



DEPARTMENT OF HEALTH

Rheynn Slaynt

End of Life Care Framework and Implementation Plan for Adults 2012 - 2015



Isle of Man
Government

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"How people die remains in the memory of those who live on"

- Dame Cicely Saunders (1918–2005)



Foreword

Whilst death is inevitable, and all of us at some time experience the death of friends and loved ones, death remains a subject which we are all very reluctant to discuss, often until it is too late to do so. Nonetheless, in the Isle of Man Health Service it is a subject which we have to deal with every day. We understand the importance of the care which people receive in the final stages of their lives, and the profound effect that death has on those left behind.

Over a period of several years leading up to 2009 we began to realise that the range of care we provided for dying patients was falling behind the integrated care increasingly provided by the UK National Health Service which had, for several years, invested heavily in improving End of Life Care. We needed to catch up and therefore, with the invaluable and most generous support of Macmillan Cancer Support we were able to appoint Kirstie Turner to the post of End of Life Care Project Facilitator, on a 2-year secondment from Hospice Isle of Man. Kirstie has researched best practice across the World and, most importantly, conducted a survey of people who had been affected by death or were interested in End of Life Care. The response of the Manx public was outstanding – over 1200 responses resulting in over 30,000 items of information. One unexpected but very welcome result of the survey was that we discovered that it had encouraged people to think and speak about death with their friends and relations, and to plan ahead. The results of survey and the research, plus input from professional and interested community groups and the comments of individuals has provided the core information for the creation of this, the Isle of Man's first ever End of Life Care Framework.

Of course, Frameworks, Plans and Strategies are of no use at all if they simply sit on a shelf and are never implemented. We are determined that this Framework **will** be implemented and it therefore contains an Implementation Plan which will guide the development of End of Life Care Services for the next three years.

I hope that as many people as possible, both professional and public, will read this Framework for it contains not only information for the Health Service and other Government departments, but also members of the public themselves. They have probably the most important role of all in End of Life Care – thinking, planning and making others aware of what End of Life Care they want for their relatives, friends and – most important of all – themselves.

David M Anderson MHK
Minister for Health



Executive Summary

The process of creating the End of Life Care Framework and Implementation Plan has shown that whilst we often provide excellent care for individuals approaching the end of their lives, it can be inconsistent and uncoordinated. This is sometimes because of limited resources and sometimes because staff and carers lack the necessary knowledge and skills. We therefore need to invest more time and resources in education, training, communication and the coordination of services. Much of this can be achieved within existing resources by working smarter and communicating more effectively.

There is also considerable unmet need around enabling people to make choices of where they wish to die and then delivering the support they require to achieve that. This will require the department to realign some of the services we provide and to adopt a more thorough and consistent approach to care planning for those reaching the end of their lives.

At the very end of life, there are some relatively straight forward procedural and guideline changes which we can make, supported by education and training, to improve the care we provide.

We also need to provide more educational, skills and practical support for carers, including informal carers such as family members, and provide them with more support after the death of the patient.

Finally, perhaps the biggest and most challenging task is to lead a change in society's recognition, understanding and acceptance of death as relevant to everyone. To enable society to recognise end of life care as an acceptable and indeed important topic for discussion, and something in which everyone can play a part in helping to improve the experiences of those who die, and those who are left behind.



End of Life Care Framework and Implementation Plan

1. Introduction

This End of Life Care Framework and Implementation Plan represent an important milestone for Health and Social Care Services on the Isle of Man. It is the first comprehensive framework aimed at promoting high quality care, throughout the Island, for all adults approaching the end of life.

The End of Life Care Project was a two-year project, established to produce an End of Life Care Framework for the Isle of Man. The Framework is based on the views and wishes of the people of the Island and how they would want end of life care to be delivered to them. Macmillan Cancer Support has funded this two year project.

An important feature of this framework is the public's involvement in providing key information on which the strategic direction is based. In addition, the framework considers the department's ability to provide care through multidisciplinary teams from health, social care and the third sector.

Every year around 820 people die on the Isle of Man. We know that although most people receive excellent end of life care, some do not. One of the fundamental issues is that services are not always joined up and as a result communication between staff and services is not always as good as it should be. From our End of Life Care questionnaire '*Getting Your Views*' (2011) we know that 43% of respondents would wish to die at home, given the opportunity and right support, however many others would wish to die elsewhere.

Although every individual may have a different idea about what would for them constitute a 'good death', for many these would involve:

- Being treated as an individual, with dignity and respect;
- Being without pain and other distressing symptoms;
- Being in familiar surroundings;
- Being in the company of close family; and
- Being in the company of friends.

The End of Life Care Project questionnaire '*Getting Your Views*' (2011) gave the public the opportunity to express their views on end of life care. Health and Social Care Professionals and Third sector groups and individuals also had the opportunity to participate through focus groups.



The questionnaire resulted in 1215 responses and approximately 30,000 items of data and information. This response equates to 1.9% of the adult population.

For many people, and their families, the ability to choose where they are cared for in the final phase of their life, and having the ability to determine, as far as possible, the place of their death, is important. However, this is not always possible due to circumstances beyond our control. In other circumstances, where such may be possible, their wishes cannot be complied with due to the lack of sufficient and flexible care provision.

Aim of the End of Life Framework

The Framework builds on the vision and expertise of many people from a wide number of Health and Social Care organisations.

The aim of the framework and implementation plan is to bring about improvements in all aspects of end of life care. This is for all people approaching the end of life, their carers and families, irrespective of age, gender, ethnicity, religious belief, sexual orientation, diagnosis or socio-economic deprivation. Implementation of this plan will enhance sustainable choice, quality, equality and value for money.

The aim can be achieved through the following objectives:

- To increase public awareness and discussion of death and dying. This will make it easier for people to discuss their own preferences around end of life care and should also act as a driver to improve overall service quality;
- To ensure that all people are treated with dignity and respect at the end of their lives;
- To ensure that pain and suffering amongst people approaching the end of life are kept to an absolute minimum, with access to skilful symptom management for optimum quality of life;
- To ensure that people's individual needs, priorities and preferences for end of life care are identified, documented, reviewed, respected and acted upon;
- To ensure that the many services people need are well coordinated, so that patients receive seamless care;
- To ensure that high quality care is provided in the last days of life and after death in all care settings;
- To ensure that carers are appropriately supported both during a patient's life and into bereavement;



- To ensure that health and social care professionals at all levels are provided with the necessary education and training to enable them to provide high quality care; and
- To ensure that services provide good value for money for the taxpayer.

