# Needs Assessment:

## Integrated Palliative and End of Life Care for the Isle of Man
## 2020

Workstream 1
*From Vision to Reality*
Island Plan for Integrated Palliative and End of Life Care

Hospice Isle of Man
care for our community

CVO
Isle of Man Council of Voluntary Organisations
Giving a Voice to the Third Sector

Isle of Man Government
Department of Health and Social Care

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## Executive summary

Caring for people in the last phase of life is challenging for families, carers and service providers. As the population of the Isle of Man ages and people live longer, we will have a greater proportion of older, relative to younger, people. This will result in more deaths per year and these will be of older people. Since 2016, when Hospice Isle of Man extended its services to those without cancer, referrals to Hospice have increased by 24%. This rise will continue and we also do not know how many more people might benefit from specialist palliative or end of life care and are not receiving it.

We report here a needs assessment which aims to examine the current and near future needs of the Isle of Man as an evidence base for an Island Plan for Integrated Palliative and End of Life Care. This needs assessment is Workstream 1 of the Strategic Partnership Steering Group (SPSG) led by Hospice Isle of Man with the Department of Health and Social Care (DHSC) and Third Sector partners. The SPSG was set up in 2018 to deliver this Plan.

The needs assessment was funded by the Manx Lottery Trust (as delegated partner of Big Lottery Fund UK), the Gough Ritchie Charitable Trust, the Masonic Charitable Foundation and the Elizabeth Clucas Charitable Trust. Data sources included Government published and unpublished data, interviews with professionals from all relevant services and Third Sector groups and views of members of the public, schoolchildren and students from University College Isle of Man. Data was collected between May 2018 and August 2019. All methods and detailed results are to be found in the full report and its associated appendices.

Questions to be answered by the needs assessment are:

1. What services are currently available for palliative and end of life care?
2. How many people on the Island could benefit from palliative and end of life care?
3. Who and how many is Hospice helping?
4. What do people want from these services?
5. What is currently working well and not so well?
6. How close are we to delivering appropriate care and what remains to be done?

### What services are currently available for palliative and end of life care?

Hospice Isle of Man is the only specialist provider of palliative and end of life care on the Island but many other services deliver general palliative and end of life care in the community. These include general practitioners (GPs), district nurses, long-term conditions coordinators, specialist nurses and social care services. Third sector organisations are also involved in patient, family and carer support.

### How many people on the Island could benefit from palliative and end of life care?

Between 2013 and 2018, there were an average of 834 deaths per year but this number is expected to rise to over 1,100 a year by 2036, an increase of over 30%. Using data from registered deaths we estimated that 64% of those who died had a condition which could have benefited from palliative care; however only around 30% of those who died were known to Hospice leaving a further 34% who might have benefited from referral. The fastest growing conditions among those who might benefit from palliative care is dementia (21% growth from 2013 to 2018), followed by neurodegenerative conditions at 12%. Cancer growth rates are flat but, given that more and more non-cancer cases are being referred to Hospice, the implications for workload and capacity are serious.

These concerns have prompted SPSG Workstream 4 which focuses on Hospice services to develop its Community Plan through which resources will be invested in community-based care to ensure as many as possible who can benefit from Hospice-influenced care will receive it.

### Who and how many is Hospice helping?

More people (41%) died in hospital, between 2013 and 2018, than in any other setting. However, increasing numbers of people were dying at home (including Nursing and Residential Homes). The majority of people with cancer still die in Hospice. Most people with dementia or neurodegenerative disease die in their Nursing Home, often with Hospice involvement. Those with organ failure tend to die in hospital, sometimes because of reluctance to engage with Hospice or fast deterioration. The time that someone is under Hospice care tends to be much shorter for those who have a condition other than cancer. Many of the non-cancer cases spend only a few days with Hospice and this is not optimal in terms of the benefit they might have received through earlier referral.

### What do people want from palliative and end of life services?

Most people, and the professionals who care for them, prefer that end of life care is delivered as far as possible at home. Major areas of need to achieve this are 24-hour support and an urgent response service which could avoid unnecessary admissions to hospital. More availability of respite care would avoid carer burnout and people being transferred to long-term care. Integration of care across services and with the Third Sector is desired but difficult to achieve at present because of lack of staff, difficulties in communication and access to care records and lack of information on services available.

Those who know of Hospice tend to be happy with its care but more information about the services available is needed by professionals as well as the community. All sectors of the community, as well as Third Sector interviewees, would like to see more discussion about death and care at the end of life; young people thought this might reduce stigma. Advance Care Plans (ACPs) were considered useful by most professionals but there was also uncertainty about who should be responsible for their completion; more training and encouragement of professionals might enhance their use and result in better adherence to patient's wishes. All age groups were keen that Hospice services be sustainable in the longer term.

### What is currently working well and not so well?

All staff involved in end of life care go 'above and beyond' in their attempts to deliver an integrated service but the extra work this involves is not sustainable. The current system is complex with navigation and coordination difficult for patients and families; they would benefit from a designated keyworker. Carers feel that the essential role they play in coordination of care is not recognised by the services while Third Sector groups also believe that their complementary role is not always acknowledged. Patients and carers face challenges, including off-Island care, and feel the need for more physical and emotional support. Carer assessments are not always carried out as they should, partly because providers or Third Sector groups are concerned that the needed services are not available.

Communication between professionals and patients/families could be improved, especially in hospital wards but also between all professionals in the different services. The computer-based record systems were identified by every respondent as a particular problem due to non-connectivity and resulting delays, confusion and inefficiencies. Concerns about paying for off-Island care and on-Island 24-hour support were expressed. It was felt that appropriate triggers for referral to Hospice which were agreed with community providers would help ensure fairness and timeliness of Hospice involvement.

### How close are we to delivering appropriate care and what remains to be done?

The evidence collected during the needs assessment has been used by the SPSG Workstreams to design and deliver improved services. In October 2019, the National Institute of Health and Care Excellence (NICE) released an evidence-based guideline for adult end of life care (End of life care for adults: service delivery, NICE Guideline ng142 16th October 2019). While the actions of the SPSG Workstreams will go a long way to meeting the NICE recommendations, there are some actions still needed to ensure that the NICE guidelines can be met, partly because the system on the Island is different to that in UK. The table below shows how the SPSG Workstreams will ensure we meet many of the guidelines and the following table shows the work remaining to be done.

| **SPSG Workstream no. and theme** | **Workstream Actions** | **Guideline 142 Recommendation** | **Island Plan Outcomes** |
|---|---|---|---|
| 2. Compassionate Isle of Man | Compassionate citizens are involved in and supported to care for people nearing the end of life. | 3 | *Compassionate citizens come together to offer each other support at the end of life.* |
| 3. Person centred and coordinated care | Ensure multidisciplinary agreement on holistic assessment, care plans and provision of information to support individuals and families to be involved in decision making | 2, 4, 5, 7, 8 and 9 | *My physical, emotional, spiritual and practical needs are met* |
| | Consider appointing a keyworker for those receiving end of life care. | 9, 10 and 11 | *I am at the centre* |
| 4. Much More than a Building | Enhance information to GPs and other practitioners about specialist Hospice services, who is eligible for them and how to refer. | 4 and 11 | *Health and care professionals and carers are more knowledgeable about palliative and end of life care* |
| | Increase use of the Gold Standard Framework in general practice, hospital and care homes. | 1, 5 and 7 | *We work for my goals and the quality of my life and death* |
| | Ensure the Community Model is available 24-hours, 7 day a week so Hospice or Hospice-influenced care is experienced by all Island residents who need it | 3, 5, 7, 10 and 12 | *I have responsive, timely support day and night* |
| 5. Developing our Workforce Together | Continue to expand the upskilling of those delivering palliative and end of life care in care homes, hospital and community settings | 1, 2, 3, 5, 9 and 10 | *Health and care professionals and carers are more knowledgeable and confident about palliative care and work together for the individual's goals and the quality of their life and death.* |
| | Ensure carers and others who are important to people at the end of life are identified and recorded. | 1 and 3 | *The people who are important to me are at the centre of my support* |
| | Ensure all professionals who manage people at the end of life are prepared to discuss treatment and | 5, 6 and 7 | *I have honest discussions and the chance to plan* |

| | | | |
|---|---|---|---|
| | care preferences with individuals and their chosen family members and encourage completion of an ACP. | | |
| | Improve timely discussion of palliative care support and review of treatment options with patients in hospital and their families | 1, 3, 4, 5 and 6 | *Care is provided in the place of my choice* |
| 6. Monitoring Progress and Measuring Impact | Monitor information on the demand, capacity and quality of palliative and end of life care services | | |
| | The services delivered are based on predicted population needs, informed by evidence and lived experience and prioritise what is important to local people, professionals and organisations | | |

| **Action required** | | **Guideline 142 Recommendation** |
|---|---|---|
| Discuss further with Hospice partners | Fully implement the **Isle of Man Carers' Charter** to support carers for all who have palliative or end of life care needs, regardless of their condition, and consider the availability of respite services to support carers and avoid premature admissions to long-term care | 3 |
| | Ensure **data-sharing agreements and improvements to electronic information-sharing** continue so that care plans and treatment plans can be shared and reviewed and ACPs bridge hospital and community services. | 6, 8 and 10 |
| | Improve communication and information transfer between **off-island providers** and islands services, residents and family members | 10 and 11 |

As further data becomes available on the Island, it is important to look in more detail at e.g. case mix at the different levels of the system to monitor access to specialist end of life care to ensure equity of access for the whole population. Better data would also enable us to assess our services against the NICE Quality Standards QS13, QS14 and QS15 for End of life care, Care of dying adults in the last days of life and Patient experience in adult NHS services, respectively.

Contents

# Introduction and background

Caring for people in the last phase of life is challenging, though potentially rewarding, for families, carers and service providers. If services and support are to be extended to all who might benefit, limited resources will be further stretched. A plan is required to ensure that this is done fairly and in a way which maximises benefit to the population.

This report examines the current and near future needs of the Isle of Man in the area of palliative and end of life care. It is intended to form an evidence base for recommendations to be considered by policy makers as part of the transformation of services on the Island and to feed into any relevant Joint Strategic Needs Assessment. It is aimed at a wide audience who have an interest in the improvement of palliative and end of life care on the Island.

As the population of the Isle of Man ages and people live longer, we expect to have a greater proportion of older, relative to younger, people. The Government estimates that the number of older people (over 65 years) will increase by 30% by 2036, regardless of any changes in migration patterns; this will result in approximately 1.5% more deaths each year (7).

The primary purpose of the Hospice service is to provide specialist palliative and end of life care; an approach that improves the quality of life of patients facing life-limiting illness, and of those who matter to them. From 2016 when Hospice Isle of Man extended its services to those without cancer to 2018, referrals to Hospice increased by 24% (8). The demand for Hospice services increases each year with, in 2018, referrals up 7% on 2017 and those supported in their final days up by 17%. This trend is expected to continue but we do not how many more people might benefit from specialist palliative or end of life care and are not receiving it. Hospice is committed to providing a service that is fair to everyone by developing new ways of working to support people with terminal or life-limiting illnesses on the Island (9). The challenge is to develop and deliver an integrated palliative and end of life care service that provides the right care, at the right time, in the right place.

