



UNIVERSITY of LIMERICK
OLLSCOIL LUIMNIGH

“With comfort and dignity and support”



**An evaluation of the Hospice at Home
Service delivered by Milford Care Centre**



Care Centre to develop practice guidelines for the continuing evolution of the Service.

The full report can be found at <http://www.milfordcarecentre.ie/>

The
A T L A N T I C
Philanthropies

This research recognises the support received from The Atlantic Philanthropies
and the Health Service Executive



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

SUMMARY OF RECOMMENDATIONS FOR FURTHER DEVELOPMENT OF THE SERVICE**1. Co-ordination of Teams**

Stronger clinical and organisational support is required to ensure greater clarity on management structures that reflect an increasingly diverse and complex team (see page 87 of full report, Theme 1b The new Hospice at Home Service; page 89 of full report, Theme 2b Multi-professional visiting, and Theme 2c Co-ordination of Hospice at Home Service; page 92 of full report, Themes 3a-3d communication, information sharing and building relationships; pg 95 of full report, Theme 4b Support structures for staff).

2. Provision of Information to Carers and Patients

Information should be provided and updated at different times and in different formats relevant to each case and information content should be enhanced to include all aspects of the Service (see pages 66/67 and 77/78 of full report, Information and communication).

3. Communication

Timing of discussions relating to place of death and advance care planning with family/carers should be reviewed (see page 50 of full report regarding the discussion of place of death). Training should be provided to health professionals to optimise communication with patients, carers and their families (see page 68 of full report, Patients 003, 012; page 89 of full report, Theme 2b Multi-professional visiting; page 46 of full report, Telephone contact).

4. Bereavement Support

Information should be reviewed regarding bereavement support (see page 82 of full report, Bereavement support).

5. Information Management

Enhancements are required for accessing patient-related information including updating of personal data, data storage and management, and information sharing with external agencies (see page 93 of full report, Theme 3c Information Sharing).

6. Quality Assurance

Common evaluation tools should be used to enhance patient management and optimise communication, and align with best practice and nationally agreed guidelines. The findings and recommendations from this evaluation of the Hospice at Home Service can be used by Milford

The members of the Hospice at Home team and Milford Care Centre demonstrated a high level of commitment to the Service. The development and growth of the Service presented challenges to those involved in providing the Service, particularly around professional roles. The organisation, management and communication within and between members of the team and Milford Care Centre were identified as an area that required improvement. The main area of the Service that carers thought could be improved related to the dissemination of information, particularly regarding the availability of different aspects of the Service. Specific issues that were considered to affect patient care were the lack of clear management structures and lines of communication, access to information, and knowledge of key performance indicators related to best practice. Most of the recommendations from the evaluation relate to addressing this aspect of the Service.

The evaluation involved an extensive range of consultations with various stakeholders who used, provided or worked with the Hospice at Home Service. Its main limitation relates to the small sample size, but the quality of care compares favourably with other studies of end of life care in other settings. The Hospice at Home service consistently rated higher than McKeown et al (2010) Irish study, with some questions replicated in this study. Similarly, there are favourable comparisons with the findings from other international studies, with support for carers and quality of care all being rated positively (Lucas et al, 2008; Jansma, 2005). As in other studies, practical ongoing support was an area requiring more input (Grande et al, 2004, Zapart et al, 2007).

The Service incorporates the principles of the National Advisory Committee on Palliative Care (2001) within the provision of a specialist palliative care team in the community. Murray (2011) identified the Mid West's community palliative care service as a national example for supporting carers/families and patients.

In conclusion, Milford Care Centre is leading the way to meet the recommendations of the National Advisory Committee on Palliative Care report in a manner that makes a difference to the patient and family experience and to the efficient use of resources nationally/regionally.

It gives me great pleasure to present the independent evaluation of Milford Care Centre's Hospice at Home Service completed by the University of Limerick. The seeds of this worthy project were first sown as far back as 2003, initially as a Care Assistant at Home project. Following its positive evaluation, that initiative then developed across the Mid West Region into Ireland's first specialist led multidisciplinary Hospice at Home Service, operating from a Specialist In-patient Unit, all of which were key recommendations contained in the Report of the National Advisory Committee for Palliative Care in 2001. It is evident from this report that MCC's vision to bring a fully developed specialist palliative care service to the community - to enable people be cared for and die in their preferred location - is clearly valued by patients and their families across the Mid-West. As a pilot project, we can also see great learning from the evaluation for ourselves as a service provider and for other providers who embrace the challenge of providing multidisciplinary, community based services to patients with complex needs at the end of life and their families.

