From Vision to Reality

Island Plan for Integrated Palliative and End of Life Care

2018 -2023

Isle of Man Government
Reiltys Ellan Vannin
DEPARTMENT OF HEALTH AND SOCIAL CARE

CVO
ISLE OF MAN COUNCIL OF VOLUNTARY ORGANISATIONS

Hospice
ISLE OF MAN
care for our community

Foreword

Delivering Longer Healthier Lives - our vision to become the best small island-based health and care system, incorporates as a key thread - right care, at the right time, as close to home as possible.

The best chance to achieve this vision is integration, teams of people working collectively. Teams built of partnerships. Teams built of trusting and trusted relationships. Collectively we understand that the needs of children, of adults below retirement age and of older people are different, and wherever possible should be supported to follow the natural life cycle approach of start well, live well, age well, die well.

This document, a plan for Palliative and End of Life Care, based on what matters to people and their families, has been informed by engagement with local communities. The Department of Health and Social Care is proud to work in partnership with Hospice Isle of Man and the Council of Voluntary Organisations; together we aim to learn and improve in order that people, families, communities, volunteers and professionals can deliver, where it matters and when required, the best possible palliative care and end of life care, to all who need it.

This plan for Integrated Palliative and End of Life Care is an enabler for Delivering Longer Healthier Lives and is key to the implementation and success of the overall vision.

Michaela Morris
Executive Director Health and Care
Department of Health and Social Care

About this document

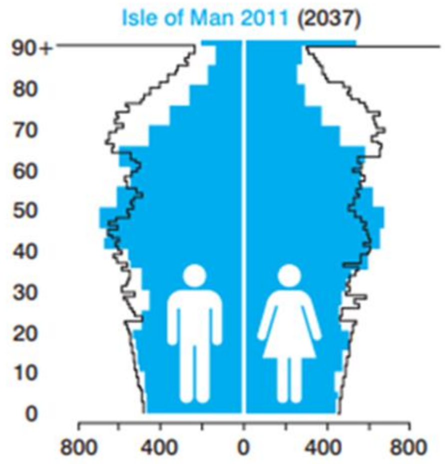
A Strategic Partnership Steering Group, led by Hospice Isle of Man with the Department of Health and Social Care and Third Sector partners, has developed an ambitious five year plan for Integrated Palliative and End of Life Care on our Island. The aim is to deliver excellent palliative care for all who need it in a way that is affordable, sustainable and supports more people to have their end of life care in community settings.

This work builds on the Isle of Man End of Life Care Framework and Implementation Plan for Adults 2012-2015 and on the End of Life Matters initiative that aims to bring about a change in society's recognition, understanding and acceptance of death as being relevant to everyone. The plan for Integrated Palliative and End of Life Care is a key enabler for *Delivering Longer Healthier Lives,* our journey to become the best small Island-based health and care system – providing the right care, at the right time, in the right way, as close to home as possible.

Why This Matters

Palliative care is holistic support to prevent and relieve pain and suffering throughout any serious or life limiting illness as well as in the last stage of life and in bereavement. It aims to improve the quality of life for people of all ages through early identification, assessment and treatment of pain and other physical, psychological, social or spiritual problems.

In 2014, the World Health Assembly – the governing body of the World Health Organisation - passed a resolution requiring all governments to make provision for palliative care in their national health policies. This is because palliative and end of life care has proven value, is a human rights, public health and equalities issue, and the need for it is growing in a society that is ageing. In the last five years, the average age on the Isle of Man has risen by more than one year. Registry records confirm that 845 people died in 2017 of which Hospice were involved in about one-third of the cases. This figure does not represent all of those who could have benefited from specialist palliative and end of life care. According to the *Isle of Man Social Attitudes*



Source: British Irish Council

Survey 2017, around 14% of people on the Island described themselves as a carer. Approximately half of respondents were caring for elderly or disabled relatives. Only 9% of all carers received support from the government or charity for their care work.