To varying degrees, integrated palliative and end of life care is currently provided by a range of organisations, professionals and community members. Many people have informal carers e.g. family members and almost all health-related services on the Island are involved in palliative or end of life care to some extent, along with Third Sector organisations.

In 2018 The Strategic Partnership Steering Group (SPSG), led by Hospice Isle of Man with the Department of Health and Social Care (DHSC) and Third Sector partners, developed an ambitious five-year plan for Integrated Palliative and End of Life Care on our island. This plan, the Island Plan for Palliative and Integrated Care 2018-2023 *From Vision to Reality* (10) aims to deliver excellent palliative care for all those who need it in a way that is affordable, sustainable and supports more people to have their end of life care in the community setting if that is their choice.

The first workstream in this plan is a comprehensive needs assessment of integrated palliative and end of life care on the Island. Funding for this was provided by the Manx Lottery Trust (as delegated partner of Big Lottery Fund UK), the Gough Ritchie Charitable Trust, the Masonic Charitable Foundation and the Elizabeth Clucas Charitable Trust and the needs assessment was carried out between May 2018 and August 2019.

A needs assessment aims to examine the needs and provision of care for a defined population, in this case the population of the Isle of Man, and to identify gaps and potential solutions. This report provides a summary of the work conducted for the needs assessment and is intended as an evidence base for the other five SPSG workstreams which are Strengthening compassion in the Isle of Man (Workstream 2), Person-centred and coordinated care (Workstream 3), Much more than a building (Workstream 4) Developing our workforce together (Workstream 5) and Monitoring progress, measuring impact (Workstream 6).

The workstreams aim to 'deliver excellent palliative care for all who need it in a way that is affordable and sustainable and which supports more people to have their end of life care in community settings' (10) (p.3).

This report on the needs assessment sets out

1) the local and international context to the needs assessment

2) the methods that were used in the needs assessment

3) what services are currently supplied

4) results obtained from locally available data

5) views of the local community

6) views of patients and carers

7) results obtained from consulting with local professionals and

8) the recommendations on end of life care from the UK National Institute for Health and Care Excellence (NICE) and further recommendations for the Island.

A summary of each section is presented here and more details for each section, including details of the methods used, are supplied in a set of appendices.

## 1. The local and international context

(Full details are in Appendix 1)

In 2012, the Isle of Man End of Life Care Framework and Implementation Plan 2012-2015 was launched by the Department of Health (11). This was followed in 2018 by the Island Plan for Palliative and Integrated Care 2018-2023 (10) which recommended that the needs assessment be carried out and that five further workstreams use the findings of the needs assessment as the basis for actions that would achieve the Plan's aims. These are Workstream 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 and 6 - Monitoring progress.

Meanwhile, in 2013, a Carers' Charter (3), which recognised the need for more support of carers, had been signed by the Ministers and Chief Executives of the Government Departments of Health, Social Care and Education and by the Chief Executives of Crossroads Care, Manx Cancer Help and Live at Home. The recommendations of this Charter were not fully implemented.

In 2014, the World Health Assembly had published a resolution calling on all member states to integrate palliative care into national health care systems (12), recognising that it improves quality of life, is an ethical responsibility and is needed across disease groups. Improving access to palliative and end of life care is the ambition of the Hospice movement (13) and Hospice Isle of Man (9). As a result, in the UK, there have been a number of strategic guidelines published, the most recent of which, from NICE, is a list of evidence-based recommendations for the service delivery of end of life care for adults (2). This NICE guideline has been applied to the evidence gathered in this needs assessment and the results are described in Section 8.

## 2. Aim and methods of the needs assessment

(Full details of methods are in Appendix 2)

The aim of the needs assessment was to provide an evidence base for the Workstreams of the SPSG as they take forward the Island Plan for Integrated Palliative and End of Life Care. The questions this needs assessment aimed to answer were:

1. What services are currently available for palliative and end of life care?
2. How many people on the Island could benefit from palliative and end of life care?
3. Who and how many is Hospice helping?

4. What do people want from these services?
5. What is currently working well and not so well?
6. How close are we to delivering appropriate care and what remains to be done?

The needs assessment used a variety of sources to obtain information including population data collected by Government departments, both published and unpublished and the experience and views of people involved in providing or receiving care. While many other needs assessments use small groups of informed people as part of their data collection, in the face of limited alternative sources of data, we carried out many individual interviews where respondents were freely able to express their views. These included:

- Interviews with patients and carers and focus groups with nursing homes.
- Interviews with professionals working in relevant services including hospital and community, public and private services and other Third Sector staff and volunteers.
- ‘Listening events’ with local shoppers and community groups, schoolchildren and college students where people were asked what would be important to them if they were using end of life care themselves or for a loved one.

Finally, in order to make sure the experience of general practitioners (GPs) was included, we offered them a short survey.

## 3. Population and medical record data analyses

(Methods are in Appendix 2, supplementary information on results and all tables are in Appendix 3)

### Isle of Man Demographics

According to the 2016 census (14), those aged 65 or over accounted for 21% of all residents. Moderate population projections to 2036 (7) predict the number of those 65 years and over to increase by an average of 1.2% per year, an increase of 32% from 2016 to 2036. This means that, in 2036, 25% of the population will be aged 65 years or over compared with 21% in 2016.

### Mortality

Between 2013 and 2018, there were 5,005 deaths on the Island, an average of 834 per year (range 784-875; Appendix 4, Table 1). On average, women died at an older age (81 years) than men (75 years). The distribution of deaths by age group is shown below (Figure 1) and the top three causes of death in 2017 were cancer, circulatory disease and respiratory disease (15).

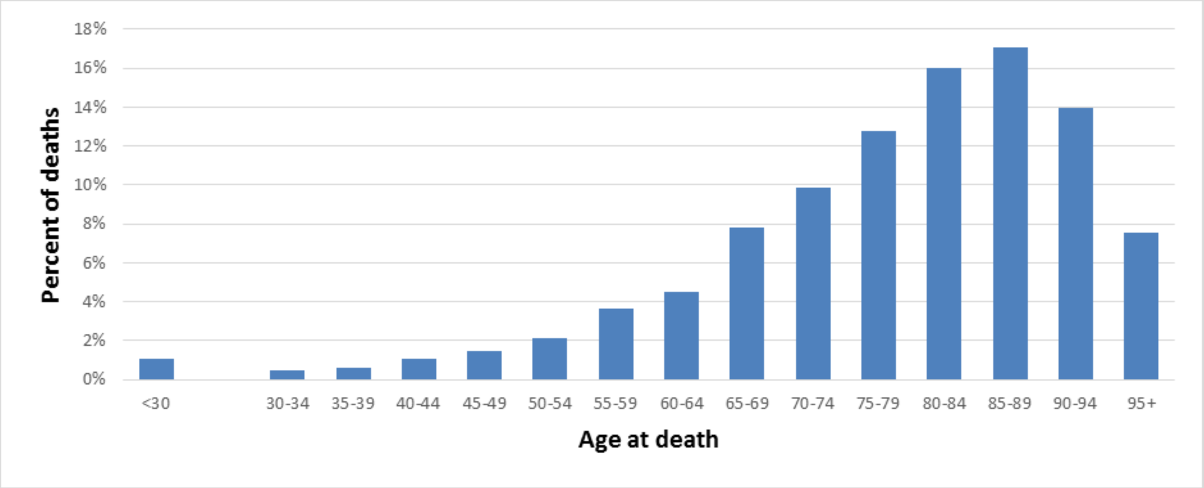


Figure 1. Distribution of deaths by age, 2013-2018

### Place of death

Between 2013 and 2018, 41% of people died in Noble's Hospital, 18% in a nursing home, 16% in Hospice, 16% at home and 5% in a residential home (Figure 2).

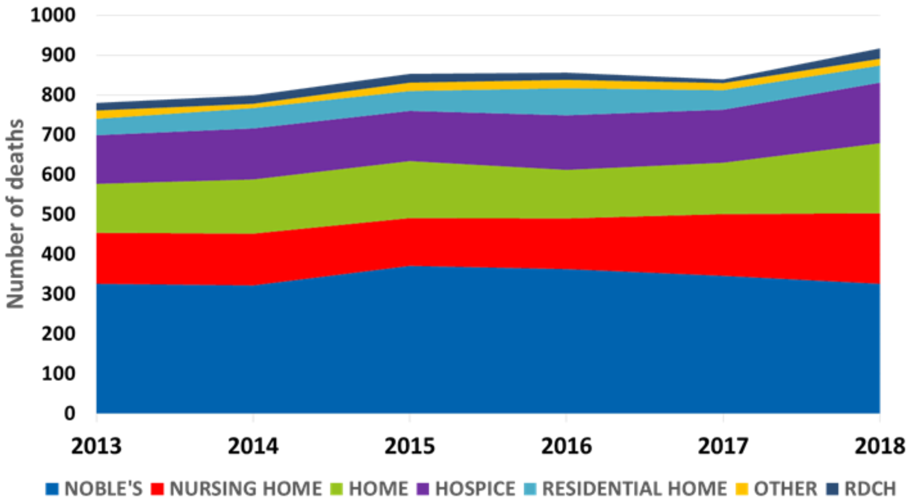


Figure 2. Place of death, 2013-2018

There was a difference in place of death by sex and age with women more likely to die in a nursing home (24% versus 12%) or in their usual place of residence (42% vs 33%) than men. The average age at death was higher when someone died in a nursing or residential home (87 years) compared to Noble's Hospital (78 years), home (73 years) or Hospice (72 years).

Marital status was associated with the place of death with 52% of those who died in Hospice being married compared to 20% of those who died in a nursing home and 17% in a residential home. Over half of those who died in a residential home (56%) or a nursing home were widowed (58%) compared to 26% of those who died at home.

Between 2013 and 2018, the number of deaths in nursing homes increased by 37% (an average of 6% per year) and 90% of nursing home residents were able to stay there at the end of their life while 49% of residential home residents were able to die in their residential home. (increasing by around 2% every year).

Between 2013 and 2018, the cause of death was associated with the place of death. Cancer patients were more likely to die in Hospice compared to all other conditions (Figure 3). From 2016 (when Hospice changed its criteria to welcome non-cancer patients) to 2018, 51% of cancer cases died in Hospice as did 12% of patients who died of a neurodegenerative condition, 7% who died of organ failure and 3% who died of dementia; overall, 57% of those who died of organ failure did so in Noble's Hospital.