A working Definition of End of Life Care

End of life care is care that:

Helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support. (National Council for Palliative Care 2006)

What this End of Life Framework will mean for patients and carers

Implementation of this Framework will mean that patients and carers will have access to:

- a) The opportunity to discuss personal needs and preferences with professionals, who can support them. The patient's preferences and choices will be taken into account and accommodated wherever possible.
- b) Coordinated care and support, ensuring that the patient's needs are met irrespective of who is delivering the service.
- c) Specialist advice and clinical assessment wherever the patient is being cared for.
- d) High quality care and support during the last days of the patient's life.
- e) Services that treat the patient, their family and carers with dignity and respect both before and after death.
- f) Appropriate support and advice for families and carers.

2. Challenges of End of Life Care

The End of Life Care Framework and Implementation Plan provides the strategic direction for End of Life Care on the Island for the next three years. It is designed to inform and guide all of those involved in the delivery of End of Life Care wherever that may be. Crucially the document is also designed as a collaborative approach, between Health Care, Social Care, and the Third Sector.



The demographics of death in relation to age profile, cause of death and place of death have changed radically over the course of the past century. During the 1900's many people died suddenly and at any age largely from infectious diseases and most people died in their own homes.

Familiarity with death within society as a whole has decreased. Many people nowadays do not experience the death of someone close to them until they are well into midlife. Many have not seen a dead body, except on television. As a society we do not discuss death and dying openly. The resulting cultural resistance to acknowledging the reality of death and dying as inevitable and integral parts of life and reluctance to discuss these, particularly in the context of health service focussed on "cure" rather than "care", can contribute to poor communication and planning of end of life care. (End of Life Care Strategy 2008; Living and Dying Well 2008).

Local statistics similar to those in the UK identify that the majority of deaths occur following a period of chronic illness related to conditions such as

Primary diagnosis	Admissions in 2011 to Noble's Hospital
Chronic Obstructive Pulmonary Disease	107
Stroke	128
Diabetes	71
Cancer	607
Heart disease - chronic	445
Liver disease - chronic	128
Renal disease - chronic	71
Neurological disease – including MND, MS, Parkinson's disease	259

Dementia – as of 2007, 1110 individuals on the Island had dementia, by 2051 this is estimated to be 2817.

Currently approx 820 people per year die in the Isle of Man, unlike the past, the majority of deaths now occur in adults over the age of 65.

The population profile of the Isle of Man, like that of the UK, is showing an increasing proportion of older people. By 2030 people over the age of 65 will account for 86% of deaths and those over 85 will account for 44% of deaths (Gomes and Higginson 2008).

The Isle of Man Treasury predict that the number of those aged over 65 years will increase by 56% in the 20 years between 2006 and 2026, this would give an older population in 14 years time of over 21,000 (Third Sector/Government Liaison Group Work 2011-13).



By 2030 life expectancy will rise to:

Men – Average age 88 years

Women – Average age 92 years

This projection identifies the wide reaching implications for the type of care that will be required and the demand for services.

As a nation we face multiple challenges within Health and Social care if we are to meet the needs and preferences of people. Our local survey *'Getting Your Views'* (2011) identified several themes:-

- Choice of preferred place of care and place of death ensuring resources are available;
- Communication – as a society we do not talk openly about death and dying thus very few people have expressed their preferences for care provision;
- Education and Training – staff have received little training in how to approach the subject of death and dying;
- Multi agency care provision needs to be coordinated and flexible with accessible support over 24 hours.

Implementation of this Framework will facilitate a change in access to high quality care for all people approaching the end of life irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic deprivation. The prime focus of this strategy is to provide high quality end of life care that should be universally available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere. There should be fairness and equity of service provision allowing and encouraging patients, families and carers to have a choice in where they are cared for and by whom and with accessible support when needed.

2.1 Drivers for Change

A number of key documents have helped form the Isle of Man End of Life Care Framework and Implementation Plan.

The documents from the UK include:

- The NHS End of Life Care Programme (2004 – 2007), which has contributed significantly to the rollout of programmes such as the Gold Standards Framework (GSF), Liverpool Care Pathway for the Dying Patient (LCP) and Preferred Priorities for Care (PPC), Advance Care Planning (ACP), ADRT (Advance Decision to Refuse Treatment), ADA (After Death Analysis);



- End of Life Care Strategy (2008) Department of Health UK;
- Numerous examples of innovative practice, which have been piloted in the UK since their End of Life Care Strategy;
- Living and Dying Well (2008) NHS Scotland;
- Dying Well Matters (2008 – 2011) Wales.

As well as these UK documents, the Isle of Man has the following locally derived documents that have played an important part of the development of this strategy:

- End of Life Care questionnaire “Getting your views” (2011)
- Professional and Third sector focus groups (2011)
- Future of the Health Services in the Isle of Man, Department of Health (2011)
- Hospice Isle of Man Strategy (draft 2012)
- Cancer Strategy (draft, 2011)
- Carers Strategy (draft 2012 – 2015)
- National Assistance Act 1951
- Chronically Sick and Disabled Persons Act (1981)
- Care Programme Approach
- Mental Health Act (1988)

3. Getting your views - What we asked and heard

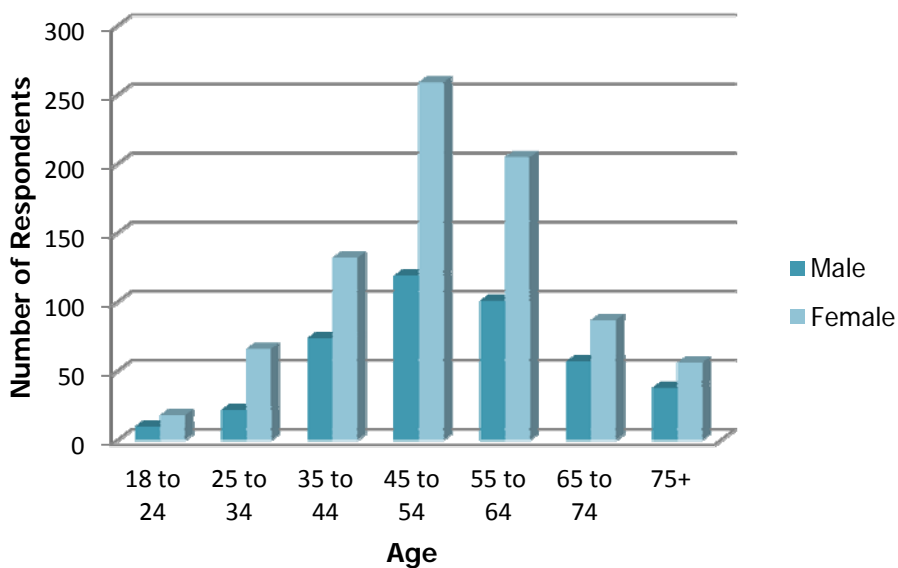
Results of the End of Life Care questionnaire

The End of Life Care questionnaire ‘*Getting Your Views*’ (2011) enabled the Islands public to express their views on existing and future end of life care wishes. The following graphs and commentary are the main results arising out of the Survey.