What this means for patients and families - Case Study

Judy was diagnosed with a neurodegenerative condition. Her diagnosis was reached after a period of about 3 years of developing symptoms and increasing problems with mobility, anxiety and distress. As the disease and dependence progressed, her husband, Sam, became her primary carer**. Her wishes were to remain at home for as long as possible until it was time to go to Hospice.**

Due to the complexity of her condition, a long-term conditions coordinator was appointed to help manage her care. Family moved from overseas to help with her care. In the last two years of her life, Sam became gradually overwhelmed and under increased pressure to get additional support. Respite was provided by Hospice, Crossroads Care, Age IOM, a private care agency and Ramsey District and Cottage Hospital. In the last 18 months of life, Judy was seen by 35 different care providers, not counting family and friends. The involvement of a long-term conditions coordinator was invaluable to the management of her care. Judy achieved her wishes with the help of palliative and end of life care provided by generalists, specialists, private and voluntary organisations, family and friends working with and supporting Sam.

In Sam's words:

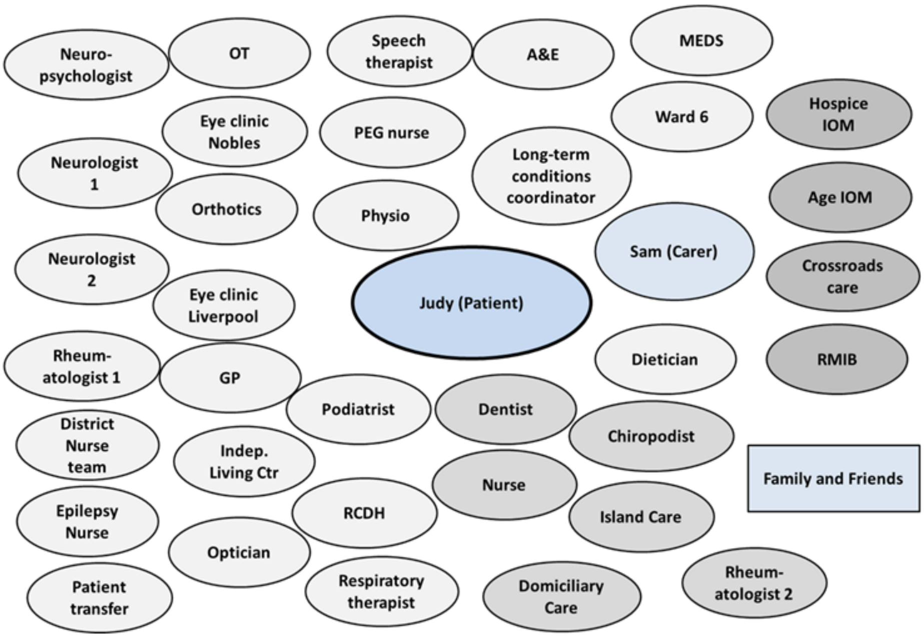
"It was invidious the way it took away my wife of 50 odd years. She was still the same person but her body wasn't and she knew it herself. Towards the end I had to do everything- shower, took her to the toilet- it was I don't know… a lack of dignity?

Thinking back, the main thing that helped, the thing that was the biggest relief to both of us was when [long-term conditions coordinator] appeared. That was the main safety valve. She appeared on the scene like a breath of fresh air. She made all the problems appear solvable.

Having Hospice at Home and the night nurses we hired gave me the strength to carry on during the day time. A lot of carers feel guilt- that they don't have the physical strength to care – and a lot carers like me – felt that I was failing if I needed help… it's the acceptance that help is not a sign of failure that helped make things easier at the end."

Judy's Care Map illustrates the many relationships that have to be developed and maintained by patients, carers and families. Often, responsibility for coordination of the many health and social care professionals, volunteers, private and family carer supports resides with the patient and/or their carer. *Note: There are many other organisations that provide valuable services. The services involved will depend on a person's circumstances. No one size fits all.*

Judy's Care Plan



This complex landscape is difficult to navigate and often leads to:

- lack of 'ownership' of the person's problem;
- lack of involvement of users and carers in their own care;
- poor communication between partners in care;
- duplication of tasks or gaps in care;
- treating one condition in isolation without recognising others;
- poor outcomes for the person, carer *and* the system

A holistic and person centred approach starts with patients, carers, families, volunteers and communities, supported by health and care professionals with different skills and expertise who work in many different settings - at home, in primary care, care homes, hospice and hospital services. A simple and reliable system to coordinate care and to support the needs of the carer in their own right is critical to ensure the right care, at the right time, in the right place.

What Matters to You Matters to Us

The Strategic Partnership Steering Group has adopted a person centred and human rights based approach, reflected in the words of the late Dame Cicely Saunders.