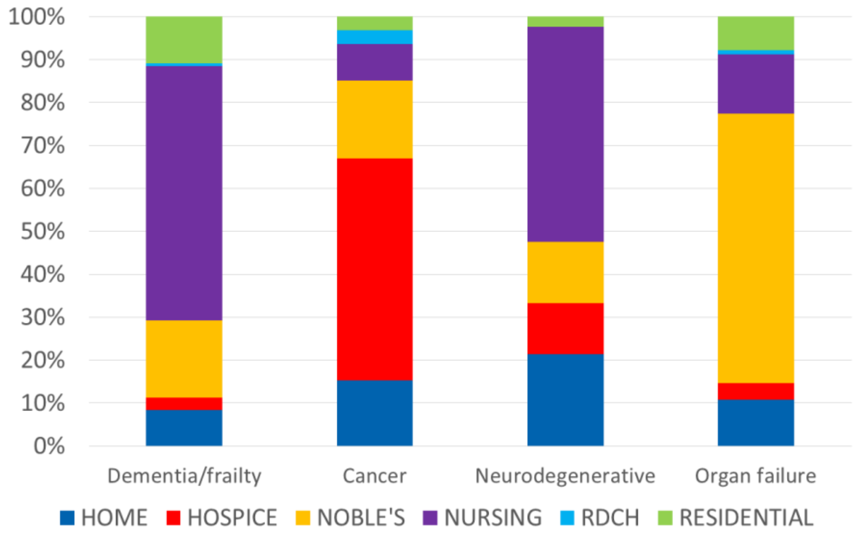


Figure 3. Cause of death and place of death, 2013-2018

### Mortality projections and palliative care need

According to moderate population projections (personal correspondence with the Department of Economic Affairs), the number of deaths is predicted to increase 30% from

2018 to 2036 at a rate of about 1.5% per year; this reflects the larger population and more people in older age groups.

It has been estimated that approximately 75% of all deaths in high income countries, like the Isle of Man, could benefit from palliative care (16, 17). Data from death certificates of those who died here in the six years between 2013 and 2018 suggest that 64% had at least one condition such as cancer, dementia or frailty, neurodegenerative disease or organ failure and so could have benefitted from palliative care. Hospice had provided some aspect of care for almost half of the 64% i.e. 30% of all deaths, leaving the remaining 34% who could have benefited from palliative care but we do not know whether they received it (Figure 4).

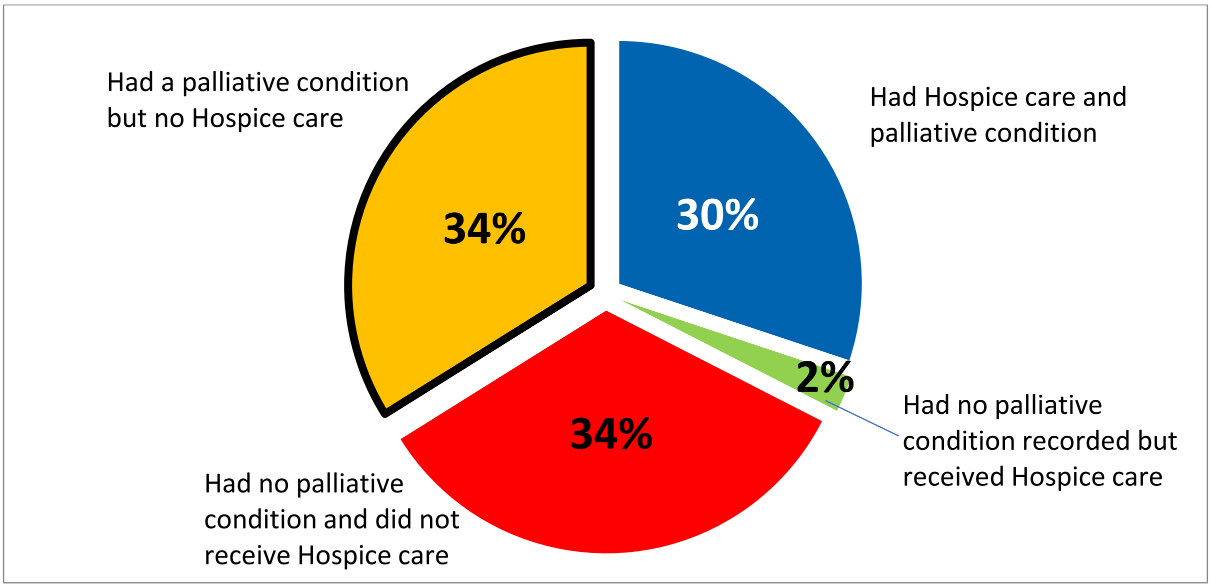


Figure 4: Match of estimated need for palliative care with whether Hospice care was provided

Using these estimates of 75% or 64% of those who die on the Island being able to benefit from palliative care, and applying this to the projections in mortality, we can see that estimated need for palliative care is likely to increase as shown in Figure 5.

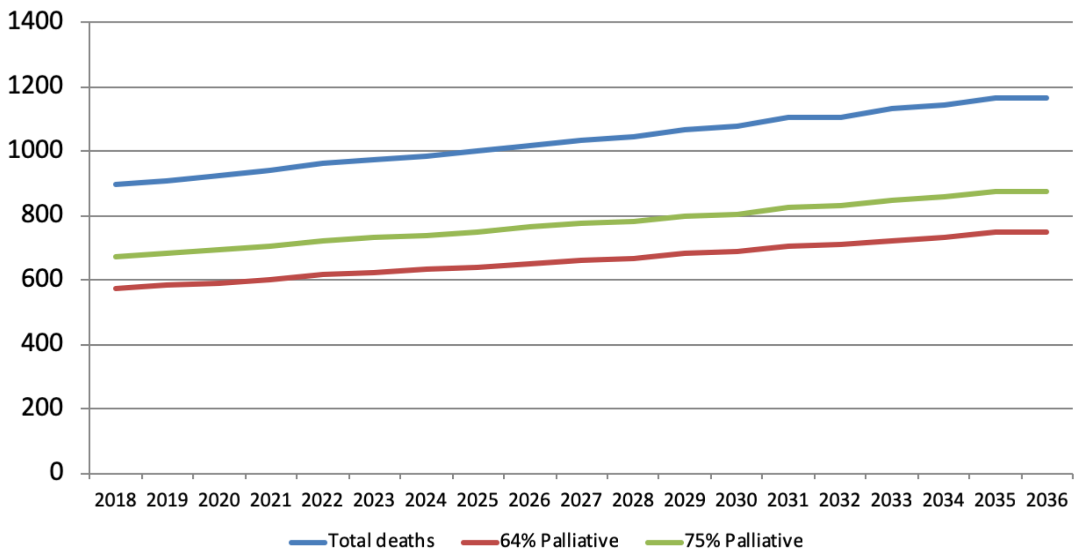


Figure 5. Mortality projections assuming moderate population growth and palliative care need from 2018 to 2036

Further examination of death certificates from 2013 to 2018 shows the annual growth rate in deaths from conditions which might benefit from palliative care (Figure 6).

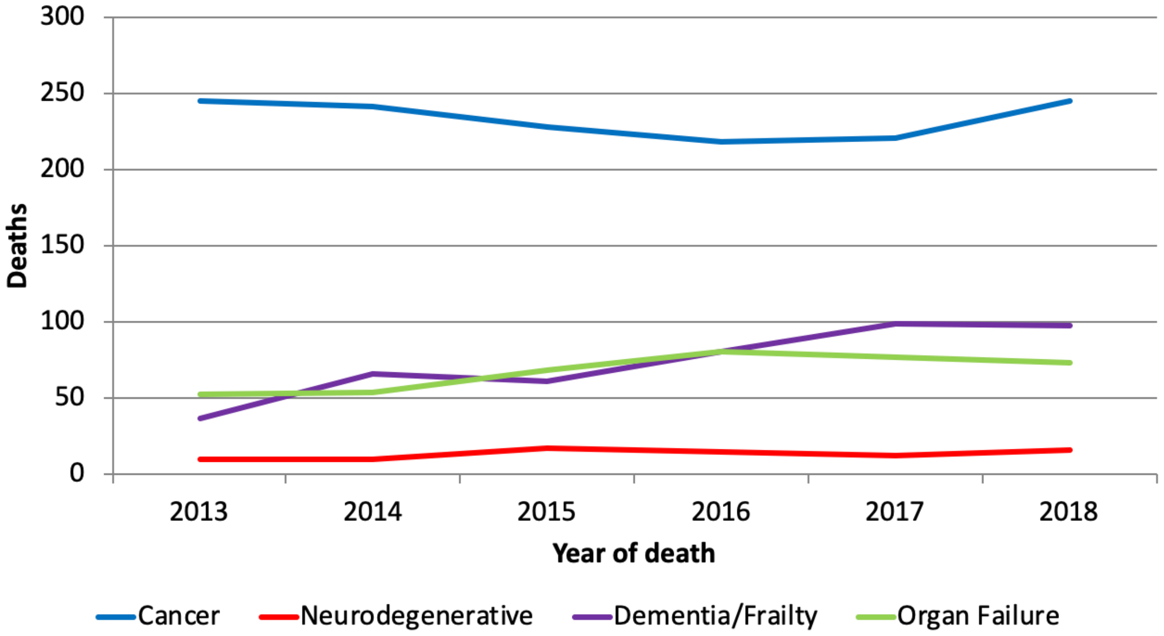


Figure 6. Trends in palliative conditions as a cause of death, 2013 to 2018

Deaths due to dementia or frailty increased by 21% per year, neurodegenerative conditions by 12%, organ failure by 7% but deaths from cancer did not increase year on year. It must be noted that the extraction of this information was wholly dependent on the quality of the recorded information on the death certificates and some part of the increases could be due to better awareness and recording; this is an area that would benefit from further examination and improvement in data quality.

Hospice had opened up its referral criteria in 2016 to include these other life-limiting conditions and we estimate that, since 2016, Hospice cared for 88% of those who died of cancer on the Island but only 28% of those who died of organ failure, 26% of those who died of neurodegenerative disease and 16% of those who died of dementia or frailty. There may already be a need for greater involvement by Hospice in some of these cases but note must be taken that they are increasing, as causes of death, faster than cases of cancer.