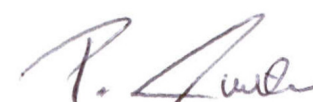
I would like to acknowledge the professionalism and commitment of the Research Team at UL who conducted this study and the Evaluation Committee who worked with them, to commend the hard work of the Steering Committee that oversaw the development of the project, to recognise formally the dedicated staff who deliver the service and sincerely thank the patients, families and professionals who contributed to the evaluation study itself.

This study was funded by The Atlantic Philanthropies who were able to identify with our vision of Hospice at Home and to assist us to make this model of service delivery a reality and to develop into what has now become part of mainstream service provision for patients and their families in the Mid-West. This project is yet another tribute to the wonderful generosity of Chuck Feeney and all at Atlantic Philanthropies, for whose support we are truly grateful.

One of the great strengths of palliative care service provision in the Mid West is the excellent partnership that has evolved down through the years between the Health Service Executive and Milford Care Centre. At the outset of this project the HSE responded positively by part funding the initiative and in more recent times, in recognition of the very positive impact of this service, they have agreed with MCC to co-fund the ongoing costs of this service, which effectively guarantees its sustainability into the future.

Clearly, many of the original objectives set for this project have been achieved. We are committed to implementing the findings of this important evaluation study, which no doubt will further enhance the quality of care for patients and their families in the communities throughout the Mid West Region.

I look forward to the continued development of the Hospice at Home Service and its positive impact on people's end of life experience.



Pat Quinlan, Chief Executive, MCC

April 2012

RESEARCH TEAM

Dr Elizabeth McKay, Department of Occupational Therapy, University of Limerick/Brunel University.
Email elizabeth.mckay@brunel.ac.uk

Dr Ann Taylor, Department of Physiotherapy, University of Limerick.
Email ann.taylor@ul.ie

Dr Claire Armstrong, Department of Occupational Therapy, University of Limerick.
Email claire.armstrong@ul.ie

Mary-Beth Gallagher, Department of Occupational Therapy, University of Limerick.
Email marybeth.gallagher@ul.ie

Maria Bailey, Department of Nursing and Midwifery, University of Limerick.
Email maria.bailey@ul.ie

Margaret Graham, Department of Nursing and Midwifery, University of Limerick.
Email margaret.graham@ul.ie

Dr Jason Ward, Consultant in Palliative Medicine, St Gemma's Hospice, Leeds, UK.
Email jasonw@st-gemmas.co.uk

The team acknowledges the support from Mary O'Sullivan (researcher) in the preparation of the final report.

gained from health professionals who interacted with the Service on an external basis. These included Public Health Nurses, General Practitioners and other members of Primary Care Teams.

KEY FINDINGS

The overarching finding from the evaluation was that the Hospice at Home Service was highly regarded and valued by its recipients. In general both carers and patients were highly satisfied with their interactions with members of the team and the service they provided.

With respect to the research questions the main findings are presented below:

1a. Do patients and their families experience the Service as helpful and supportive in terms of alleviating and mitigating the burden of illness and loss?

The evaluation indicated that overall the service exceeded the expectations of carers and it provided a high level of care and support. Carers commented on the responsiveness of the team regarding managing the patients symptoms, and team members were considered to be sensitive to the needs of carers and patients.

1b. Is the Service supporting the choice of patients and their families to be cared for at home and/or the patient's choice to die at home?

Importantly, the Service enabled patients to be cared for at home in accordance to their wishes and their symptoms were managed to an acceptable level which facilitated carers and family to spend time with the patient, and the majority of patients died in their preferred place.

2a. Is the Service well managed in terms of effectively co-ordinating all service inputs from professionals within Milford Care Centre?

Whilst carers and patients were satisfied with the service they received, its organisation, co-ordination and management needs to be reviewed to meet the demands of an evolving service.

2b. Is there effective co-ordination between the Service and the HSE's Primary Care Teams, notably those within the GP and PHN professional cohorts?

The Primary Care Teams regarded the Hospice at Home Service as a beneficial service, but they needed greater awareness of its range of services and clearer communication to maximise the benefits for patients and carers.

- 2a. Is the Service well managed in terms of effectively co-ordinating all service inputs from professionals within Milford Care Centre?
- 2b. Is there effective co-ordination between the Service and the HSE's Primary Care Teams, notably those within the GP and PHN professional cohorts?