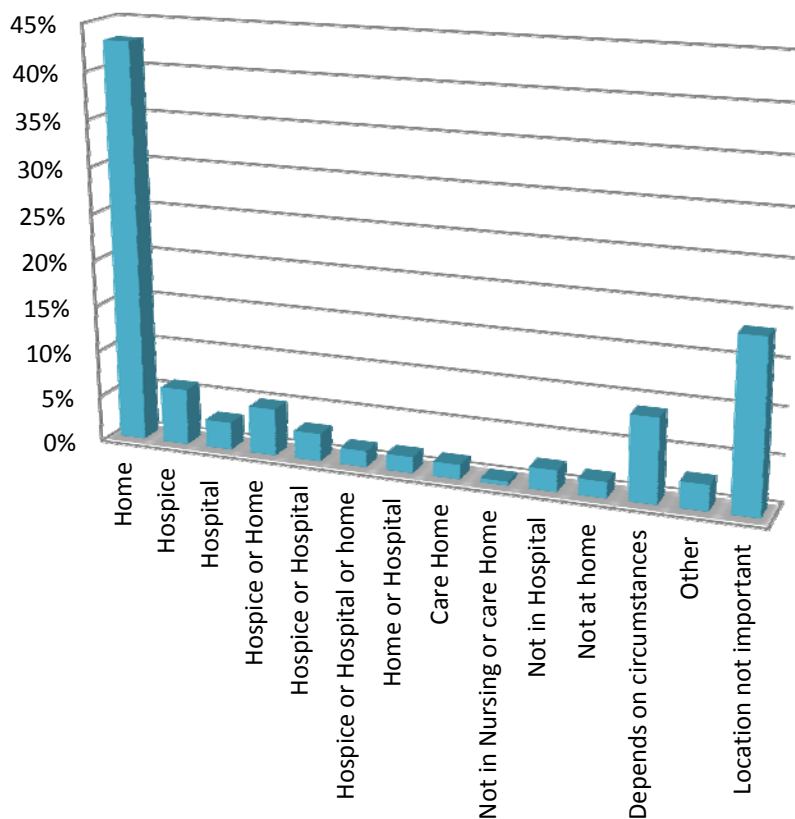
1215 completed questionnaires were received by the completion date of 15th August 2011; 533 of the respondents answered the questionnaire online, whilst 582 respondents replied by post. The free text sections of the questionnaires provided approximately 30,000 items of data.



Gender and Age Profile of Respondents



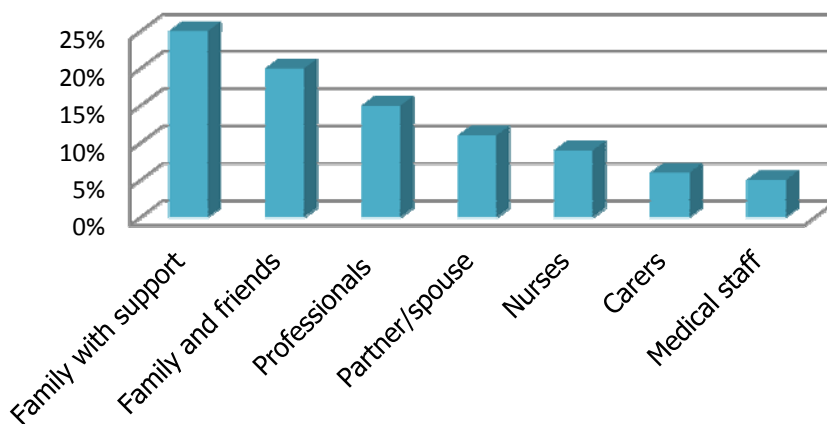
When the time comes , where do you want to die?





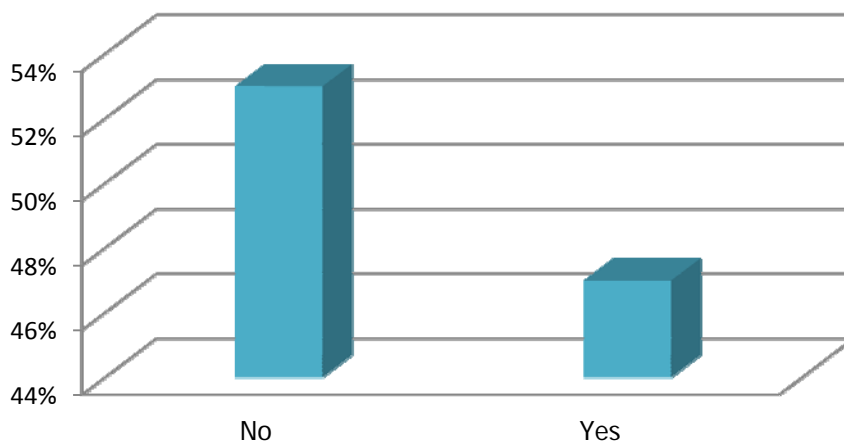
Forty three percent of 1140 respondents said they wanted to die at home, 22.2% chose one of a variety of settings they would wish to die in whilst 18.4% stated that the location they preferred to die in was not important, 4.4% did not want to die at home, a care home or the hospital. 8.3% felt place of death depended on the circumstances and 2.8% suggested other places e.g. at a holiday destination.
(Figures are to the nearest decimal point).

Thinking about yourself, when the time comes, who would you like to care for you?



The above graph indicates the importance of family carers providing care with support from services, followed by professionals.

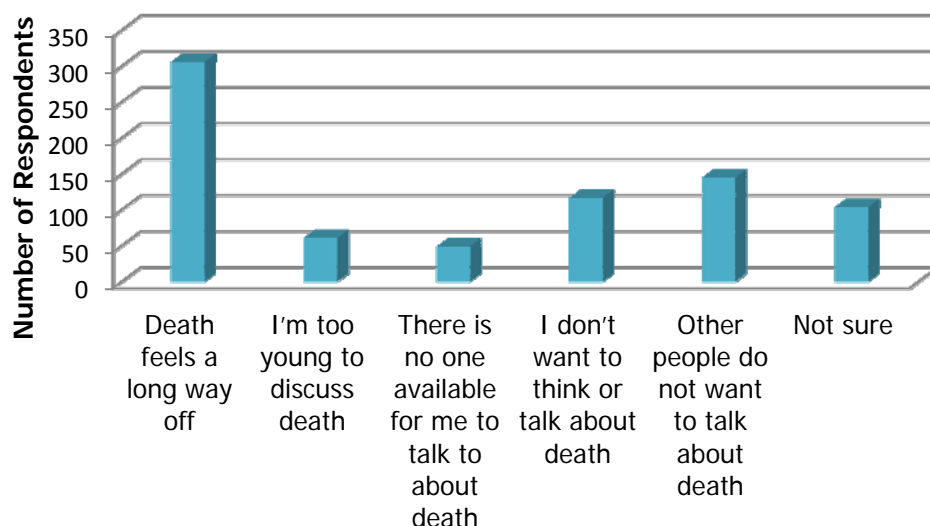
Have you ever discussed with someone what your wishes would be if you did not have long to live?