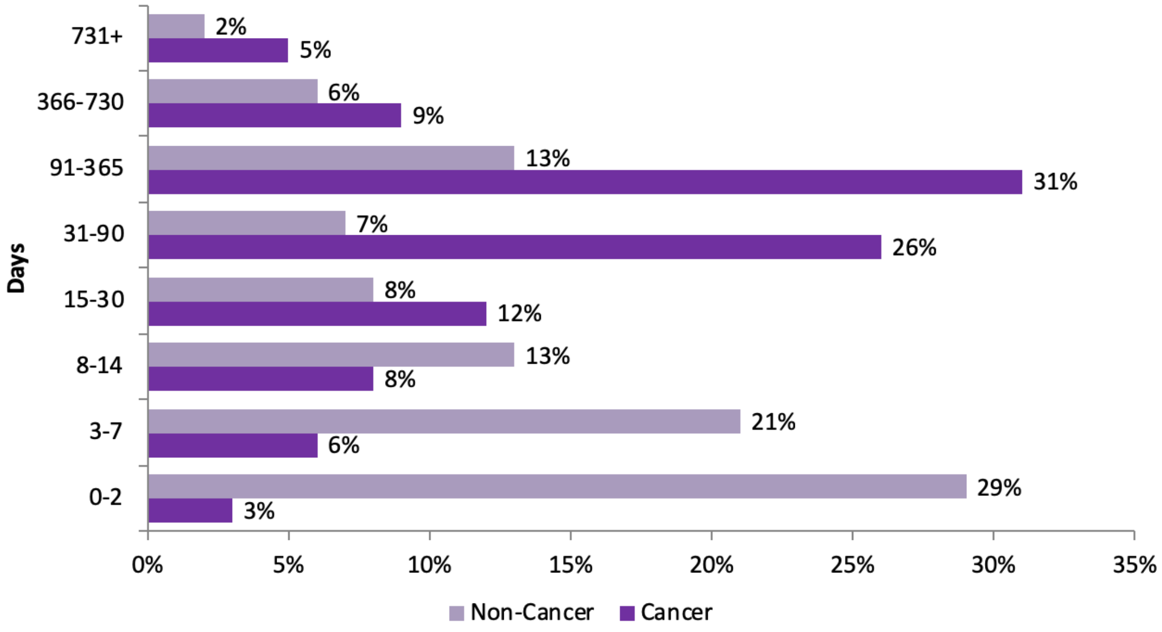
## Hospice referrals

In 2018, Hospice received 527 new referrals, an increase of 24% from 2016. Since the change in referral criteria in 2016, non-cancer referrals had increased by 131% while cancer referrals increased by 22%.

The majority of referrals to Hospice originate in Noble's Hospital. An analysis of 449 Hospice patients who died between October 2017 and May 2019 showed that 68% were referred to Hospice by a consultant or a specialist nurse from Noble's Hospital, 21% by a GP and 6% by a hospital in the UK; 35% of these were non-cancer patients.

### Hospice length of care

The length of care provided by Hospice ranged from less than 1 day to nearly 11 years with a median (middle value with half less and half more) of 38 days and an average of 163 days. The vast majority (88%) received care for a year or less and 43% for a month or less. Of very late referrals (a length of care of two days or less), 63% were admitted for diagnoses that could have benefited from earlier intervention. The length of care differed by whether someone had cancer or not with the median number of days of care for cancer patients being 78 days compared with 7 days for non-cancer patients (Figure 7).



Source: Hospice EMIS, May 2019

Figure 7. Hospice length of care of patients with and without cancer who died between October 2017 and May 2019.

## Need for community support for end of life care

In 2018, 70% of people who died had a condition mentioned in their death certificate (cancer, neurodegenerative, dementia/frailty, organ failure) which might have benefitted from palliative care. Of these, 70% (424 people) lived at home at the time of death. Assuming that those living at home had similar preferences to Hospice patients, 40% (170 people) would have preferred to die at home but only 89 people (21%) are recorded in the death certificate as dying at home. It is therefore possible that 81 people would have preferred to die at home and did not, although the reasons for this are unknown. Of those residential home residents who died in 2018, 30% died in Noble’s Hospital and 56% in their residential home. It is impossible to know, at the present time, how many people who died in hospital might have been able to be supported to die in their residential home. Of nursing home residents, 91% died at their nursing home. Community-based end of life support is mostly needed for those remaining at home or a residential home although nursing home staff may require specialist support in certain cases. Although patient and family wishes may change at the very end, this provides an estimate of the extent of generalist and specialist palliative care support needed in the community.

## 4. Views of the public

(Full details of methods and results are in Appendix 4)

### Adults

Consultations with 278 people (63% female with 68% aged over 54) were recorded. The majority of respondents had a positive (62%) or neutral (33%) perception of Hospice.

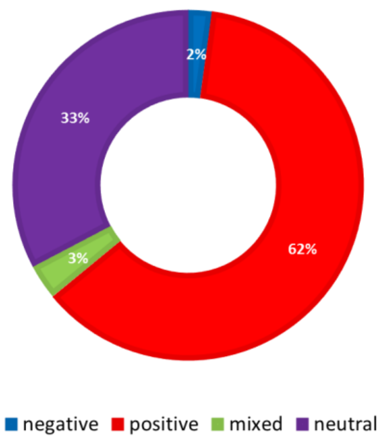


Figure 8. Public's perception of Hospice

Amongst people who had experienced or had a connection with Hospice (n=89), most (82%) regarded it positively, 3% were negative, 5% had mixed feelings and 10% were neutral. Of those with no prior experience, the majority felt positive (52%) or neutral (43%) about Hospice with only a few who had negative (2%) or mixed (3%) feelings.

What mattered most to respondents was effective care, emotional support, person-centred care, equity, communication and education, choosing their preferred place of care, kindness, honesty, knowledgeable staff personal visitors and having a calm environment. Comments about Hospice were related to sustainability, working in the community, expansion of services and wider access; specific comments included the need for more information, being sustainable, having an advice line for people who want to find ways to support friends and co-workers at end of life, and bereavement support. Also mentioned was education for carers, support for people using off-Island services, stronger partnerships between services to complement existing care, financial support for patients and carers, more varied transport options and help with transitions between hospital and home. They would also like people to have earlier discussions about death.

## Schoolchildren

When asked about their current understanding of hospice care, 203 students (48% female, aged 11 to 16 years) described Hospice as “helping”, “caring”, “supporting”, “looking after” and “care of the dying”. They understood that Hospice is a charity and does fundraising. Cancer was mentioned as well as respite. While several believed that Hospice is for older people, others were aware of the children’s hospice, Rebecca House, and bereavement care; however, many knew nothing about Hospice. Misconceptions included confusing Hospice with cancer research, financial assistance and a mental health service.

There were three main themes of what mattered most to the schoolchildren: to be treated as a living person not a dying one, friends and family, and comfort. A sense of normality was desired, alongside patient independence and respect. It was suggested that Hospice could have a bright, colourful, homely, non-clinical, young-person-friendly environment with animals, technology, games, TV and films. It was important to have confidentiality and honesty about illness and prognosis. Schoolchildren valued responsive staff, the ability to take part in activities for as long as possible, to have visitors at any time of the day or night, appetizing food and drink, and a pleasant outdoor environment.

Participants suggested that it would be helpful for Hospice to feature more prominently within the local community and online, to increase awareness and reduce stigma or fear around using the services. Some wished for greater understanding and awareness of palliative and end of life care and suggested more partnership working with schools and work experience. Some were concerned about meeting the needs of more families and having more respite facilities, with suggestions that Hospice could be supported through increased government subsidy.

## College students

Discussions were held with 647 students (average age 17.7 years, range 16 to 39, 59% male) across 22 sessions. Most students were open and willing to discuss death and dying. It was felt that the concept of a ‘good’ death is subjective, but ideally would be quick, with time to prepare and before quality of life is impaired. Control of what was happening was key to preserving the dignity of the dying person. Physical, psychological and spiritual peace and comfort were important as well as the aftercare of the family. Many felt we should plan for the end of life but live life to its fullest now. The Hospice of the future would accommodate all ages and have activities for young people, and be bright and colourful as well as calm and quiet. It was important to students that clients should be treated normally.

A key theme was that, whilst most participants agreed that planning for end of life is important, it was not something they were ready to consider yet. Most did not know about end of life care or advance care planning on the Isle of Man, however there seemed to be a thirst for knowledge, with participants recommending public engagement to increase awareness of Hospice and reduce the taboo around death and dying.

Participants emphasised the importance of enough inpatient beds to meet the needs of the Island population. It was felt that “the right care at the right time in the right place” translated to students as care within the Hospice inpatient unit, so better communication with the public might be needed to dispel this view. Another issue raised was being able to choose when to die which was favoured by some.

## 5. Views of patients and carers

(Full details of methods and results are in Appendix 5)

As revealed by analysis of diaries kept by those with long-term illness and their carers, the number of services encountered when dealing with a complex or terminal illness can be vast, crossing all sectors. Judy’s care map (names have been changed) shows the caregivers with whom one person was in contact in the last 18 months of life (Figure 8); there were multiple contacts with these care providers across public services, private services and charities.

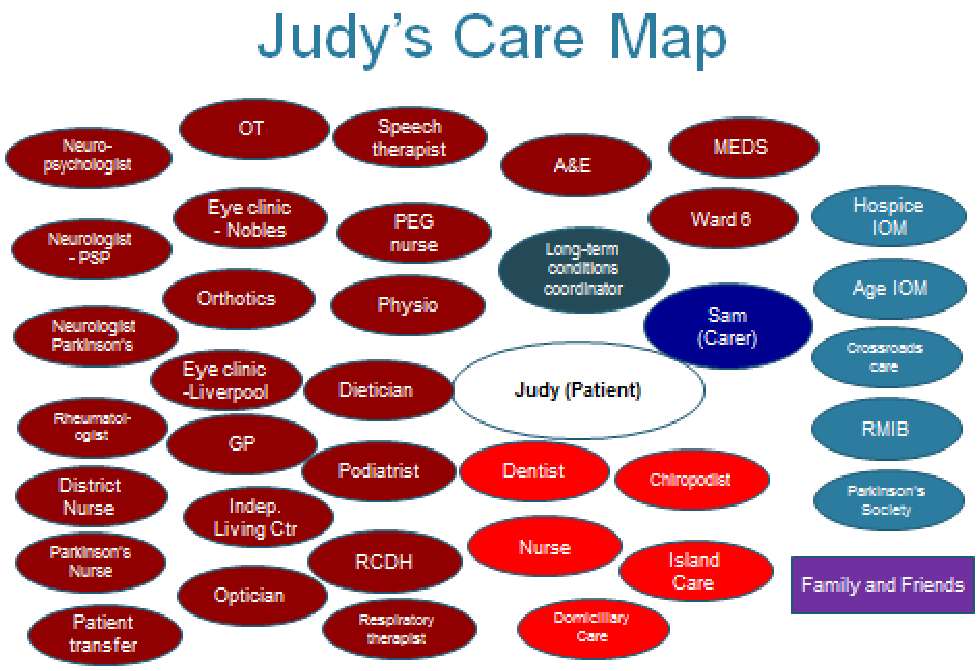


Figure 9. The ecosystem of care during the last 18 months of life of one individual

Interviews with twelve people who were patients with a life-limiting condition, carers or in some cases both, revealed the following main themes:

- **Need for better communication between professionals**

Patients and carers reported having to repeat their health history at each new encounter and witnessed the difficulty of professionals accessing records and information during consultations.

- **Need for better communication and involvement in decisions**

Patients were not always copied into communication between professionals, including those that happened off-Island. Decisions about care were made but the patient or carer was not involved.

