

**SUBMISSION TO JOINT COMMITTEE ON HEALTH AND
CHILDREN**

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LEINSTER HOUSE,

DUBLIN 2.

DR. PAUL GREGAN,

Consultant Palliative Medicine, Blackrock Hospice, Dublin (half time) and
Principal in General Practice, Deansgrange, Co. Dublin (half time).

DEATH IN THE COMMUNITY

“Life is mostly froth and bubble,
Two things stand like stone.
Kindness in another's trouble,
Courage in your own.”

Adam Lindsay Gordon (1833 – 1870)

Introduction

The Irish people have been historically attuned to the concept of death. This is reflected in our history, literature, mythology, cultural practices and archaeology from Newgrange to martyrdom to ‘waking’ the dead. This aliveness to the concept of dying has allowed the care of those near to death to achieve a special standing in our healthcare system. These are the patients for whom clinicians will “go the extra mile” and this ‘above and beyond’ care is special. It is a manifestation of true empathy, a recognition that ‘they’ will one day be each of us. Planning the care of the dying is also planning the care of ourselves and ‘our own’ in due course.

There is a symmetry in our lives in that we are laboured into, and out of this world. Often it is the care of people in this last labour that can most challenge, yet most reward us as health care professionals. Ask any doctor or nurse why they embarked on their career in the first place and they will tell you that it was to help the sick get better. Palliating illness - making people feel better despite their illness- is therefore a central part of why we do what we do, in no matter what branch of healthcare a person works.

Because Palliative care in effect flavours all clinical care, it should be integrated across all systems of medical care in this country. There is no country in the world without its bureaucratic or financial restrictions but every country can have a palliative ethos to its care.

Palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness. It is individualised, patient centred, holistic care. It is life affirming, and whilst care of the *imminently* dying is part of the care provided, living before dying is its central focus.

Palliative care services may be structured in three levels of ascending specialisation according to the expertise of the staff providing the service.

- **Level one – Palliative Care Approach:** Palliative care principles should be appropriately applied by all health care professionals.
- **Level two – General Palliative Care:** At an intermediate level, a proportion of patients and families will benefit from the expertise of health care professionals who, although not engaged full time in palliative care, have had some additional training and experience in palliative care. ('generalist')
- **Level three – Specialist Palliative Care:** Specialist palliative care services are those services whose core activity is limited to the provision of palliative care.

Primary palliative care

This is level 1 and level 2 palliative care delivered in the community by GPs and primary care team/nursing home team. In fact 90% of the care in the last year of a person's life is provided by the GP and the primary care team.

Up to very recently, the domain of palliative care has traditionally been linked with cancer, and associated with specialist palliative care (SPC) services. Those dying from non malignant disease, however, account for 71% of all deaths and it has been recognised for some time that the palliative care of people dying of such illnesses is equally necessary. There is also recognition that not every person with life limiting illness requires specialist palliative care input. High quality care of those with life limiting illness and uncomplicated dying should be a routine for primary care clinicians.

International developments

Prague charter

The Prague Charter for palliative care as a human right (2013) was formulated by a collective of world palliative care bodies to urge governments of the developing and developed world to:

1. Develop and adopt health policies that address the needs of patients with life limiting or terminal illnesses.
2. Ensure access to essential medicines for all who need them.
3. Ensure that healthcare workers receive adequate training on palliative care and pain management at undergraduate and subsequent levels.
4. Ensure the integration of palliative care into health-care systems at all levels.

In other jurisdictions, for the past decade, there has been significant policy and strategic developments to support primary care teams responding to the palliative care needs of those with life-limiting disease. The UK End of Life Care strategy, which was published in 2008, has provided the NHS with guidance and frameworks to support and monitor developments in the area of care at end of life in all settings, and these are co-ordinated by the National End of Life Care Programme.

The recent review of funding that has been linked to the implementation of the UK End of Life Care strategy has recommended that models of funding and service delivery need to ensure equity of provision in this area of care.

2011 has seen the emergence of international guidance and research structures to support the development of primary palliative care, including the establishment by the European Association of Palliative care of the Taskforce on Primary Palliative care, and the publication of a report by WHO Collaborating Centre for Public Health Palliative Care.

