

**Irish Medical Organisation  
Submission to the  
Irish Hospice Foundation's  
End-of Life Forum**

**March 2009**

## **IMO Submission to the Irish Hospice Foundation's End-of Life Forum**

The Irish Medical Organisation welcomes the opportunity to make a submission to the End of Life Forum under the heading of Healthcare. The IMO supports the work of the Irish Hospice Foundation and would like to commend them on the excellent work carried out, and for initiating a holistic discussion on this complex and sensitive issue.

### **Lack of resources**

Approximately 28,000 people die in Ireland each year. Two-thirds (18,000) die in acute or general hospitals. (40% die in an acute hospital setting), of which approximately half (9,000) are people over 65 years. A further 9,000 people over 65 years die in community hospitals and nursing homes for the elderly.<sup>1</sup>

In recent years, there has been a focus on transferring the best practice from the hospice setting to acute and long stay settings because this is where the majority of people die. This has led to initiatives such as the Hospice Friendly Hospital Programme and the HIQA – Draft National Quality Standards for Residential Care Settings for Older People.

While the IMO welcomes and supports such initiatives, the IMO is concerned that policy is not put into practice and that resources to fund such initiatives are severely lacking. A clear HSE strategy on palliative care in the acute hospital setting is required.

While the majority of people die with dignity, recent studies<sup>2 3</sup> into end-of-life or palliative care in acute and long stay settings have consistently highlighted the following issues:

- Availability of single rooms at time of death is low in acute hospitals with those available prioritised for infection control (MRSA etc);
- Few designated palliative care beds, in both acute and long-stay settings;
- Low levels of access to consultant-led palliative care teams particularly in long-stay facilities;
- Lack of formal palliative care training in non-specialist healthcare staff;
- Low provision of formal bereavement support services available before and after death in both acute and long-stay facilities;
- Poor facilities for families and friends.

If the needs of end-of-life patients and the control of infection are to be met the ratio of separate single units of accommodation to multi-occupancy wards must be higher than 50%.<sup>4</sup> Substantial investment in single-room accommodation is required to meet those needs.

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<sup>1</sup> Hospice Friendly Hospitals, *The Hospice Friendly Hospitals Design and Dignity Guidelines for Physical Environments of Hospitals Supporting End-of-Life Care*. 2008, Irish Hospice Foundation: Dublin.

<sup>2</sup> Irish Hospice Foundation, *A Baseline Study on the provision of Hospice/Specialist Palliative Care Services in Ireland*. 2006: Dublin.

<sup>3</sup> O'Shea, E., Murphy, K., Larkin, P., Payne, S., Froggatt, K., Casey, D., Ní Léime, A. and Keys, M., 2008. *End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland*. Dublin: NCAOP/IHF.

<sup>4</sup> Hospice Friendly Hospitals...2008,

Investment is also needed in the provision of palliative care beds and teams outside of the acute hospital setting. According to the IHF, it would appear that where there is a shortfall in hospice and specialist palliative care services or where they are underdeveloped, more people die in acute general hospitals. Where services are more developed, there appears to be an increased incidence of death occurring in a hospice/palliative care inpatient unit or home setting.<sup>5</sup>

While the majority of referrals to general hospital from nursing homes are appropriate,<sup>6</sup> in the final stages of their illness many older patients are transferred needlessly to general hospitals due to understaffing and lack of training in long-stay facilities.<sup>7</sup> This often results in discontinuity of care and the disruption can also cause confusion and deterioration of their condition.<sup>8</sup>

Palliative care is a core component of training in gerontological nursing. With adequate numbers of trained gerontological nursing staff combined with access to specialist palliative care teams, older patients need only be transferred from long-stay care to acute hospitals for clinical reasons.

Palliative training for non-specialist staff in general hospitals and communication between settings can ensure continuity of care when transfer is needed.

In both settings, staff trained in palliative care can also better communicate with patients and their families regarding their end-of-life needs and requests. Management also need training in palliative care ethos in order to support changes in care practice and organisational structure<sup>9</sup> so the needs and requests of patients and their families are met.

## **Older People and End-of-Life Care**

End of life care involves more than just the transfer of hospice care principles to the acute hospital and long-term care setting. End of life care for old people suffering from non-malignant chronic diseases is a particular area of neglect and mirrors the under-assessment of older people's wider needs often encountered in the health system.<sup>10</sup>

The 2008 report *End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland* further highlighted the following barriers to good end-of-life care for older people:

- Low access to Specialist Palliative Care for patients with non-malignant life-limiting diseases;
- Lack of communication between services leading to lack of continuity of care;
- Poor symptom control.

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<sup>5</sup> IHF... 2006

<sup>6</sup> P Gallagher, N O'Riordan, O O'Sullivan, C Henry *Analysis of admissions to an acute hospital from long-term care facilities* Irish Journal Of Medical Science, Vol. 174 No. 3 Sup. 2 p38.