*"Sometimes we are not told until after they (multi-disciplinary team meetings) happen. They make decisions and tell you what is going to happen."*

Patients and carers expressed frustration at not being able to speak to someone when they called a professional or service. Communication about the reasons for and benefits of palliative care is needed and palliative care needs to be introduced earlier in the disease.

- **Carers provide and coordinate care but they are not recognised by the system**

Carers have devised systems to organise documents and relevant information to keep track of the complexity accompanying care; they know about all aspects of care and can identify areas in which duplication could be reduced. Through experience, many carers have learned to identify symptoms that require urgent care. However, the system does not formally recognise carers' role and many face difficulties when discussing care and making appointments. Training for carers would be beneficial as many aspects of care were learned through trial and error.

- **Having a professional to help navigate the system is invaluable**

Patients felt daunted by the complexity and lack of transparency of the care system. The long-term conditions coordinator "*made all the problems appear solvable*". Others expressed the desire for "*somebody we could pick up the phone (to) and say help, can you come?"* A coordinator or key worker could take a holistic view of the patient's situation and help advocate for what is important to them.

- **Patients and professionals need better information about services**

Even for those who were aware of Hospice services, referral criteria are not clear and families said that "*how you get in is a mystery*." The current system requires a referral from a medical professional but not all professionals were clear on when it was appropriate to refer to Hospice.

- **Carers need physical, social, and emotional support**

Carers felt that "*nobody can do a lot of the things that I do*" and do not always know how to take up offers of help, when given. Respite care was considered essential to give carers "*the strength to carry on".* Caring could be a "*full-time job*" and financial assistance for carers was insufficient

- **Patients and carers feel alone and not understood**

Patients and carers could experience isolation, some due to 'self-imposed' isolation where a person does not want to interact with others but others with life-limiting illnesses found that "*people when you get sick don't want to know you".* Patients would also like to hear about what to expect from someone who has experienced what they are about to go through.

*"The clinicians can tell you but they have not experienced it."*

- **Off-Island care is a substantial burden for patients and carers**

Patients not wishing to travel back and forth during long spells of care must pay for weekend accommodation out of pocket. The burden of travelling for people who are not well outweighs the benefits of a short follow-up appointment with off-Island providers. Some wondered why teleconferencing was not used more widely. Care plans were not always in place for those returning from off-Island treatment.

- **Out of hours service is lacking**

Patients can have a team of professionals supporting them at home that are "*fantastic*" but in cases of rapid deterioration out of hours, the response can be poor. Carers who experienced this described the lack of clarity as to whose responsibility it was to look after a patient and thought that doctors might not have all the relevant information to hand e.g. codes for 'just in case' boxes.

- **Patients want to maintain independence but need to know they are safe**

Maintaining independence was important to patients as it affected their mental health. However, patients and carers needed the reassurance that if they required help, they could get it at any time, in a timely manner.

- **Care staff need skills to recognise when a patient is in the last days of life**

Community care staff did not always recognise when someone was in the last days of life and this could lead to unnecessary suffering for the patient and anxiety for the family.

- **Patients and carers experience mental health problems when facing end of life**

Patients felt helpless and hated being a burden on their family. The change in role from wife or husband to carer had an effect on mental wellbeing. Accessing help was not always easy; even accepting that they needed help could be difficult.

*"I felt that I was failing if I needed help."*

### Nursing homes

Group meetings with residents, nurses and carers showed that staff felt they were working together, motivated and had good teamwork. Carers and residents were confident in the care, support and availability of staff at the home. Hospice was considered approachable and care for the family was appreciated but both residents and their carers had thought that Hospice was only for cancer patients. Staff commended the prompt response to referrals to Hospice. Everyone was pleased that consultants from Noble's Hospital would come to see patients at the nursing home rather than require them to travel to the hospital. Nurses noted that relationships and information-sharing were good between GPs, Hospice nurses and health care professionals but suggested that information on disease processes and Hospice services would be helpful for families.

## 6. Views of professionals and Third Sector

(Full details of methods and results are in Appendix 6)

We interviewed 63 professionals who work with people at the end of life or in need of palliative care. They told us what they felt was working, not working and made suggestions. The services they work in can be conceptualised as a pyramid:

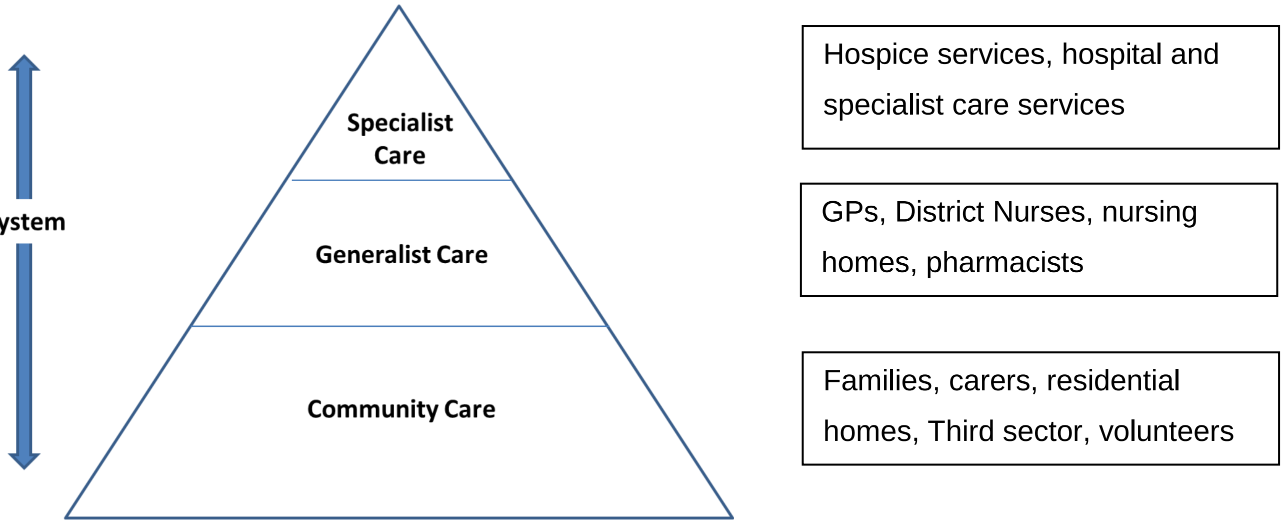


Figure 10. Services for integrated palliative and end of life care

Focussing on each level separately, the major themes have been drawn out of these professionals' experiences and are summarised below with full details in Appendix 7.

### Specialist care

- **Hospice care is very good when you can get it**

The extension of working hours to cover weekends makes a massive difference to other services; the support given by Hospice to Nobles' bereavement team is excellent. The Hospice at Home team is really stretched so cannot support MEDS (Manx Emergency Doctor Service) and other services as much as wished.

*"The service users we've had recently have been very, very well supported by Hospice"*

*"Hospice as an organisation is proactive and forward thinking"*

- **The way Hospice is used might be improved**

Referrals to Hospice may be made to free a hospital bed rather than for patient needs; the Hospice at Home service might be the default because someone can't afford private care or it's not available; some people are frightened of going to Hospice so it is good to get them involved much earlier; it is useful to introduce Hospice as respite care before further intervention is needed, give people easier access, emphasise the quality of life, not end of life.

- **The hospital staff work within their constraints**

Hospital ward staff do their best with end of life cases e.g. moving to a side room if possible. UK consultants can be very helpful with video links and visits, although some professionals ask why we don’t have more video communication.

- **Better inter-professional communication is needed**

There are some current barriers e.g. hospital ward nurses usually know at admission when the patient is receiving Hospice care because the patient tells them but data protection regulations can prevent Hospice alerting the specialist services that a patient has been admitted to the Hospice inpatient unit while Hospice is not always informed of late stage cancer admissions and discharges. The Hospice referral form is seen as laborious (4 pages) and many ward staff don’t know about the services available e.g. the Fatigue and Breathlessness programme (FAB).

Patient discussions in the UK about stopping treatment or referral to palliative care are not always discussed with the island specialty team or even the family; the patient may also receive inadequate information from the UK staff.

*“Then the letter will go back to the GP and they don't copy the referring consultant in”*

- **Simple handover between specialist and Hospice not ideal**

The end of life process for some conditions can be drawn out complicating a simple hand-over referral from specialist to Hospice; patient and family acceptance might be slow and input from both specialist and Hospice for a time would be ideal – also an opportunity for the specialist nurse to improve palliative skills; if this process does not go well, the patient may end up in hospital at a late stage and die there.

- **More communication about end of life is needed in hospital**

End of life is not always acknowledged in hospital and people are put through inappropriate tests; end of life arrangements are made too late at times because doctors shy away from being open with the family; there is a perception that consultants might just ‘send to Hospice’ rather than discuss a patient’s needs; it is suggested that doctors should talk more openly about death e.g. when end-stage patients come into the ward with medical problems.

*“The consultant hadn’t had that conversation with the family”*

*“No one had actually spoken to the family”*

- **Care needs to be better integrated**

There is fragmentation of services and inadequate information transfer: e.g. someone admitted to hospital but no communication that they are under mental health or district nursing services; variable attention to holistic care because of time pressure; we need to find a balance between upskilling and de-skilling hospital staff; we need a rapid response e.g. to a nursing home to put an end of life plan in place and avoid the emergency department (ED).

> *"It's getting so big it's getting fragmented, and it's hard to keep track of everybody"*

Could we have a Hospice-ED link person? Could we distinguish generalist and specialist care needs to assist allocation to services? Could staff have/use wider skills to avoid calling out other specialists? Could volunteers have expanded roles?

Some palliative care services are already quite well integrated but others, despite trying, find there is no cross-fertilisation or shared knowledge between them and implementation of new ways of working takes a long time.

> "*There's an awful lot of things happening very much in isolation of each other and without that cross-pollination of knowledge*"

- **Perceived inequity**

Those who travel for care in the UK have to pay upfront for their travel and accommodation and some find it difficult to afford. There is a feeling that some disease groups e.g. cancer and stroke have more services available to them perhaps because of Third Sector campaigning and funding. Island specialist nurses do a lot more than UK-based ones such as arranging travel and communicating with a lot of off-island providers.

## Generalist care

The middle, generalist level has been organised into one of the main themes which emerged: right place, right care, right time.

### Right place – supporting people in the community

- **Preference to stay at home as long as possible**

This was believed by almost all professionals to be the case (care homes are also considered as 'home' in this section). All relevant professionals work to try to achieve this but some of the essential resources are not in place or not available to everyone.

- **An urgent response team is needed to deal with emergencies**

Even if something is only perceived as an emergency by the family, a quick response is essential to maintaining confidence in keeping someone at home. This is even more essential out of hours. While managing end of life emergencies has become a bit easier with the 7-day Hospice service, the limited service at night means some people end up in the ED because MEDS cannot respond and the ED staff might only be able to register the patient and create an end of life pathway. An urgent response service has been proposed and this could enable people to remain longer at home. Extending the remit of ambulance staff is another suggestion made.