Research in the delivery of primary palliative care has highlighted the need for greater role clarity amongst professional groups as to their responsibilities in 'generalist palliative care delivery' as well as further provision of education and training in communication and symptom control in order to enhance their service provision.

Irish context

Death and Dying in Ireland

The delivery of palliative care is the responsibility of the whole healthcare system. Only 10% of deaths are sudden and unexpected so the care of 90% of people dying can be planned at individual and population health levels. The care of the dying is an absolutely predictable need, and varies little at population level year to year. Planning such care is thus eminently do-able for a modern healthcare system.

The projected demographic shifts relating to life expectancy signal that people in Ireland will live longer, albeit with associated chronic illnesses. This increase in comorbidity coupled with an ageing population (effectively doubling numbers of people >65 years old between 1996 and 2031) will result in greater demands on community-based health care services.

Specialist palliative care (SPC) community teams are potentially available to every person who might die at home (although not all areas have a 7 day a week service). These services respond to those who are dying with complex and demanding care needs, and support primary care teams delivering palliative care to only about 23% of those who die in community settings every year. This means that the care of over ¾ of those dying in the community (albeit with usually less complex need) is provided solely by GPs and community nursing services as the main providers of 'generalist' palliative care for those living before dying at home or in the nursing home. The report of the National Advisory Council on Palliative Care recommended that SPC nurses should act as a resource

to community-based health professionals, and that a 24-hour telephone advisory service should be available to support the provision of palliative care in all care settings.

An Irish Hospice Foundation study in 2004 found that two thirds of people wish to die at home (and just 10% expressed a preference to die in hospital). However of the 29,000 deaths per annum in Ireland, the majority of deaths (43%) occur in acute hospitals and just 26% of these deaths take place at home. The remainder 25% of deaths take place in long stay facilities with 6% taking place in hospice settings

HSE PALLIATIVE CARE PROGRAMME

The aim of the HSE's Palliative Care Programme is to ensure that patients with life-limiting conditions and their families can easily access a level of palliative care service that is appropriate to their needs regardless of care setting or the nature of their diagnosis. While it does not have the operational control to mandate service developments, the Programme can set the strategic direction for future service development.

In 2012, one of the clear objectives articulated was to strengthen generalist palliative care services in order to strengthen access and quality of care.

Primary care

Research shows that 90% of the last year of life is spent in community settings, with care delivered by the GP/ primary care teams (PCTs). The average fulltime GP will manage the medical care of 12 deaths per year or 1 a month, nearly half of which will occur either at home or in another community setting e.g. nursing home.

With often prior knowledge of an individual patient, his/her background, medical history, and wider psychosocial perspective, GPs and public health nurses/nursing home nurses are in fact extraordinarily well positioned to provide excellent care to those expected to die imminently or soon. They are in a unique position to reach patients with all life threatening illnesses, to start early in the course of the disease, provide care in clinics, home and at care homes, prevent unnecessary hospital admissions and support family and carers right through to their bereavement. Most are skilled in holistic type care engaging in physical, psychological, social and spiritual dimensions in the care. GPs and primary care teams need nurturing and support in their provision of this care which for many is contemporaneously the most difficult and most rewarding that they will provide.

However, while there is an expectation that they will manage this community end of life care, they will need financial, practical, educational and emotional support to do so.

Such care is relatively inexpensive but is threatened by general financial reductions in primary care which is critically threatening general practice as we know it in this country (FEMPI reductions). This undermines the delivery of palliative care by over- stretched primary care teams and risks jeopardising the unseen pro bono effort that GPs in particular make.

There is ample evidence that practical structural measures (such as the Gold Standards Framework (GSF) in the UK) help primary care co-ordinate and manage the care of their dying in the community, and since 2005 a primary palliative care research group is up and running within the European Association of Palliative Care to enhance the research base behind such measures. However in Ireland, unlike other countries, there is no formal framework to support community-based health care staff to assist them identify and respond to the palliative care needs of those people who are facing death in the community.

Educational support is a necessary scaffolding for the delivery of any service and targeting education at the providers of this care will be helpful in ensuring its quality. Specific educational modules to GPs providing out of hours services would be helpful.

Emotional support is something that primary care teams usually lack. There can be ongoing emotional pressure and distress imparted to a primary care team trying to manage the care of the dying in the community. Recognition of this in the form of availability of counselling support to debrief following difficult and critical interventions will help to keep the primary care team healthy.