Fifty three percent of respondents had not discussed their end of life wishes, whilst 47% had discussed their wishes.

Reasons given for not discussing your wishes

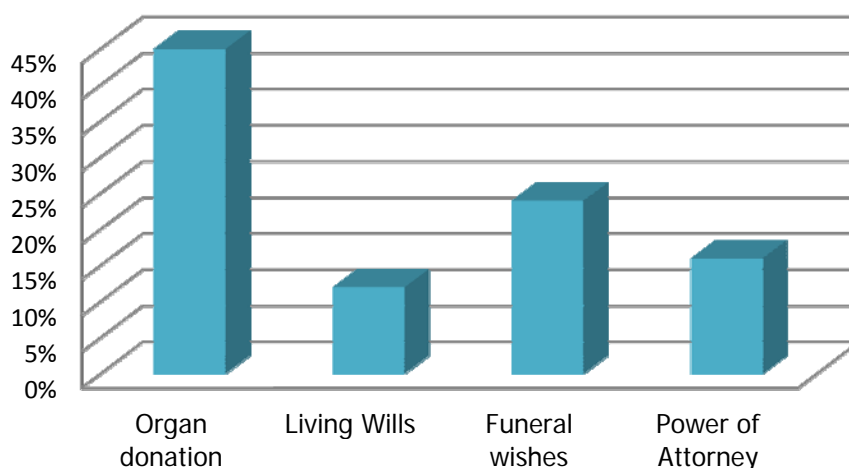


Respondents gave one or more reasons why death is not discussed, however the prime reason is that "death feels a long way off", followed by a sense that "other people do not want to talk about death".

Following on from the above it is of little surprise therefore, that only 59% of respondents stated they had made a will, whilst even less respondents reported they had made plans for;

- Organ Donation
- Living Wills
- Funeral Wishes
- Power of attorney

Written Plans





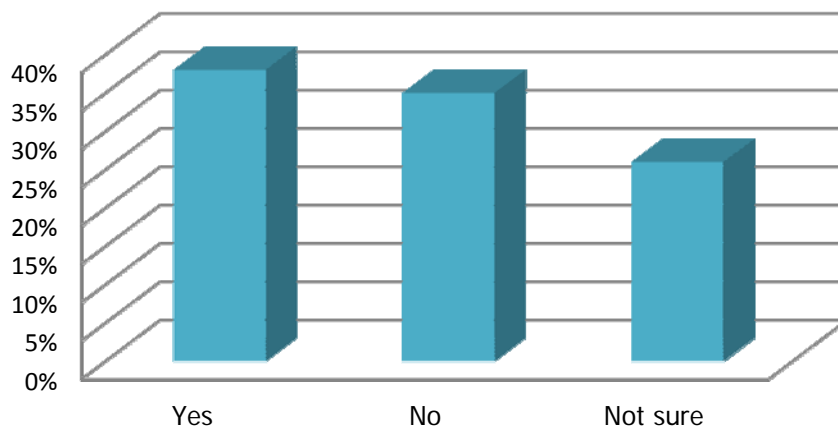
What carers said

Three hundred and forty three (28.4%) of the 1215 responders had been, or were currently carers. Carers were asked what would make caring easier. Carers described both positive and negative experiences of the services and support available to them in their caring role. The following are examples of quotes taken from the description of care provided by respondent carers and is evidence of the mixed range of experiences;

- "A consultant had the right compassion and tone to impart difficult information".
- "Supported my sister-in-law who chose to die at home. The care and support from District Nurse/Hospice was unbelievable and enabled her die as she wished surrounded by her family"
- "Her social worker was very good at advocating for her and coordinating services."
- "The main difficulty is in locating appropriate care packages quickly and then finding the funding".
- "Care impersonal and not enough"
- "They knew best attitude"

Carers were also asked the following questions;

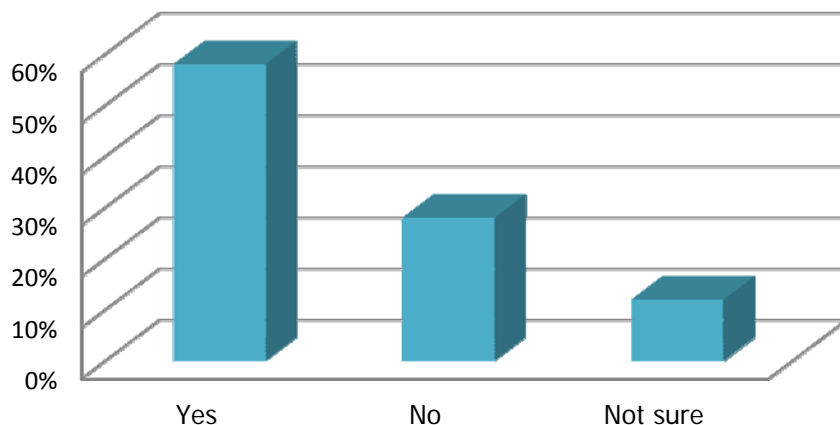
Did the deceased person die where they wanted to?



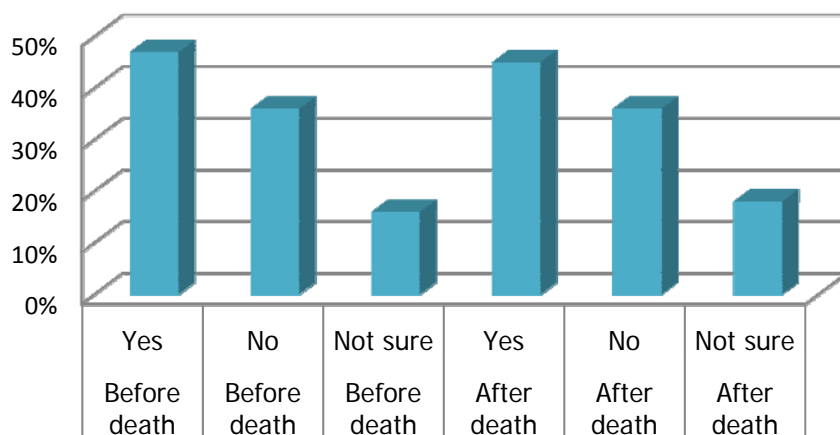
From the questionnaire data some people did indeed die where they would have wished (38% of 134 responders), however that still means 62% of people did not die where they wanted to or the carer was not sure.



Do you feel the dying person received adequate support?



Did you receive adequate support before and after the death of the person you cared for?