*"24/7 palliative care irrespective of the location. That would be the dream."*

*"The other gap is….. the nursing care out of hours and therefore being able to die at home"*

- **There is a need for appropriate respite care**

There is almost no respite available for those with nursing needs, even in an emergency. Nursing homes might make a temporary vacant room available but only until a permanent resident needs it and there are very few double rooms so couples are split up. Residential home respite beds are oversubscribed. This lack of appropriate, temporary, respite care can result in someone moving to permanent care. Every week there are 1 or 2 notified crises which require respite. The services struggle to keep people at home and carers become exhausted. For dementia cases, a facility somewhere between a residential and a nursing home would be welcomed.

- **Families need to be supported to manage care at home**

Apart from a need for rapid response and respite care, families can also be confused about who to contact even during the day, for example, calling for an ambulance when the problem could be better dealt with by the district nurse, not knowing what Hospice can offer. Specialist services have some difficulties in managing the recommended holistic needs assessments - finding the correct time after diagnosis, engaging with the patient and family; third sector colleagues might be better placed to do these

- **Integration rather than partition of care is needed**

Health care professionals are increasingly specialised and busier and share care responsibilities; when care is handed over, e.g. at the end of life, long term relationships can be disrupted, professionals are de-skilled and feel task-oriented and dissatisfied. Integrating care should be easier on the Island due to size but it is difficult to slot new ways of working into an old system.

Statutory services are often unable to provide care packages for complex conditions for more than a few days so several private agencies may work together long term. These relationships can be disrupted when end of life care is needed.

*“Others won’t, not won’t do it, but maybe don’t have the competencies”*

- **Intersectoral relationships are essential**

Some intersectoral relationships work well e.g. mental health services and the Alzheimer’s Society, district nurses working with private and third sector agencies. There are gaps in the services to back up private care at end of life and a general lack of knowledge of available services which prevents appropriate signposting to useful services.

- **Some things going in the right direction and a “window of opportunity”**

It was felt to be time consuming to develop the necessary shared vision and there is a lack of system support for communication. However, ‘*the island could lead on integrated care’* if it could concentrate resources on the areas of need and integrating care could solve many of the problems that services are facing.

- **Communication between professionals needs better systems**

Every single respondent that shared or referred patients said that the non-connectivity of IT systems was a big problem resulting in duplicated work and referrals, patient confusion, complicated and time-consuming processes and losing contact with patients. It impacts workload and patient care. The community use EMIS, the hospital uses Medway and Mediviewer, the mental health and social services use Rio and some, but not all cancer specialist nurses use the Somerset Cancer Registry. Ambulances rely on paper records because they have no access to digital services in the van. Many systems give no feedback so a referring clinician will not know if referral is delayed or not taken up and cannot follow up. Community staff rely on informal communications, including email which relies on remembering to do it; communications with off-island specialists is often informal and uncertain, e.g. knowing that community care needs to be re-started when someone comes back home. The public assume the professionals are ‘joined-up’ so may not alert one provider of care by another. Although problems with EMIS were raised some found it useful but wished all community staff were on EMIS together and cited data sharing issues.

- **Better outcome measures are needed**

Some professionals commented that the outcome measures they use in their service are not ideal, creating the wrong incentives; the most appropriate outcome would be keeping people in their homes and out of hospital; lack of data was felt to prevent the appropriate allocation of resources.

### Right care

- **Hospice support in the community is very good**

It was appreciated that Hospice take non-cancer cases and Hospice services are very useful e.g. the FAB programme and Hospice at Home; there is a good interaction between Hospice and other community service providers while Hospice support to residential and nursing homes is working well.

- **Identifying the correct provider and referring to Hospice**

Knowing who is at end of life can be challenging and not all GP Practices hold regular Gold Standard Framework meetings. There is no end of life pathway for those with learning difficulties but a Hospice link person might be useful. Very frail and isolated people are likely to miss out on services since they are often housebound. Residential homes identified differences in Hospice support for residents with similar needs and some professionals were uncertain of the best time to refer to Hospice. Prior to their referral to Hospice, some people had not had input to their care from relevant specialist nurses.

- **Staff go "above and beyond".**

It was clear that people working in every sector 'go above and beyond' to ensure that good care is delivered in the appropriate setting and people are passionate about delivering good end of life care. The system only works at present because of this extra commitment by staff but it is not sustainable

### Right time

- **Consider appropriate trigger points for early referral to Hospice**

Being able to refer people to the Hospice Day Unit avoids separate referrals to specific services and eases people into palliative services. Referral, e.g. at diagnosis of metastatic disease could assist future management.

- **Late referral to Hospice could be avoided with better communication**

Some people come to hospital at end of life, with organ failure, having had no previous specialist input and no Hospice referral. Often these people are alone. Poor communication with UK specialists can also hinder referrals to Hospice by specialist nurses.

## Community care

- **More support for carers is required**

This was a constantly recurring theme. Some people have no carers, some carers don't ask for help but many do and the supply of support services is inadequate. Those carers with links to Hospice are thought to be well supported. Carers' needs can be complex including financial, practical, psychological and self-care issues; they need to coordinate many services and appointments. The recommended carer assessments are not always done and the subsidised carer support service is always full. A particular problem is overnight support which, if available, has to be paid for out of the person's own pocket.

- **Third Sector groups complement the statutory services**

The variety of clients and age ranges served means that third sector groups provide a range of services but those with specific needs e.g. for toileting can still be excluded. There has been a notable rise in requests for dementia support; some groups are promoting self-management and intergenerational activities are producing two-way benefits.

- **The third sector might benefit from working more together**

Third sector staff and volunteers can identify changes in health conditions and might be trained to assist palliative care more. Communication between groups is poor but working in partnership would improve the use of resources. There are differences in standards across organisations but larger charities could support smaller ones and smaller ones might come together; all agencies could usefully coordinate their end of life planning since different approaches are used at present.

- **The role of volunteers**

Volunteers are an essential resource without which there would be many unmet needs. Some roles do not attract volunteers, some need paid staff and needs are seasonal. Mental health benefits and friendships result from volunteering, the cared-for person is eased into more formal services and specialist staff time can be saved.

- **Third sector support relies on appropriate care planning**

Third Sector providers need to be adequately informed of hospital discharges or care plans in order to provide help to clients. There is a perception that mental health needs are not always met and, although a dementia pathway was developed, it was never implemented.

- **Third sector care should be better recognised**

It was felt that the contribution of the Third Sector is not always properly recognised e.g. by Government and that legislation governing Third Sector organisations is lacking. Some non-health services, e.g. airport staff, do not appreciate the difficulties of frail people having to travel off island for care. Some groups feel the Third Sector should lead new initiatives and some are becoming involved in integrated care.

- **We should all talk more easily about end of life**

Both health care and Third Sector professionals felt that, while some people find the words ‘hospice’ and ‘palliative care’ frightening, they did not want to lose the concept of these services, especially as Hospice was considered a comfort to many. There were many comments about not knowing when and how to have conversations about end of life and how to deal with those who do not want to talk about it. More training might help and also regular reminders to initiate such conversations. Recognising when it was appropriate was a problem for some e.g. staff in residential care homes who do not access medical records. Most felt that earlier was better to prepare patients and/or carers and some said that patients were thinking about it even before it was discussed.

Advance care plans (ACPs) were felt to be useful by most types of staff and the lack of one made the emergency services’ tasks more difficult. For ambulance staff in particular, a paper-based ACP is needed. “Do not resuscitate” (DNR) requests do not travel between hospital and community which some interviewees found frustrating and regretted that people were being asked repeatedly when they shifted service. On the other hand, patient and family views might change so a flexible system was required. Some felt that, at present, a DNR request was not always properly discussed with the patient and family nor reviewed as required and, even when present in notes, was not always seen. ACP conversations could be difficult but people and their family often felt better afterwards. Perhaps Third Sector staff and volunteers could be trained to discuss ACPs with clients. It was also felt that expectations of end of life should be managed, perhaps starting with young people and children.

### General practitioners (GPs)

Seven GPs responded to the online survey. The majority defined end of life as the time when "*curative treatment has not worked and treatment is for symptom control*". All would refer cancer patients to Hospice for patient or family needs (physical or emotional), uncontrolled symptoms, reaching the palliative or end of life phase or patient choice. For organ failure, four would refer and one mentioned uncontrolled symptoms as a reason. One GP felt this patient group rarely requires referral and another that this group of *patients "may take longer to come round to the idea of Hospice*". All GPs would refer those with neurodegenerative conditions with reasons including uncontrolled symptoms and *"patient struggling to maintain independent living".* Five did not regularly refer those with dementia because they are likely to be looked after elsewhere.

Four respondents (57%) felt that Island services for palliative and end-of-life care meet the needs of patients well saying *"end-of-life care tends to bring out the best in all the services involved*" and "*they provide an excellent service*". Three respondents felt that services met the needs less well with insufficient community support, "*very little Hospice at Home service, but great if you can access it*" and "*not enough Hospice beds for patients who chose Hospice as preferred place of death*".

Suggestions were for increased staff to provide palliative care, better access to Hospice services, more time to provide the 'human' element of care and better support in the community including appropriate packages of care at hospital discharge. Improved communication with other services, "*realistic clinical advice*" from consultants, improved liaison with nursing homes to discuss end of life issues with patients and families would avoid hospital admissions.

## 7. The current services available for palliative and end of life care

### Specialist level services

Hospice Isle of Man is the only specialist provider of palliative and end of life care services in the Isle of Man. Some palliative and end of life care services are offered by statutory services including Noble's Hospital, GPs, long-term conditions coordinators, specialist and district nurses. There are a number of Third Sector and church organisations that offer psychological, physical and/or spiritual support and care at various stages of a life-limiting illness; some of these are disease-specific and some are not, some focus on carers, some on patients or both patients and carers, and some offer social support and/or opportunities to socialise. Private services such as nursing homes and care agencies also provide care.

At present the majority of referrals to Hospice specialist care come from Noble’s hospital and many of these are people who come to Hospice for a few days only and who might have benefitted from earlier referral. Comments from patients and families revealed feelings that end of life was not discussed enough or soon enough in some cases so patients and families found themselves unprepared to make decisions about stopping treatment and/or referral to Hospice. When patients are in the dying phase in hospital, the staff frequently involve Hospice services and endeavour to provide good symptom management in a dignified and peaceful environment however, this may not always be possible due to the demands on their resources.

Others referrals from Noble’s hospital come via the specialist nurses with whom Hospice usually has good relationships. Problems highlighted in this pathway are the non-connectivity of the IT systems and difficulties in establishing the various professionals and services involved in the patient’s care. There were a few suggestions about clearer guidelines for referral and for sharing care.

The next largest group of referrals to Hospice come from GPs. Some differences in referral practices were noted and clearer referral guidelines/procedures were suggested.

Some nursing homes had previously been uncertain about the possibility and procedure for involving Hospice with a resident. However, use of Project ECHO since late 2018 and the consequent strengthening of communication between Hospice and Nursing Homes is resolving that problem. Project ECHO started with Residential Homes at the beginning of 2020 with hopes of achieving similar improvements.