The innate humanity, dignity and flexibility in the care that these professionals provide, in often unsupported situations, is something that cannot be taught or bought. But it must be supported by adequate resourcing and accessible educational provision.

Primary palliative care initiative

In 2010 the Irish Hospice Foundation, in partnership with the Irish College of General Practitioners and the HSE established the Primary Palliative Care (PPC) initiative, in order to identify improvements and initiatives that would support the primary care team's palliative care provision to adults living with advancing life-limiting diseases in the community. The National Steering Committee, which was established to support the work of this programme, was representative of professional groups and relevant HSE structures covering both primary care and specialist palliative care.

One of the first actions of the programme was to undertake a survey in 2010 of 182 primary care healthcare professionals in five local health areas (over one quarter of respondents were GPs). Respondents were asked about their experience of caring for the dying and what initiatives would help them in delivering end-of-life care in the community.

Among the varied findings of the survey, 66% of respondents felt that training in symptom control such as pain and emotional distress would be a useful educational initiative and 47% looked for further training in care for imminently dying patients at home— something particularly favoured by nurses. Another 31% of respondents wanted more education in prescribing in palliative care. This was sought primarily by GPs.

The survey also found that one in three family doctors never informed their out-of-hours service about patients who were at home with palliative care needs. This parallels other research suggesting that 82 % of doctors do not *routinely* do so.

During an extensive consultation process, healthcare professionals in the community identified key practical aspects of service development which would enhance patient palliative care in the community.

72% wanted access to a Specialist Palliative Care 24 hour helpline

60% wanted a summary of patient notes available in the home setting

60% sought education in symptom control

Nearly **40%** supported the introduction of a method to identify patients in the community who require palliative care approach.

Based on this consultation as well as other research, and a review of best practice and emerging developments, the second phase of the Primary Palliative Care initiative has begun. This involves the implementation of a number of initiatives contained in the report *Primary Palliative Care in Ireland. Identifying Improvements in Primary Care to Support the Care of Those in Their Last Year of Life* (IHF, HSE, ICGP_2011).

The implementation phase is attempting among other things to develop an electronic palliative care handover form (similar to a Scottish model) to allow family doctors to regularly update GP Out of Hours Services, with relevant background information on the changing needs of dying patients. This may ultimately be helpful to transmit information across various interfaces between services e.g ambulance service, Accident and Emergency depts., night nursing services etc.

The programme is also looking to develop a practice based system to identify and respond to patients with palliative care needs in the community

Professional bodies involved in the training and development of primary health care staff will be encouraged to signpost existing education and training options in palliative care.

The programme is attempting to clarify the extent and means of accessing advice and information from specialist palliative care on a 24-hour basis. This may involve currently operational consultant rotas providing out of hours advice to GPs, to assist them in their out of hours decision making and management of palliative care patients in the catchment area (if required).

In addition to developing new initiatives and also making better use of existing resources over the next year, there are also some recommendations aimed at filling significant gaps in service provision such as:

- The need for flexible out of hours nursing, building on the Irish Cancer Society Night nursing service
- Better communication systems between primary, secondary and tertiary care providers
- Timely access to specialized equipment and palliative medication
- Further research into the management of syringe drivers by members of the primary care team

The main thrust of this work is in trying to secure a more comprehensive coordination in planned care, bettering communication between all the professionals involved in the care of the dying in the

community. This will help to further ensure that the patient enjoys a good quality of life in what little time remains.

The work is timely as we have an ageing population that will nearly double in number over the next 20 years. Ahead of this, it is essential that we look now to see how we can enhance the end-of-life service that is being offered to our patients and their families and begin to establish a framework to support the delivery of this care by community based healthcare professionals. It is also feasible to improve this aspect of care delivery within the current fiscal restrictions by doing the simple but important things well.

It stands to reason that the more support the primary care team can be given, the better the chance that people, with life limiting illness, will have their advancing care needs anticipated and be cared for in the most appropriate setting.

In effect, two central pillars of governments focus must be to support the dying, and to support the professionals who in turn support the dying. Ultimately, the aim is to enable people to die comfortably in the care setting that best suits their needs and help reduce inappropriate emergency admissions to expensive acute hospitals.