<sup>7</sup> O'Shea, et al. ...2008 p49

<sup>8</sup> O'Shea, et al. ...2008 p 48-49

<sup>9</sup> O'Shea, et al. ...2008 p 49-50

<sup>10</sup> AGS Panel on Persistent Pain in Older Persons. *The management of persistent pain in older persons*. Journal of the American Geriatrics Society, 2002, 50:S205-S224.

Unfortunately, this report was weakened by a failure to assess the level of gerontological nursing expertise within long term care, an extraordinary omission given the key role that gerontological expertise provides in end-of-life care. The report recognised this deficit by recommending that new models and approaches which bring about a greater fusion between end-of-life and gerontological care within all long-stay settings in Ireland should be tested.<sup>11</sup>

End-of-life care needs to take into account the long-term and unpredictable trajectories of chronic non-malignant diseases affecting older people. The most common causes of death amongst older people are cardio-vascular disease including stroke, cancer and chronic obstructive pulmonary disease (COPD). Old people often suffer from one or more chronic diseases making it difficult to ascertain the actual cause of death. Similarly dementia and frailty are also important and increasing causes of death among older people, but are not generally recorded as the primary cause of death.<sup>12</sup>

The disease trajectory of cancer is characterised by steady progression ending in a short period of evident decline when palliative care services need to be mobilised. The trajectory of people suffering from heart failure or COPD shows a pattern of gradual decline with intermittent exacerbations often requiring emergency hospital admission and ending in sudden death. While the trajectory of those suffering from dementia, frailty, disabling stroke and motor neuron disease is of pro-longed decline from an already low baseline of physical or cognitive functioning.<sup>1314</sup>

End-of-life care needs to incorporate palliation as a during-life component of elderly health care, starting at a low base, and rising to eventually become the predominant theme.<sup>15</sup> Because of the unpredictable and long-term trajectories of non-malignant diseases, geriatricians are faced with the difficult task of negotiating the juncture between being gravely ill and dying.<sup>16</sup> For such diseases it is often appropriate that non-specialist or specialist palliative care should be provided alongside disease modifying and life-prolonging interventions.<sup>17</sup>

Also people with life-limiting chronic disease require services from a wide variety of healthcare professionals, along with self-management and the participation of family or carers.<sup>18</sup> Often the majority of care is provided at home with transfer to acute or long-stay facilities at intermittent intervals or as the patient comes closer to death. As mentioned above non-specialist health professionals, including GPs, are inadequately trained in palliative care. In addition the needs of informal carers are often poorly understood and adequate support should be provided.<sup>19</sup>

## Conclusion

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<sup>11</sup> O'Shea et al...2008 p 22

<sup>12</sup> IHF... 2006 p30

<sup>13</sup> Lynn J, Adamson DM. *Living well at the end of life: adapting health care to serious chronic illness in old age*. Arlington, VA, Rand Health, 2003.

<sup>14</sup> HSE and IHF, *Palliative care for all- Integrating Palliative Care into disease management frameworks*, 2008

<sup>15</sup> Lynn and Adamson...2003

<sup>16</sup> Finucane TE. *How gravely ill becomes dying: a key to end-of-life care*. JAMA. 1999 Nov 3;282(17):1670.

<sup>17</sup> HSE and IHF...2008 p15

<sup>18</sup> HSE and IHF...2008 p11

<sup>19</sup> Shipman C, et al. *Improving generalist end of life care: national consultation with practitioners, commissioners, academics, and service user groups*. BMJ. 2008 Oct 1;337:a1720.

The IMO is concerned that current initiatives to improve palliative care in acute hospital and long-stay care facilities are under-resourced. However end of life care is broader in focus and needs to incorporate palliation as a during-life component of elderly healthcare as old people are the demographic group most affected.

**IMO Recommendations:**

- A clear HSE strategy on palliative care in the acute hospital setting is required;
- Palliative care services need to be adequately funded;
- Training programmes for all health care professionals should include awareness of end-of-life issues;
- All clinical health care professionals should be given compulsory training in palliative care provision;
- The recommendation of the Leas Cross report, strengthening the input of gerontological nursing into nursing home care, should be fully implemented, so as to ensure that palliative principles are incorporated into the during-life care of older people in nursing homes;
- Dialogue and collaborative work should continue between palliative care, geriatric medicine, old age psychiatry and general practice as to optimal models of palliative care for older people;
- Palliative care should also be integrated into all chronic and life-limiting disease management programme;
- End-of-life care should be patient focused - Communication and continuity of care across all healthcare settings needs to be improved;
- Needs of informal family home-carers should be assessed and adequate support provided.