### Community level services

When someone has either expressed a preference to remain at home or is in need of specialist care but not as an inpatient, Hospice provides a community-based service, Hospice at Home. This has been seriously under-resourced relative to need and is now facing increased demand due both to greater numbers who could benefit but also more people requesting the service. SPSG Workstream 4, which deals with the provision of specialist services, has taken this on board and created a new community model of care, using the findings from this needs assessment. The community plan was launched in October 2019 and is described further in Section 8.

Third Sector groups including Crossroads Care, Live at Home, Cruse Bereavement Care and Compassionate Isle of Man provide support for carers and/or patients at end of life. Quality of service is sometimes enhanced for certain conditions due to specific advocacy and there are a number of disease specific groups for e.g. cancer, Alzheimer's disease, motor-neurone disease and Parkinson's disease. Some of the disease-specific groups are driven by proactive community members with a personal interest. Volunteers are an essential resource for this sector, without which there would be many unmet needs; however some roles do not attract many volunteers, others need paid staff but needs tend to be seasonal. Organisations feel that better services could be achieved through increased recognition, financial support and appropriate training opportunities. Members of various Third Sector groups contribute to several of the SPSG workstreams.

## 8. Assessment: where are we now?

### Island Plan for Integrated Palliative and End of Life Care and NICE Guideline 142

In October 2019, NICE released an evidence-based guideline for adult end of life care (2). Nice Guideline 142 on end of life care for adults applies to an important part of the continuum of supportive care addressed in the Island Plan for Integrated Palliative and End of Life Care which was launched by the Strategic Partnership Steering Group (SPSG) in 2018.

As detailed in the Island Plan, the SPSG has 6 workstreams. Workstream 1, the needs assessment, has produced this report to provide evidence for the planning of integrated palliative and end of life care on the Isle of Man (IOM). The other 5 workstreams are using this evidence to produce their plans for action in specific areas of care and evaluation:

Workstream 2 – Strengthening compassion in IOM – is creating a compassionate community in which volunteers will try to provide care in areas which are beyond the reach of other services e.g. providing company in the last days of life.

Workstream 3 – Person-centred and coordinated care – is developing the Western Wellbeing Centre services. This initiative in delivering integrated care to a geographical area on the Island includes end of life care in a larger structure in which all relevant organisations and groups will work together to deliver integrated care.

Workstream 4 – Much more than a building - deals with the specialist services delivered by Hospice. They have produced a Community Model of Care: Delivering Care in the Community (1) with an intention to deliver appropriate specialist services to all who can benefit.

Workstream 5 – Developing our workforce together – has created a plan for training which has taken account of the gaps in palliative and end of life care skills in the different services which were identified by the practitioners who were interviewed for the needs assessment.

Workstream 6 – Monitoring progress – has identified outcome measures by which the implementation of the Island Plan will be assessed at levels ranging from activities carried out up to high level outcomes achieved.

The next section details the NICE recommendations and summarises the local evidence obtained through the needs assessment to identify our current situation with respect to these recommendations. As part of this process, specific recommendations are suggested for IOM to account for local gaps in services or to address specific local needs. The SPSG Workstreams are then mapped to the NICE recommendations to provide a snapshot of current progress in this important area of adult supportive care. Finally areas which require further action and discussion with Hospice partners are identified.

## Nice Guideline 142 on end of life care for adults and IOM evidence

Note: All of the information to back up the specific IOM recommendations can be found in the earlier sections of this report and its appendices.

| NICE recommendation 1.1 | Identifying adults who may be approaching the end of their |
|---|---|

| | life, their carers and other people important to them |
|---|---|
| 1.1.1 | People managing and delivering services should develop systems to identify adults who are likely to be approaching the end of their life (for example, using tools such as the Gold Standards Framework, the Amber Care Bundle or the Supportive and Palliative Care Indicators Tool [SPICT]). This will enable health and social care practitioners to start discussions about advance care planning, provide the care needed, and to support people's preferences for where they would like to be cared for and die. |
| 1.1.2 | Health and social care practitioners should identify carers and other people important to adults who are likely to be approaching the end of their life. |

**Applicability to current situation in IOM:**

Good relationships are currently maintained between Hospice and specialist nurses, staff in Noble’s hospital and general practices. However, the use of the Gold Standards Framework (GSF), and joint meetings based on it, has apparently diminished in the community. More widespread use of the GSF by GP practices and resulting joint discussions with Hospice staff would enable us to better meet this NICE recommendation. Carers and other important people are not always identified and/or recorded. Hospice has implemented systems to identify carers and who or what matters to the referred person; however such systems are patchy in other services.

*IOM recommendation 1: Increase use of GSF in general practice.*

*IOM recommendation 2: Consider how carers and others who are important to people at the end of life can be identified and recorded*

| NICE recommendation 1.2 | Assessing holistic needs |
|---|---|
| 1.2.1 | If it is thought that an adult is approaching the end of their life, carry out an initial holistic needs assessment with the person and document this. This will enable the right support to be provided when it is needed. |
| 1.2.2 | People managing services should ensure that health and social care practitioners caring for adults approaching the end of their life have the training and skills to sensitively carry out holistic needs assessments. |
| 1.2.3 | Healthcare practitioners should be aware of the requirement to offer a carer's needs assessment in line with the Care Act 2014 (18) and a young carer's needs assessment in line with the Children and Families Act 2014 (19). |

**Applicability to current situation in IOM:**

The assessment of holistic needs is not always carried out due to time pressure, uncertainty at which point it should be done and the concern that it will identify needs which cannot currently be addressed. Improving this situation will require multidisciplinary agreement, better information provision to professionals of services available and adequate resources to ensure needs can be met. Carer assessments tend to be conducted informally, if at all, without a clear system in place. Clearer guidelines about who should do carer assessments, a safety net to catch those who do not receive them and support, including resources, for these to take place in the most appropriate settings would help meet this recommendation. As well as this requirement, many other principles included in the Isle of Man Carers' Charter (3) are still not in place and, if implemented, would go some way to meeting these recommendations. There is no equivalent legislation on IOM to the UK Care Act of 2014 (18).

*IOM recommendation 3: Ensure multidisciplinary agreement on implementing holistic assessments and resulting care plans, ensuring that adequate information on services and adequate resources to meet needs are provided.*

*IOM recommendation 4: Fully implement the existing IOM Carers' Charter.*

| NICE recommendation 1.3 | Supporting carers |
|---|---|
| 1.3.1 | People managing and delivering services should think about what practical and emotional support can be provided to carers of adults approaching the end of their life and review this when needed. |
| 1.3.2 | When carers' needs are identified, take into account that the support needs of a young carer are likely to be different to those of an older carer. |

**Applicability to current situation in IOM:**

One of the greatest challenges and largest needs for carers at present is obtaining adequate respite to maintain their own health and be able to continue to provide required care. The practical and emotional support mentioned in NICE recommendation 1.3.1 should include these respite services which are under-provided at present. Carers' support is addressed in the Carers' Charter (3) mentioned under comments to

Recommendation 1.2. These NICE recommendations reinforce the need to fully implement this Charter (IOM recommendation 4).

*IOM recommendation 5: Consider the availability of short and longer-term respite services in order to support carers and avoid long term residential admissions.*

| NICE recommendation 1.4 | Providing information |
|---|---|
| 1.4.1 | For advice on communication, information and shared decision making, see the NICE guidelines on patient experience in adult NHS services and people's experience in adult social care services. Apply the same principles for communication and information giving to carers of all ages. |
| 1.4.2 | For people with learning disabilities, use this guideline alongside the recommendations on end of life care in the NICE guideline on care and support of people growing older with learning disabilities. |
| 1.4.3 | Support and enable adults approaching the end of their life to actively participate in decision making by having in place: processes to establish the amount and type of information they would prefer, systems to provide information in a way that meets their communication needs and preferences, for example, how it is given (verbally, on paper, by text, email, or other assistive technologies) and provision of professional interpreters arrangements to review and anticipate their information needs and preferences as circumstances change. |

**Applicability to current situation in IOM:**

Poor communication with multiple staff members from different services and inadequate involvement in decision-making was a major source of concern for patients and carers in the needs assessment. Timely discussions about end-of-life and options available were not always a feature of end of life care in hospital. Appropriate access to information was a problem for many including those with learning disabilities, their families and friends. In nursing and residential homes, the curriculum for Project ECHO includes, at the homes' request, sessions on having discussions with individuals and their families. A particular problem for IOM residents is the added complexity of receiving information from UK providers and the difficulty of involving family members in off-island discussions.

*IOM recommendation 6:  Continue and expand the upskilling of those delivering end of life care in the community through Project ECHO.*

*IOM recommendation 7: Enhance the provision of person-centred information and involvement of individuals in end-of-life decision-making at hospital and community levels of care, including specific attention to those with learning disabilities.*

*IOM recommendation 8: Improve communication between off-island providers and residents, including family members.*

| NICE recommendation 1.5 | Reviewing current treatment |
|---|---|
| 1.5.1 | For advice on reducing treatment burden and reviewing medicines and other treatments, see the NICE guidelines on multimorbidity and medicines optimisation. |
| 1.5.2 | Develop policies for reviewing treatment within all specialties to meet the changing needs of adults approaching the end of their life and to reduce the burden of unhelpful treatments. Different services should work together and share information about treatment reviews (see section 1.10 on providing end of life care coordination). |
| 1.5.3 | The lead healthcare professional should ensure that the person approaching the end of their life is offered opportunities to discuss their existing treatment plans with a healthcare professional. The person's carers and other people important to them should be included in the discussions, if the person agrees. This should include discussing: any changes that could optimise care and improve their quality of life (for example, reducing the number of unnecessary routine appointments, organising appointments close to the person's home, starting new treatments or stopping unhelpful treatments) community support available to help with their treatment. |

**Applicability to current situation in IOM:**

The lack of timely discussion of treatment options available to patients in hospital was a concern of professionals and families and could result in futile treatment being continued as well as palliative care being delayed. IOM provides long-term conditions coordinators for a proportion of those with complex conditions and it goes some way to providing the environment for NICE recommendation 1.5.3 to be met, for those who have this service. Given existing problems with sharing information across specialities and services, it is difficult to see how this recommendation could be met for the majority of people without assigning a keyworker (i.e. identifying the most appropriate existing care provider as a coordinator) for all those approaching the end of life and enabling that keyworker to access all relevant information. The Western Wellbeing Partnership is examining, in a pilot project, how such a keyworker system and relevant information sharing could be accomplished. A current initiative by pharmacists in which nursing home residents' medications are reviewed will help meet this recommendation if continued.