> ***''You matter because you are you, and you matter till the end of your life."***

The development of this Plan has been enriched by listening to the stories and views of many patients and carers and by conversations about the outcomes that matter to local people. The Research Team from the Hospice Isle of Man Scholl Academic Centre have engaged with 630 people across the Island to understand the views of patients, carers, professionals, local people, communities and voluntary organisations about palliative and end of life care support and services – what is good now and what we want to see in the future. The insights from these conversations have shaped our vision for integrated palliative and end of life care on our island.

> ***"A compassionate island where we all work together to help everyone who has a life limiting illness, and their families and carers, live the best life possible, have a good death, and appropriate bereavement support."***

Our vision is inspired by the narrative in *Every Moment Counts* produced in 2015 by National Voices and the National Council for Palliative Care, in partnership with NHS England.

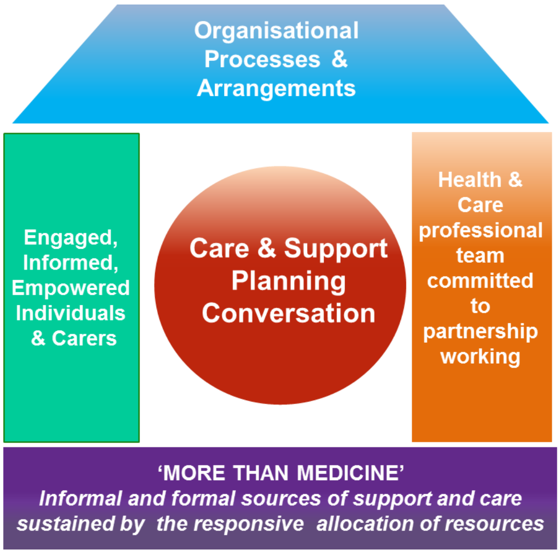
> ***"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."***

The end of a life is a unique and personal experience that we will all face at some time. To make sure those moments count we must be prepared to do what matters for each person, when, and where it matters. By implementing this Plan alongside the other initiatives set out in *Delivering Longer Healthier Lives*, we aim to provide coordinated, personal and flexible palliative and end of life care so that everyone can achieve their best outcomes.

Realising our Vision

Realising our vision will require a fundamental shift in the relationship between citizens and professionals so that individuals, carers, families and local communities have more control over their health and care, and are supported to live well and to die well. We will adapt the 'House of Care' framework to describe the actions we will take to make this shift.

All of the components of the House of Care must be in place if we are to construct a well-balanced, robust framework centred on care and support planning conversations that focus on the outcomes that matter to people. The Isle of Man has an active and diverse third sector of voluntary, community and faith groups and Social Enterprise companies that engage across every aspect of Island life. These groups and countless individual volunteers offer valuable 'more than medicine' community support. The task is to harness this vital capacity as a solid foundation for a compassionate island community, and enable it to grow in order to achieve the best outcomes for, and with, our people and communities.



Source: houseofcare.wordpress.com

The six work streams in the Plan represent the different components of the House of Care:

1. Joint Strategic Needs Analysis
2. Strengthening compassion in the Isle of Man
3. Person Centred and Coordinated Care
4. Much More than a Building
5. Developing our Workforce Together
6. Monitoring Progress, Measuring Impact

Work streams

1. Joint Strategic Needs Analysis

Aim

To understand the current need for, and provision of, integrated palliative and end of life care on the Island and predict how needs will change over the next five years.

Actions

Gather views from patients, families, carers, relevant professionals and volunteers on what is currently working well and gaps in care through surveys, interviews, focus groups, care-diaries and interviews. Listen to the views of local people through engagement and listening events in local schools, community venues, workshops and individual interviews.

Success

The plan is informed by evidence and lived experience, is based on predicted population needs, and prioritises what is important to local people, professionals and organisations.

2. Strengthening compassion in the Isle of Man

Aim

Strengthen the resilience of individuals and communities at times of crisis and personal loss through a culture of care and compassion.

Actions

Lead a five year change programme to create community connections, strengthen the natural support systems of family, friends and neighbours, and build a dynamic network that offers compassionate care and companionship at the end of life.

Success

Compassionate citizens come together to offer each other support at the end of life.