METHODS

The methodology for the evaluation incorporated a range of approaches, including interviews, focus groups and questionnaires to ensure that the service users' (patients and families/carers), staff and other key stakeholders' perceptions of the Service were captured and that an in-depth exploration of differing agendas and priorities informed the findings. Of particular importance were the direct consultations and feedback from patients and their families/carers which emphasised a patient-centred approach. Whilst the methodology aimed to ensure depth and flexibility, the research team was cognisant of the sensitivity of the issues being explored.

STAGES OF THE EVALUATION

Following consultations between the research team and the Steering Committee, four phases of the research project were identified and conducted between February 2009 and June 2011. The first phase focused on the conceptual background for the research study and included the development of a framework for the evaluation and reviews of literature, policies and national and local databases, each of which informed the methodological aspects of the research. Following on from the identification of local datasets in the first phase, a strategy for identifying and recruiting participants was established, together with the selection of a mixed methods approach to optimise the quantity and quality of the data.

The second and third phases of the study were primarily concerned with surveying patients and families/carers who had been recipients of the Hospice at Home Service. This was conducted via questionnaires and semi-structured interviews and covered a range of issues common to both groups concerning their viewpoints of the Service. Concomitant with the collection of information from the service-users, the views of Milford Care Centre staff were collected by both focus groups and individual interviews. This fourth phase of the study coincided with the second and third phases, and was conducted by a group of researchers independent to those gathering information from the service users, thus maintaining objectivity and unbiased reporting. Further perspectives on the Service were

MILFORD CARE CENTRE HOSPICE AT HOME EVALUATION STEERING COMMITTEE

Dr Kathleen McLoughlin, Head of Education, Research and Professional Development, Milford Care Centre (Chairperson)

Jim Rhatigan, Head of Therapy and Social Care, Milford Care Centre (Vice Chairperson)

Dr Sinead McGilloway, Senior Lecturer in Psychology, NUI Maynooth (External Adviser)

Dr Penny Mainstone, Locum Palliative Medicine Consultant, HSE/Milford Care Centre

Edith McMahon, Hospice at Home Project Co-Ordinator, Milford Care Centre

Carol Murray, Head of Non Clinical Support Services, Milford Care Centre

Jacqueline Holmes, Deputy Director of Nursing, Milford Care Centre

Martina O'Reilly, Quality and Safety Co-Ordinator, Milford Care Centre

Gail Birkbeck, The Atlantic Philanthropies.

ACKNOWLEDGEMENTS

This evaluation would not have been possible without the support and commitment of the Management Team and staff members of the Hospice at Home Service at Milford Care Centre and in particular, members of the Evaluation Steering Committee.

The input from external professionals within the Primary Care Teams as well as GPs in the region who have been involved in the Hospice at Home Service has been of considerable value to the evaluation process and complemented the input from those within Milford Care Centre.

Of particular note is the enormous contribution and efforts that patients, their families and carers have made to this evaluation process in sharing their experiences and opinions so openly for the benefit of others.

EXECUTIVE SUMMARY

BACKGROUND AND CONTEXT

Milford Care Centre is the lead organisation that provides a comprehensive range of services for the elderly and palliative care patients in the Mid West Region. In tandem with the growing requirement for specialist palliative care in the community, it expanded its existing and limited community-based services in 2006 to include a specialist 'Hospice at Home' service for patients who require palliative care in their own homes. With inputs from a multi-disciplinary clinical team, the Hospice at Home Service delivered by Milford Care Centre represents the first service of its kind within the Republic of Ireland.

The Hospice at Home Service is supported by funding from the HSE and donations from the public, as well as a significant donation from The Atlantic Philanthropies. A condition of the funding from The Atlantic Philanthropies was that the Service would be evaluated, thus providing Milford Care Centre with research information regarding various aspects of the service, including the viewpoints of carers and patients.

In 2009, Milford Care Centre commissioned the University of Limerick to undertake an independent evaluation of the Hospice at Home Service, with the aim of examining whether it offered a viable and effective model for delivering a range of palliative care services to patients and their families in the community. The evaluation was conducted between February 2009 and June 2011. It should be noted that an evaluation of the cost effectiveness of the Service was also commissioned and will be undertaken by another group.

AIMS AND OBJECTIVES

The Terms of Reference for the evaluation identified two core themes to be examined:

- The quality of the Service and its impact on quality of life for carers and patients; and
- The management and co-ordination of the Service at both intra-agency and inter-agency levels.

Based on these themes, the evaluation sought to answer specific questions regarding the Hospice at Home Service:

- 1a. Do patients and their families experience the Service as helpful and supportive in terms of alleviating and mitigating the burden of illness and loss?
- 1b. Is the Service supporting the choice of patients and their families to be cared for at home and/or the patient's choice to die at home?