terminal care admissions. This patient and her family coped with several changes of circumstances over a relatively short period of time i.e. acute medical treatment to terminal care.

Support Awaiting Admission - Faull and Nyatanga (2005) identify the numbers of people wanting to die at home and the relatively few who achieve it. Some patients request **not** to die at home. **Mr X** lived alone. He had positive memories of a family member who had died at MSH and wanted to die there. As he did not have complex palliative care needs, a bed was not immediately available. We visited and supported him at home until admission was possible. Difficulties arise if an obviously dying patient does not have the complex symptom control issues allowing referral to specialist palliative care unit like MSH. Beds are not always available. We do get requests at home for hospice admission at the end of life, and units like MSH are not "hospices" in the old sense of the word. One of the challenges in palliative care today is to provide hospice type care in other settings such as hospital wards and nursing homes - the settings where the majority of patients will find themselves at the end of life.

Facilitation of Readmission - Mrs Z (recently discharged from MSH) was assessed at home by an Outreach nurse who confirmed the need for and facilitated readmission to MSH for complex pain management. Gannon (2005) talks about the urgency of controlling symptoms in patients with a short life expectancy. Appropriate changes can be made quickly when nursing and medical staff are available 24 hours a day to monitor and supervise. One of the dangers though is over dependence on the institution, even becoming too comfortable and the perceived difficulties of managing at home once more.

If relatives at home are unprepared for the signs of impending death they may panic and ring for an ambulance. In MSH it has been known for a relative to try and "resuscitate" a loved one whilst taking his last breath. Families at home may think they cannot cope. One of the questions is if they knew the patient was dying would that change their perspective? Might they be able to call on extra family support?

Support to die at home - Mr N was dying at home when the Outreach nurse arrived. Within an hour she had had to encourage a family member to 1) not go out on an errand, 2) answer questions about the dying process, 3) witness the patient's death, 4) share part of this time with one of the community nurses that she hadn't met before, and 5) talk about what to do next with a family who had never witnessed a death before. It felt like a privilege and demonstrated the intricacies of caring for both family and patient at time of death.

Education and Support - A student nurse visited the Outreach office recently. She expressed how much it would have helped her, to have known more about the signs of dying when her own father died at home. Marie Curie nursing services have recently produced a helpful leaflet on this, called "coping with dying" it can be given to relatives if this seems appropriate. (www.lcp-mariecurie.org.uk)

Dying at home is only going to be realistically possible if the main carer is "on board" and feels secure and supported. The MSH Outreach service offers support on a short-term basis helping those at home over a few days. We now record the preferred place of care in our documentation in preparation for audit. Noting the preferred place of care makes it more likely that this wish will be fulfilled (Thomas 2003). The Lancashire and South Cumbria Cancer Network have devised and piloted a Preferred Place of Care documentation, which is identified in the NICE (2004) guidance as improving palliative care services (www.cancerlancashire.org.uk). The PPC is a patient-held record that follows the patient through their path of care into the variety of differing health and social care settings.

In summary our aims on the Outreach team remain the holistic care of the dying and their families, with symptoms controlled, and (where possible) in the preferred place of care. The Team members nurse patients in MSH as well as at home. We continue to learn from seeing things from both sides.

Referrals to the Outreach team may be made by telephoning us on 01923 844596 (office hours/answer machine)

Kaye (1994) A to Z of Hospice and Palliative Medicine p 88 EPL Publications UK
 DOH (2000) NHS Cancer Plan, HMSO
 Dunlop & Hockley (1998) Hospital-Based Palliative Care Teams The Hospital-Hospice Interface Second Edition
 Faull & Nayatana (2005) in Handbook of palliative care (eds Faull, Carter and Daniels)
 Gannon (2005) in Hidden aspects of palliative care (eds Nyatanga and Ashley-Pepper)
 Nice (2004) Supportive and Palliative Care Guidance
 Thomas (2003) Caring for the dying at home - Companions on the journey
 Storey (2003) Place of death: Hobson's choice or patients Choice? International Journal of Palliative Nursing, Vol 9,10: 439

Michael Sobell House Education & Training:

- Aug** 11th Palliative Care Update (ward based)
- 25th Palliative Care Update (ward based)
- Sept** 1st Reflection on Practice Set
- 7th Syringe Driver Training 1
- 8th Palliative Care Study Day (Trained Nurses)
- 8th Palliative Care Update (ward based)
- 14th Volunteer Training
- 16th Palliative Care Symposia – Constipation
- 22nd Care of Hickman /PICC Line (am)
- Pain Management Update (pm)
- Palliative Care Update (ward based)
- 28th Principles of Palliative Care (Uni of Hertfordshire)
- 29th Principles of Palliative Care (Uni of Hertfordshire)
- 29th Reflection on Practice Set
- Oct** 6th Palliative Care Update (ward based)
- 12th Tens Machines in Palliative Care
- 14th Palliative Care Symposia – Ethical Issues
- 19th Graseby Syringe Driver Training 2
- 20th Principles of Palliative Care (Uni of Hertfordshire)
- Palliative Care Update (ward based)
- 21st Principles of Palliative Care (Uni of Hertfordshire)
- 26th Volunteer Training (am)
- Lymphoedema Training (pm)
- 27th Breaking Bad News/Communication Workshop

For enquires and booking forms contact Anni Hall (Education Co-ordinator) on ext 4177

Useful Contact Numbers:

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Palliative Care Registrar	Ext 4281/Bleep 547
MSH Outreach Team	01923 844596
Garden House Hospice (Letchworth)	01462 679517
Harlington Day Hospice (Hayes)	0208 7590453
Peace Hospice (Watford)	01923 330330
Pasque Hospice (Luton)	01582 492330
St Francis Hospice (Berkhamstead)	01441 862960
St Lukes Hospice (Harrow)	0208 3828000
Berkhamstead Mac Nurses	01442 862960
Dacorum Mac Nurses	01442 240726
“	01923 330343
Hillingdon Mac Nurses	01895 279412
Ian Rennie Hospice at Home	01442 890222
Uni of Herts - Lauren Hemming	01707 285148
David Maher	01707 285265

Useful Websites

- www.breakingbadnews.co.uk
- www.cochranelibrary.com
- www.painaid.painfoundation.org
- www.albertapalliative.net