> ***"There is someone on hand to help with my worries and fears, or those of the people who are important to me."***
>
> ***"Support and advice from people who have been through the same experiences is recognised as an important service, and we are given the opportunity to use it."***
>
> ***"I am supported as much as possible to stay where I want to be."***

3. Person Centred and Coordinated Care

Aim

Develop, implement and evaluate a service that improves access, continuity, communication and coordination of person centred palliative and end of life care and maximises the choice and control that people have in their care.

How

Work together with the Integrated Care pilot project in the West of the Island to deliver holistic, effective and coordinated palliative and end of life care for people as a step towards the objective of genuine integration of care across the whole of the Isle of Man. Creating a single point of contact will ensure patients, and those close to them, have a holistic Shared Single Assessment of their physical, emotional and spiritual needs, and are fully involved in decision making and management of their care plan. Spread the learning from this pilot across the Island with support from the other workstreams.

Success

An effective integrated community model that incorporates palliative and end of life care; evidence of involvement in holistic single assessment and review; more people and families access information, advice, support and palliative care to live the best life possible.

> ***"My care plan records information about who I am: my life and past, what people value about me, my strengths and abilities, and my values."***
>
> ***"I have a care coordinator who supports me through decision making so that I get the right care in the right place at the right time."***
>
> ***"My carers are recognised as expert partners in my care. They are respected for their skills and for the vital knowledge they have about me, my condition and my preferences."***

4. Much More than a Building

Aim

Responsive and timely palliative care support, available day and night, that has the capacity and flexibility to meet individual needs and enables more people to stay at home for as long as possible and die in a place of their choice.

How

Eliminate duplication by delivering the right care, at the right time, in the right place and support individuals, and their carers, to stay independent for as long as possible. Introduce a 24-hour helpline for palliative care advice, support and reassurance and enable hospice care and hospice influenced care to be delivered at home or closer to home, day and night.

Success

Evidence that more people stay at home for as long as possible and die in a place of their choice; people have access to responsive and timely palliative care and support, day and night; and we all work for the individual's goals and the quality of their life and death.

> ***"My preference for my place to be cared for and to die is respected."***
>
> ***"Help is available to meet my needs, day or night, from people who know about me."***
>
> ***"Wherever I am, I have access to pain relief and help to manage difficult symptoms."***

5. Developing our Workforce Together

Aim

To build the knowledge, skills and confidence of all providers, carers and volunteers delivering palliative and end of life care and to develop capacity and leadership in the use of

Quality Improvement (QI) methodologies as a way of continuously improving safety and quality in palliative and end of life care service delivery.

How

Structured programme of palliative care education accessible to all healthcare professionals, care home staff, caregivers, and volunteers delivered though face to face and video enabled interdisciplinary training. This will be complemented by coaching, mentoring and Continuing Professional Development (CPD) for health and social care managers to develop skills in QI and leadership for people centred integrated care and support their teams apply these skills to drive the changes we seek.

Success

Evidence that healthcare professionals and carers have increased levels of knowledge and confidence about palliative care; more clinical professionals and managers successfully complete QI coaching /mentoring training; QI teams are established and drive changes in practice.

> ***"I am confident that staff and professionals are able to have difficult conversations with me, in order for us to decide the best treatment, care and support together."***
>
> ***"Everyone who cares for and supports me works together so that I, and the people who are important to me, can make the most of the time we have left together."***
>
> ***"Wherever I am cared for, I am helped to feel – safe – in control of my pain – comfortable and dignified, – with as little fear as possible."***

6. Monitoring Progress, Measuring Impact

Aim

To monitor implementation progress, track continuous quality improvement, and evidence the impact that the Island Plan is having on outcomes for people and for the health and care system

How

We will agree and track a comprehensive suite of process and outcome measures for the six workstreams adapted from the domains and outcomes described in *Every Moment Counts.*

- *I am at the centre*
- *Care is provided in the place of my choice*
- *I have honest discussions and the chance to plan*
- *We work for my goals and the quality of my life and death*

- *My physical, emotional, spiritual and practical needs are met*
- *I have responsive, timely support day and night*
- *The people who are important to me are at the centre of my support*

You matter because you are you, and you matter to the end of your life   Dame Cicely Saunders

OUR PERSON-CENTRED CULTURE

Success

We monitor implementation progress and demonstrate continuous quality improvement using an agreed suite of measures. We evidence the benefits for patients and those who are important to them, and improve the reach, resilience and sustainability of our palliative and end of life care services.

Acknowledgements

We would like to thank the many people who have influenced the development of this plan. Together we can make a difference.

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