Comments from the questionnaire 'free text' sections

There were a number of free text sections of the questionnaire which provided a vast array of comments from respondents which have been themed into the following categories:

- Promoting choice and flexibility for patient and families in end of life care;
- Patients and carers require a range of services;
- There is a need to support patients and carers;



- There is a need for education for all staff involved in end of life care;
- There is a need for improved communication between agencies, services and families in end of life care matters.

What Professionals and Colleagues in the Third Sector said

Professional and Third Sector focus groups were held as part of the consultation exercise; the following themes arose out of the groups

- The need for effective communication between all end of life care providers;
- The addition of legislation to support end of life care;
- Access to equipment;
- Access to services through referrals;
- Out of hours care;
- Sufficient funding.

Summary and analysis of results

The questionnaire responses indicate that we are getting end of life care right some of the time, however the purpose of the End of Life Care Framework and Implementation Plan is to ensure end of life care is right for everyone at the end of their life, wherever they die and whatever they die from.

The results will drive the direction of the End of Life Care Framework with the aim of enhancing end of life care for all those on the Isle of Man.

- The profile of respondents gender and age is indicative of the population
- The location of death seems less important to respondents on the Isle of Man, whereas in the UK two thirds of people would prefer to die at home (Higginson 2003). The difference may be related to our small island community.
- Just over half of the respondents haven't discussed their wishes for end of life care; this reflects the hope that death is a long way off. However, we all need to be encouraged to think ahead so that comprehensive end of life care wishes can be provided for.
- From the carer respondents' experiences of services, 58% felt they received adequate support. However, this needs to be increased so that appropriate support is available to all.
- The raising of awareness of ongoing support for Bereavement care also is an area that requires improvement.



4. Building on a firm foundation

It was obvious from the outset of the gap analysis that the Island does have several established End of Life Care services (Annex A). These include the use of the Hospice Isle of Man, Palliative Care Clinical Nurse Specialists, Hospice at Home, District Nurses, and Social Care, Acute services, Community services, and the Third Sector; with the support of the End of Life Care tools 'Liverpool Care Pathway for the Dying' and the 'Gold Standard Framework'. There is however, room for improvement.

A very large number of health and social care staff, working in the community, in hospitals, care homes, hospice and other places, have at least some role in the delivery of care to people at the end of their life or their families and carers. Doctors, nurses, allied health professionals, pharmacists, social care staff, chaplains, ambulance staff, porters, mortuary staff and others, including those within the third sector, all have essential roles. Each staff group must have the necessary knowledge, skills and competences to enable them to fulfil their roles effectively and deliver high quality end of life care.

Core principles and competence frameworks

One of the most pressing tasks now is to define the core principles and competence required by each staff group. Many of the core principles and competences will apply across professional groups.

In particular, consideration will need to be given as to how these break down to reflect the knowledge, skills and attitudes required to undertake each of the following roles:

- Initiating discussions about end of life issues;
- Assessment of the person's needs and preferences and advance care planning;
- Co-ordinating care;
- Delivery of physical, psychological, social and spiritual care to patients;
- Delivery of care in the last days of life;
- Delivery of care after death; and
- Assessment of carers' needs and provision of care to carers both during a patient's life and after death.



Alongside competences that relate specifically to end of life care, broader competences regarding team working, clinical decision making and management will also need to be considered.

The end of life care workforce can be segmented into three broad groups. Table 1 highlights the three groups and the suggested minimum level of skills and knowledge required.

Table 1: Workforce groups

Group definition	Minimum levels of skills and knowledge
<p>Group A – Staff working in specialist palliative care and the hospice who essentially spend the whole of their working lives dealing with end of life care. This includes:</p> <ul style="list-style-type: none"> • Physicians in palliative medicine, palliative care nurse specialists and allied health professionals, and all health and social care staff working in or with hospice. 	<ul style="list-style-type: none"> • All staff should have the highest levels of knowledge, skills and understanding through specialist training as part of further specialist registration and/or continuing professional development (CPD). • These should include communication skills, assessment, and advance care planning and symptom management as they relate to end of life care.
<p>Group B – staff who frequently deal with end of life care as part of their role. This includes:</p> <ul style="list-style-type: none"> • Secondary care staff working in A&E, acute medicine, respiratory medicine, care of the elderly, cardiology, oncology, renal medicine, long term neurological conditions, intensive care, hospital chaplains and some surgical specialities. • Primary care staff including GPs, district nurses, some care home staff, paramedic staff and community based carers. • Specialist nurses based in primary or secondary care. • Hospital and community 	<ul style="list-style-type: none"> • Staff will need to be supported to enable them to develop or apply existing skills and knowledge to end of life care through Continuing Professional Development, or further specialist training and overcome any personal or team barriers. • This group has the greatest potential training need, in particular secondary care doctors (and their immediate teams), GP's (and their teams) and district nurses, who may be key in the "trigger" discussion at the start of the pathway and with ongoing continuity of care. • These should include communication skills, assessment,



pharmacists.	advance care planning and symptom management as they relate to end of life care.
<p>Group C – Staff working as specialists or generalists within other services who infrequently have to deal with end of life care. This includes:</p> <ul style="list-style-type: none"> • Other professionals working in secondary care or in the community, for example, care home staff and day centre and social care staff not involved in hospice, as well as domiciliary care and prison services staff. • Third Sector staff providing care or support for end of life care • Informal Carers providing care or support for end of life care 	<ul style="list-style-type: none"> • This group must have a good basic grounding in the principles and practice of end of life care and be enabled to know when to refer or seek expert advice or information. • Many of the staff within care home settings and providing domiciliary care in this group have significant unmet training needs, including access to induction programmes. • Many of the staff within the Third Sector, and informal carers, also have significant unmet training and skills needs, which, if addressed (for example by access to existing training schemes), would greatly increase their effectiveness

5. Future learning and changing

The Isle of Man survey *Getting Your Views* (2011) identified inconsistent experiences in the current end of life care provision, with those affected by cancer reporting a higher standard of care provision than those with other life limiting conditions. This indicates that improvements can be made and services can be high quality. It also gives a benchmark for end of life care services that should be available for all conditions in the future.

A cultural shift in attitudes and behaviour relating to end of life care must be achieved within the health and social care workforce.

At present there are deficiencies in the knowledge, skills, attitude and behaviours of staff, Third Sector and carer groups who come into contact with people at the end of their lives.

Development of the end of life care workforce is the way forward. Programmes to skill up staff groups will result in improvements in care for patients and carers.



Using tools such as the Gold Standard Framework (GSF), Preferred Priorities for Care (PPC) and Liverpool Care Pathway (LCP) in all settings (hospitals, community and care homes) will play a major role in workforce education and result in improved quality of care.

Doctors, nurses, allied health professionals, pharmacists, social care staff, chaplains, ambulance staff and others all have roles to play.

Death is inevitable and although sad, staff must acknowledge the need to care for people from life to death. This experience of care can be immensely rewarding. An education programme for all will address the death and dying taboo and enable the workforce to become more skilled when facing people needing end of life care.