RECOMMENDATIONS FOR ACTION

PATIENT

MEDICAL CARD PROVISION

There is no doubt that the provision of a discretionary medical card to those with an estimated prognosis of 6 months or less is a most welcome support provided to people at the end of their lives. By allowing a frail and weakening person access to a suite of supports e.g. public health nursing, community occupational therapy, aids and appliances and potential home adjustments, medication, community physiotherapy, etc. makes an enormous difference to their sense of security. Recent clarification regarding eligibility has been most welcome.

Unfortunately prognostication is an inexact science and from unpublished research we estimate that about 20% of such discretionary cards require renewal after 6 months, although it is unlikely for obvious reasons that such extensions would be for very long. Clearly, however, an individual with an advancing illness is very likely to be in even greater need at that point.

ACTION POINT Renewals on the basis of a covering letter from GP or consultant would mean that the imminently dying can avoid onerous paperwork.

PRIORITISATION

That palliative care patients have a “*special patient*” status that prioritises their needs across community services. This is already informally in place for example in OT... Budget for aids and appliances for palliative care patients at home NACPC

ACTION POINT That there is a fast track to services

FAIR DEAL

ACTION POINT That palliative care patients waiting to access fair deal beds are prioritised as their prognosis often precludes waiting on a waiting list. Also that funding from the ‘Fair Deal’ scheme could be accessed to fund care packages to allow people to stay in their own homes.

ADVANCED CARE PLANNING

ACTION POINT That further role out of helpful projects in this area be considered to support people with life limiting disease, their families and health care professionals think about, talk about and document their end of life care wishes and preferences.

NURSING

ENHANCE COMMUNITY NURSING TO SUPPORT THOSE DYING AT HOME

ACTION POINT

There is a need for a designated budget for community palliative care nursing services which would include funding to provide nursing cover after 5pm, throughout the weekend and also the hours between 7am and 11am when the night nurse leaves the house.

Essentially night nursing should be integrated into the existing community palliative care service and primary care provision. Currently the Irish Cancer Society (ICS) is providing the only national nursing service at night for cancer patients who wish to remain at home for end of life care. This is all funded through charitable donations and the ICS receives no government funding for the service. Charitable Night nursing services provided by the ICS for patients dying at home, providing 7,600 nights of care to 1865 people in 2012 at cost €2.6m (includes €400,000 contributory funding by the Irish Hospice Foundation for 350 people with non malignant disease). This service allows for up to seven nights of experienced home nursing at night, during the dying phase of a person's illness. To ensure that this essential service remains, funding should be provided from statutory sources rather than relying on good will of the Irish citizens.

There is a need to fund specialist palliative care community nursing teams to provide a 7 day a week service as palliative care needs do not stop for weekends.

MEDICAL

STATUTORY SUPPORT FOR COORDINATION, DELIVERY AND EDUCATION

ACTION POINT Statutory support for the development of the electronic Palliative Care Summary

ACTION POINT Statutory support to develop GP practice based computer systems to help in the co-ordination of the care of the dying at home

ACTION POINT Statutory support for further palliative education for GPs, Primary care teams and out of hours GP services

There should be monetary acknowledgment of the additional co-ordination, communication, advance care planning and bereavement services delivered by GPs for people with chronic heart failure, respiratory disease, end stage kidney disease, advancing neurological disease and dementia. At present this applies only to the care of patients dying of cancer and HIV. This should be based on proof of quality delivery of end of life care.

ACTION POINT Enhance palliative care payment for GPs to patients with all life limiting disease

SUMMARY

There is emerging evidence to suggest that *where* people die has an impact on *how* they die, and that those who die at home and in the place they prefer have a better 'quality of dying' than those who do not, and this positively impacts on the bereavement and loss experience of their families. Evidence collated from Ireland and the UK suggests that between 22% and 40% of deaths in hospitals could have taken place at home, since the patients did not have medical needs requiring hospital treatment and therefore could have been cared for elsewhere. This strongly suggests that more could be done to facilitate people to die where they would wish.

We owe it to our dying to mind them through a very critical phase of their lives. The care of the dying is an innate intuitive response by human beings for one another. It is relatively inexpensive care and the delivery of this care at home will require ongoing leadership and championing by all who continue to deliver it.