Publication of the End of Life Care Framework will in itself start to raise the profile of end of life care in the Isle of Man. But this alone will not be enough.

Sustained leadership and drive will be needed to ensure that appropriate actions are taken at each step in the end of life care pathway and across all settings (hospitals, community, and care homes).

Quality standards will help to support this and many desired improvements may be delivered by better use of existing health and social care resources. For example, strengthening and extending existing community nursing, flexible care homes provision and enhanced hospice care may reduce hospital admissions, reduce length of stay and offer more choice to patients and their carers. Investing in care at home, the provision of a 24 hour and seven days a week advice line and a rapid response service will all go a long way towards improvement of end of life care for many.

Measurement of end of life care provision is a key lever for change and is essential to monitor progress and aid its development. This must be put in place.

Support to carers by involving third sector organisations and sourcing availability of respite care will further add to care improvements.

Coordinated approach that offers assessment for the end of life care needs that takes into account people's preferences and choices will be the key to establishing end of life care for all.

"Getting Your Views (2011)" helped us to identify what must be in place to meet end of life care needs of the Isle of Man population.

As a result, the End of Life Care model identifies and sets seven objectives necessary for delivery of end of life care.

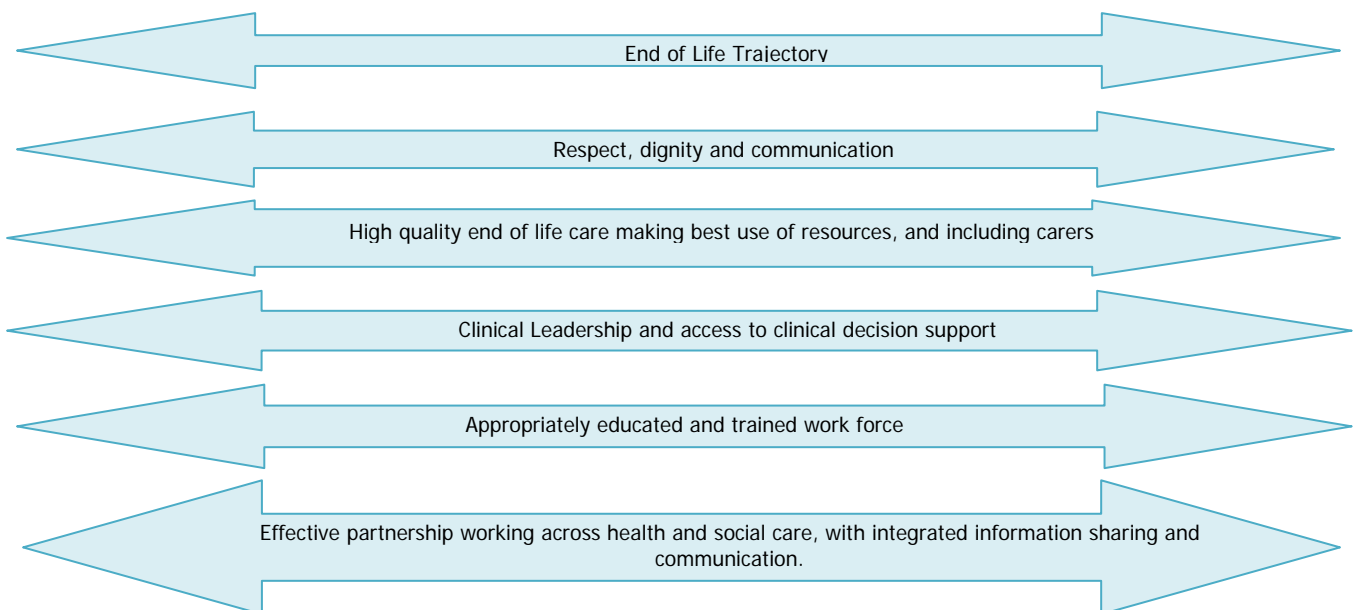


These objectives embrace quality of care, leadership, education and partnership working and are listed in the table below.



End of Life Care Model

Objective 1	Objective 2	Objective 3	Objective 4	Objective 5	Objective 6	Objective 7
A change in society's recognition, understanding and acceptance of death as relevant to everyone, appropriate for discussion, and something we can all plan for.	Identification of people approaching the end of life and initiating discussions about preferences for end of life care	Care planning: assessing needs and preferences, agreeing a care plan to reflect these and reviewing these regularly	Coordination of care	Delivery of high quality services in all locations	Care in the last few days of life	Care after death
<p>Increase public awareness and discussion of death and dying.</p> <p>Provide opportunities for public discussion of End of Life Care issues.</p> <p>Provide information about key factors people may wish to consider and plan for - Preferred Place for Care (PPC), wills, funeral arrangements, etc.</p>	<p>Open, honest communication;</p> <p>Holistic patient assessment</p> <p>Identifying triggers for discussion: Advance Care Planning (ACP), Gold Standard Framework (GSF) register</p> <p>Complete Manx Emergency Doctor Service (MEDS) Information Form.</p> <p>Assessing needs of carers</p>	<p>Agreed care plan and regular review of needs and preferences;</p> <p>Assessing needs of carers</p> <p>Check benefits</p> <p>Consider Cardio Pulmonary Resuscitation (CPR) status</p>	<p>Strategic coordination;</p> <p>Coordination of individual patient care;</p> <p>Rapid response services (if set up), Availability of Out of Hours (OOH) service</p> <p>Review ACP</p> <p>MEDS Information Form</p> <p>Check "Alert - Special Patient Alert" form</p> <p>Consider CPR Status</p> <p>Assessing needs of carers</p>	<p>High quality care provision in all settings;</p> <p>Hospitals, community, care homes, hospice.</p> <p>Ambulance services</p> <p>MEDS Information Form</p> <p>Check "special patient alert" form</p> <p>Consider CPR status</p> <p>Assessing needs of carers</p>	<p>Identification of the dying phase; Use of the Liverpool Care Pathway (LCP)</p> <p>"Just in Case Box"</p> <p>Check "special patient alert" form</p> <p>MEDS Information Form</p> <p>Review of needs and preferences for place of death;</p> <p>Support for both patient and carer; Recognition of wishes regarding organ donation</p> <p>Assessing needs of carers</p>	<p>Recognition that end of life care does not stop at the point of death;</p> <p>Timely verification and certification of death or referral to coroner;</p> <p>Care and support of carer and family, including emotional and practical bereavement support</p> <p>Assessing needs of carers</p>



Based on the End of Life Care Strategy (2008)



6. Conclusion

This End of Life Care Framework has been developed over a period of more than a year by a strategic, multi-agency working party and has consulted with over a thousand patients, relatives, carers and stakeholders across the Island. From this process, a consistent message has emerged. Whilst more than 40% of respondents have said that they would like to be able to die within their own home, what seems to be more important is that those who responded would wish to die with those who love them around them and with the right professional skills and dedicated carers to support them.

The work has shown that the Island has some wonderful and committed End of Life Care services, many of which are held dear by the Island's residents, for example the Isle of Man Hospice and the Community Health Services. These services now give us a firm foundation to build on. As the services required by people approaching the end of life will span different sectors and settings, it is vital that an integrated approach to planning and whole system service development is required across Health, Social Care and the third sector.

Caring for those approaching the end of life can be one of the most rewarding and important areas of care, although it is challenging and emotionally demanding and therefore it is critical that our staff have the necessary knowledge, skills, attitudes and support to deliver the very best care they can. Whilst in the coming years there may need to be further investment in end of life care, the work that has been completed and the ongoing action plan to be implemented demonstrates that many of the improvements envisaged can be achieved by better use of existing health and social care resources and by greater involvement of third sector partners to deliver those services. The key areas for consideration into the future will be to:

- enhance the coordination of care;
- improve physical, psychological, social and spiritual care to patients;
- consider the provision of 24 hour end of life care services;
- provide good information on end of life care to patients, families and carers; and
- improve education, training and development of staff who are involved in caring for those who are dying.



7. Implementation Plan

Objective 1

A change in society's recognition, understanding and acceptance of death as relevant to everyone, appropriate for discussion, and something we can all plan for.

Key Priorities
Next 12 Months
<p>Begin the process of increasing public awareness and discussion of death and dying by working to establish an environment where death and dying are more openly discussed.</p> <p>Raise awareness that individuals can express preferences</p> <p>Identify, train and support End of Life Care 'champions' in every area of service provision.</p>
Next 3 Years
<p>Continue to increase public awareness and discussion of death and dying as necessary and appropriate.</p> <p>Implement relevant elements of 'Dying Matters'</p>



Objective 2

Identification of people approaching the end of life and initiating discussions about preferences for end of life care.

Key Priorities
Next 12 Months
<p>Adoption of the Gold Standard Framework for all patients and professionals.</p> <p>Ensure a uniform and agreed definition of 'End of Life'</p> <p>Ensure all Health & Social Care staff involved with people moving towards the end of life have the necessary skills to identify when a person may be moving into the final year of life, and the skills to initiate the necessary discussions at that time.</p> <p>Ensure all Third Sector staff and volunteers involved with people moving towards end of life have the necessary skills to identify when a person may be moving into the final year of life, and the skills to initiate the necessary discussions at that time.</p> <p>Ensure all Carers involved with people moving towards the end of life have the necessary skills to identify when a person may be moving into the final year of life, and the skills to initiate the necessary discussions at that time.</p> <p>Ensure the key End of Life Care tools (LCP v12, GSF, and PPC) are used whenever appropriate by all those involved in caring for during their End of Life.</p> <p>Consultants to suggest to GPs which patients should be placed on the Palliative Care List/Gold Standard Framework</p> <p>Forecast demand and need for End of Life Care services in next 12 months</p> <p>Ensure 'joined up' assessment</p>
Next 3 Years
<p>With Department of Social Care complete legislation in relation to mental capacity</p> <p>Consider development of End of Life Care, Care Home capacity</p>



Objective 3

Care Planning that assesses the needs and preferences of patients, before agreeing a care plan which reflects these and is reviewed regularly.

Key Priorities
Next 12 Months
Ensure staff are trained to assist people with advance care planning.
Carers support
Respite care
Ensure all those involved in preparing care plans with the person at the end of life have the necessary training and skills.
Review current templates and guidance for Care Plans and confirm or amend, standardising as appropriate and ensuring that it is regularly updated.
Support plans or pathways with dedicated flow-charts
Support and monitor provision of holistic care plans for all patients at the end of life, and for all carers where appropriate, ensuring equity of access.
Ensure a combined and comprehensive approach to assessing the needs and preferences of individuals.
Participate in the creation of Carers Assessments in line with the Social Services Act 2011
Ensure access to care plans for end of life care patients by all professions involved in care provision, including emergency and Out of Hours services.
Next 3 Years
Create a Forum to ensure uniform Care Planning processes, to include assessment of patients and carers needs and preferences.
Develop methods and structures to ensure that individuals have easy access to information so that they can understand the care planning process and make informed choices on the options open to them.
Consider the creation of an advocacy service to assist individuals
Institute review mechanism for regular reviews of Care Planning processes
Consider creation of Patient-held Records.



Develop a range of End of Life Care service providers

Objective 4

Improving the coordination of care.

Key Priorities

Next 12 Months

Review processes so as to enable rapid discharge where appropriate.

Create a central point of communication with easy access for all

Create a patient, users, and carers' forum to inform and assist service planning.

Ensure there is strategic coordination between key service providers including Health, Social Care, and the Third Sector.

Work with providers to develop and enhance systems, including shared electronic information systems, to help ensure effective communication between the different professionals, carers, family and others involved in the care of individual patients.

Develop and enhance systems to allow the patient access to necessary services when they need them, including out of hours.

Appoint an End of Life Care Facilitator or Co-ordinator

Improve budget flexibility

Next 3 Years

Ensure that all sectors continue to work together in partnership to maintain a uniform approach

Implement measures to increase GP involvement in End of Life Care

Create a data base of resources, abilities and capacities and create easy means of access for all staff, users and carers

Create a care co-ordination resource to operate across service boundaries

Investigate the possible creation of a register to ensure patients do not encounter gaps in services

Create resource packs for use by staff and homes



Objective 5

Delivery of high quality end of life care in all locations.

Key Priorities
Next 12 Months
Nomination and training of key workers for each End of Life Care patient
Identify appropriate levels of care to be expected in different settings – work with organisations to produce a defined standard and seek ways to ensure all adopt and maintain the appropriate standard.
Work with providers to develop and enhance systems, including shared electronic information systems, to assist the delivery of the defined standard of care.
Ensure all involved in the delivery of this care, including carers and informal carers, have the appropriate skills, support & training to enable their delivery of this care, including communication skills.
Develop and enhance systems to allow the patient access to necessary services when they need them, including pharmacy, equipment, aids and other services including out of hours.
Establish a framework to ensure that staff in all areas are equipped with the relevant knowledge, skills, communications skills and attributes.
Identify, disseminate and implement examples of highest standards of care
Using an external assessor if necessary, map current services to enable maximisation and targeting of resources.
Next 3 Years
Establish a training programme to ensure appropriate and proportionate continued training and development of staff in all areas.
Consider the appropriateness and potential role of regulation in the Delivery of End of Life care.
Create opportunities for sharing best practice
Increase length of time spent in preferred place of care during last year of life
Ensure access to psychological and spiritual support for patients in all settings
Ensure access to interpreters and advocacy services is available if required.



Develop a multi-agency, multi disciplinary palliative care response team.
Monitor and audit End of Life Care provision

Objective 6

Improving care in the last few days of life.

Key Priorities

Next 12 Months

Ensure adequate arrangements are in place for the verification of death

Introduce an "Alert - Special Patient Alert" form across the services

Ensure all those involved in the patients care at this time have the necessary skills to identify when a person may be moving into the final days of life, and the skills to initiate the necessary further discussions and planning required at this time.

Ensure all appropriate care providers have the necessary skills and training to work with and apply the relevant tools & procedures as circumstances change, and to identify change including:

- LCP Version 12 Island wide
- "Just in Case Boxes"
- Other systems and protocols as appropriate.

Ensure the needs of the carer and others affected are identified and addressed, and reviewed regularly as circumstances change.

Next 3 Years

Regular review of care planning processes in the light of experience

Consider if processes can be put in place to assist with the organisation of personal affairs prior to death.

Reduce number of unscheduled deaths taking place in hospital where hospital is not the preferred place of death.

Ensure availability of 24 hour admission to Hospice if desired.

Provision of specialist telephone advice service.



Objective 7

Improving care after death and ensuring high quality bereavement support to families and carers.

Key Priorities
Next 12 Months
<p>Introduce a Bereavement support service</p> <p>Develop a 'One Stop Shop' for information and support, linked to End of Life Co-ordinator post if that post is established, and ensure that the information provided is consistent across all End of Life Care.</p> <p>Introduce the 'Living and Beyond' chapter from the Cancer Strategy Ensure all staff involved in End of Life Care have access to awareness training re Bereavement and pre-bereavement care and issues.</p> <p>Ensure all staff involved in End of Life Care know where and how to refer people for bereavement support when needed.</p> <p>Ensure systems are in place and users appropriately trained to enable timely verification and certification of death and referral to coroner.</p> <p>Ensure availability of appropriate care and support for those who are bereaved and that bereaved are aware of the support and resources available (link to the government's 'One Stop Shop').</p> <p>Notification of death to other service providers so that services can cease and distress be avoided</p>
Next 3 Years
<p>Provision of figures of end of life care deaths by the registry</p> <p>Consider need for post-event support mechanisms for staff closely involved</p> <p>Establish formal pathway of care for those suffering complicated grief</p> <p>Establish formal pathway of care for young adults and children, including liaison with Department of Education and Children</p>



Glossary

- Third Sector – voluntary, charitable and faith organisations
- MDT (Multi-Disciplinary Team) – a group of professionals from different disciplines who work together to provide or to improve care for people with particular needs. The members of such a team will vary according to the circumstances, but will normally include both healthcare and non-healthcare representatives.
- Out of hours (OOH) care - the arrangements that are made for accessing care out with what are considered as normal working hours i.e. 9am and 5pm on weekdays and throughout weekends and public holidays.
- GSF – Gold Standard Framework. Is a systematic common sense approach to formalising best practice, so that quality end of life care becomes standard for every patient. It helps clinicians identify patients in the last years of life, assess their needs, symptoms and preferences and plan care on that basis, enabling patients to live and die where they choose. GSF embodies an approach that centres on the needs of patients and their families and encourages inter-professional teams to work together. GSF can help coordinate better care provided by generalists across different settings and for any patients nearing the end of life with any stage illness in any setting.
<http://www.goldstandardframework.nhs.uk/>
- LCP - Liverpool Care Pathway for the Dying - The LCP is an integrated care pathway that is used at the bedside to drive up sustained quality of the dying in the last hours and days of life. It is recommended as a best practice model, most recently, by the Department of Health in the UK. www.mcpcil.org.uk/liverpool-care-pathway/
- Carer - In this document a Carer is defined as someone who supports a relative, friend or neighbour who for any reason needs help with daily living and receives no payment for doing so



Acronyms/abbreviations

GP – General Medical Practitioner
GSF – Gold Standard Framework
ACP – Advance Care Planning
DH – Department of Health
DSC – Department of Social Care
LCP – Liverpool Care Pathway
DNAR/DNACPR - Do Not Attempt Resuscitation/Do Not Attempt Cardio
Pulmonary Resuscitation
MEDS – Manx Emergency Doctor Service
PPC - Preferred Priorities for Care

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Annex A Services to support End of Life Care

GP	Noble's Hospital	Home care	Hospice IOM
MEDS		Meals on Wheels	Cross Roads Caring for Carers
Community nurses: District Nurses; Health Visitors; Parkinson's disease; Transfer of care coordinator; Contenance Advisor	Specialist nurses: Heart Failure; Neurological diseases; Respiratory; Diabetes Specialist Nurse; Renal CNS	Residential care	Live at home schemes (North, South, East, West)
Ambulance Paramedic Service	Interpreter services	Social worker	Day centres
RDCH	Pharmacy	Day centres	Age IOM
Occupational Therapy		Mental Health teams	Red Cross
Physiotherapy		Drug and alcohol team	Manx Cancer Help
Pharmacy		Supported Living	St John Ambulance
Oxygen supply		Learning Disabilities	Cruse
SALT			Faith groups
Dietician			Motor Neurone Disease group
Respite care			Multiple Sclerosis Group
Community Equipment stores			Parkinson disease society
			Volunteers
			Private nursing homes
			Private care homes
			Private care agencies



Annex B

End of Life Care Steering Group Members

- Norman McGregor Edwards - Director of Health Care Delivery
- Bev Critchlow - Director of Nursing, Midwifery and Professional Development
- Margaret Simpson – Chief Executive, Hospice Isle of Man
- Margaret Swindlehurst – Service Lead for Adult Community Nursing
- Cath Quilliam – Director of Community Nursing
- Dr Justine Needham – GP Cancer Lead
- David Gawne – Third Sector
- Jeremy Such - Macmillan Development Manager
- Diane Corrin –Matron, Hospice Isle of Man
- Julie Bennion – Specialist in Mental Health Promotion
- Karen Winter – Senior Social Worker
- Dr John Thomas – Consultant Physician
- Kirstie Turner - End of Life Care Project Facilitator

Annex C Project Scope

Taking into account predicted demographic changes we will:

- Carry out a patient centred review of all existing End of Life Care services for Isle of Man Patients.
- Identify the strengths and weaknesses of those services
- Identify the needs and wants of patients and carers
- Carry out a gap analysis between the above
- Produce a Framework describing the vision for patient/ carer centred End of Life Care services for the Isle of Man
- The Framework will include identified “quick wins” – actions that are achievable during the lifetime of the project and a longer term action plan.
- The action plan will be specific, measurable, achievable, realistic and time-bound.
- The report may mention areas which relate to this project, but are not seen as core to it, or which need further development, however certain



areas are outside the scope of this project and will not be included such as Assisted Suicide.

Developed by the End of Life Care Strategy Project Steering Group
June 2012



DEPARTMENT OF HEALTH

Rheynn Slaynt

**The information in this document can be provided in large print
or audio tape upon request.**



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