*IOM recommendation 9: Improve the timely discussion of end of life treatment options and involvement of palliative care with patients in hospital and their families.*

*IOM recommendation 10: Consider appointing a keyworker for those receiving end of life care.*

*IOM recommendation 11: Continue to examine how information can be shared between professionals in order to be able to review treatment as required by NICE recommendation 1.5.3.*

| NICE recommendation 1.6 | Advance care planning |
|---|---|
| 1.6.1 | Service providers should develop policies to ensure that advance care planning is offered to adults who are approaching the end of their life. Policies should take into account under-served and vulnerable groups. |
| 1.6.2 | Service providers should develop processes to support carers and other people important to the person to be involved in advance care planning, if the person approaching the end of their life agrees. |
| 1.6.3 | Service providers should have systems in place to ensure that adults approaching the end of their life each have a copy of their advance care plan available in their place of residence or with them if admitted to a hospital, care home or hospice. |
| 1.6.4 | Service providers should develop processes to take into account the views of carers and other people important to the person if the person approaching the end of their life lacks capacity to make decisions in line with the Mental Capacity Act 2005 (20). |
| 1.6.5 | For advice on supporting decision making, assessing mental capacity and advance care planning, see the NICE guidelines on decision-making and mental capacity. |
| 1.6.6 | For advice on starting advance care planning in adults who:<br>• are at risk of a medical emergency, see the NICE guideline on emergency and acute medical care in over 16s<br>• have motor neurone disease, see the NICE guideline on motor neurone disease<br>• have multimorbidity, see the NICE guideline on multimorbidity<br>• have dementia, see the NICE guideline on dementia<br>• have learning disabilities, see the NICE guideline on care and support of people growing older with |

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|  | learning disabilities. |
| 1.6.7 | For advice on organ donation, see the NICE guideline on organ donation for transplantation. |

**Applicability to current situation in IOM:**

Hospice has recently reviewed their Advance Care Planning (ACP) booklet which is available to all those experiencing end of life care in any setting. However, whether such discussions are initiated depends on the individual care provider; some feel too time-pressured, uncertain when is the correct time or unsure of their own skills. Project ECHO is helping with this in nursing and residential homes at present. One concern is that the current request to avoid resuscitation does not transfer between hospital and community. There is no Mental Capacity Act on the Island at present although guidelines are based on the UK Act (20).

*Recommendation 12: All community services who manage those at end of life should be prepared to discuss preferences with individuals and their chosen family members and encourage the completion of an ACP.*

*Recommendation 13: Create procedures so that ACPs are able to bridge hospital and community services.*

| NICE recommendation 1.7 | Reviewing needs |
|---|---|
| 1.7.1 | Develop systems enabling adults approaching the end of their life to have:<br>• regular discussions with a member of their care team about changes in their health and social care needs and preferences,<br>• repeat assessments of their holistic needs and reviews of their advance care plan when needed, for example at key transition points, such as at discharge from hospital or when the goals of treatment have changed. |

**Applicability to current situation in IOM:**

As discussed under NICE recommendation 1.5, except for those under the care of a long-term conditions coordinator, a keyworker service (IOM recommendation 10) would enable this NICE recommendation to be achieved for those approaching the end of life.

| NICE recommendation 1.8 | Communicating and sharing information between services |
|---|---|
| 1.8.1 | Adults approaching the end of their life should have care that is coordinated between health and social care practitioners within and across different services and organisations, to ensure good communication and a shared understanding of the person's needs and care. |
| 1.8.2 | Use electronic information-sharing systems that are accessible between different services and organisations to enable information to be reviewed, updated and shared efficiently within and between multipractitioner teams, across different services and organisations. |
| 1.8.3 | For specific advice on coordinating end of life support in residential settings, see the NICE guideline on people's experience in adult social care services. |

**Applicability to current situation in IOM:**

It is generally accepted that the current information-sharing across Island services is inadequate. The solutions are both better electronic information-sharing systems and appropriate data-sharing agreements. These affect all aspects of care, not just end of life care. Many people approaching the end of life are still receiving specialist services in the UK and information-sharing with these services often relies on email and telephone contact and is dependent on the individual practitioners to ensure its adequacy. Coordinating care across services and organisations will require designated keyworkers from the multidisciplinary care team (IOM recommendation 10).

*IOM Recommendation 14: Ensure that improvements to electronic information-sharing and data-sharing agreements continue and explore improved information transfer with UK providers.*

| NICE recommendation 1.9 | Providing multipractitioner care |
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| 1.9.1 | Provide access to the expertise of highly skilled health and social care practitioners, when needed, for adults approaching the end of their life, their carers and other people important to them. They should have the skills to:<br>• meet complex care and support needs<br>• anticipate and prevent or minimise crises<br>• support people's preferences for where they would like to be cared for and die, if possible. |
| 1.9.2 | Health and social care practitioners should have the skills to provide care for adults approaching the end of their life who need support in the following areas: |

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| | • disease-specific, including symptom management, hydration and nutrition, and access to medication<br>• physical<br>• psychological<br>• social, including support and advice (for example, signposting advice on benefits, finance and third-sector, local or national support services)<br>• support with activities of daily living, including access to equipment and rehabilitation services,<br>• pastoral, religious and spiritual<br>• cultural. |

**Applicability to current situation in IOM:**

Hospice has prepared an implementation plan to meet its current strategy goals of extending specialist Hospice or Hospice-influenced care to all Island residents (1) by 2025. Full implementation of this plan will ensure that the IOM meets this NICE recommendation. There is a lack of knowledge among some practitioners of the specialist services available to those who might benefit from palliative and/or end of life care; this impedes their timely referral to Hospice. Better information about services available and referral pathways would help the coordination of care across services and meet NICE recommendation 1.9.1. Project ECHO is working to ensure that those providing care in nursing and residential homes will have the opportunity to improve their skills in delivering appropriate end of life care.

*IOM Recommendation 15: Ensure that the output of SPSG Workstream 4 (Community Model of Care, October 2019) is fully implemented to ensure that Hospice or Hospice-influenced care is experienced by all Island residents.*

*IOM recommendation 16: Enhance information to GPs and other practitioners about specialist Hospice services, who is eligible for them and how to refer.*

| NICE recommendation 1.10 | Providing end of life care coordination |
|---|---|
| 1.10.1 | Provide end of life care coordination for adults who are approaching the end of their life through:<br>• community and primary care services for adults, provided by the person's GP or another health or social care practitioner in the primary or community care team<br>• hospital services for adults whose treatment is based in secondary or tertiary care, provided by health and social care practitioners based in hospices or disease- |

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| | specific specialists in hospitals. |
| 1.10.2 | For people in under-served and vulnerable groups who are approaching the end of their life, provide additional support that takes into account the challenges of coordinating care for people in these groups. |
| 1.10.3 | Ensure that there is good communication between health and social care practitioners coordinating community-based care and health and social care practitioners coordinating hospital care. |
| 1.10.4 | Health and social care practitioners providing end of life care coordination should:<br>• offer information to the person approaching the end of their life, their carers and others important to them, about who the multipractitioner team members are (including the lead healthcare professionals in each setting responsible for their care), the roles of the team members and how services are accessed<br>• ensure that holistic needs assessments are offered, and the person's wishes and needs are discussed and acted on whenever possible<br>• ensure that care is coordinated across and between the multipractitioner teams and between care settings<br>• ensure that regular discussions and reviews of care, holistic needs and advance care plans are offered<br>• share information about the person's care between members of the multipractitioner teams. |

**Applicability to current situation in IOM:**

As detailed above, the implementation of the output of Workstream 4 and the creation of keyworker roles will enhance the existing cross-service working and help to meet several of these NICE recommendations (1.10.1, 1.10.3 and 1.10.4). Under-served and vulnerable groups identified in the needs assessment include those with learning disabilities, mental health conditions and dementia. If coordination of care falls on carers who are already struggling due to lack of respite services (IOM recommendation 5) and inadequate information (IOM recommendation 7), there is a high risk of the carer being unable to cope.

*IOM recommendation 17: Ensure that previous IOM recommendations are applied also to the carers of those with learning disabilities, mental health problems and dementia.*

| NICE recommendation 1.11 | Transferring people between care settings |
|---|---|
| 1.11.1 | For advice on transitions between care settings for adults with |

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| | social care needs, see the NICE guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs. |
| 1.11.2 | Develop systems to support smooth and rapid transfer between care settings for adults approaching the end of their life. For example, organise services so that: ambulances or other transport services can move people between care settings without delay and in an efficient and compassionate way care packages and equipment are available to enable adults approaching the end of their life to move to the place where they would like to be cared for and die. |
| 1.11.3 | Develop an agreed transfer policy between ambulance service providers and acute care providers to enable the rapid transfer of adults approaching the end of their life to the place where they would like to be cared for and die whenever rapid transfer is a priority. |

**Applicability to current situation in IOM:**

One problem repeatedly identified by care providers is the need for an urgent response function that can determine the most appropriate action and determine the need for transfer to another site of care. At present, the emergency ambulance service may respond but be unable to avoid taking someone to the Emergency Department (ED) where an end of life care plan is created and a long wait ensues before the person can be transported back home. Such an urgent response plan has been proposed and would be an essential requirement to meet this NICE recommendation.

**IOM recommendation 18: Ensure an urgent response service is implemented.**

| NICE recommendation 1.12 | Providing out-of-hours care |
|---|---|
| 1.12.1 | Adults approaching the end of their life, their carers and other people important to them should have access to: a healthcare professional available 24 hours a day, 7 days a week, who can access the person's records and advance care plan, and make informed decisions about changes to care an out-of-hours end of life care advice line an out-of-hours pharmacy service that has access to medicines for symptom management in adults approaching the end of their life. |

**Applicability to current situation in IOM:**

Hospice currently provides almost a full 24-hour, 7 days a week service through its Hospice at Home team but this stretches current resources. The aim is to expand this service, resources permitting, to cater for the expected increase in numbers as Hospice increases access for those requiring specialist services. For those who do not require this level of specialist Hospice care, there is currently no regular service provided after 5pm at night, on weekends or over holidays and they have to default to the Manx Emergency Doctors Service (MEDS), ambulance or the hospital ED. End of life is a difficult time for people and their carers and unexpected events are common and often outside of normal working hours. To meet this NICE recommendation, a 24-hour, 7 day a week service outside of Hospice is essential for all those experiencing end of life but not in need of specialist Hospice care.

*Recommendation 19: Implement a 24-hour, 7 day a week service for those at end of life in the community.*

## Relationship between NICE Guideline 142 and the Island Plan

The Island Plan, and the associated workstreams and actions, will support delivery of the 12 NICE recommendations set out in NICE Guideline 142. The recommendations are:

1. Identifying adults who may be approaching the end of their life, their carers and other people important to them
2. Assessing holistic needs
3. Supporting carers
4. Providing information
5. Reviewing current treatment
6. Advance care planning
7. Reviewing needs
8. Communicating and sharing information between services
9. Providing multipractitioner care
10. Providing end of life care coordination
11. Transferring people between care settings
12. Providing out-of-hours care

The table below shows, for each workstream, the NICE guideline(s) to which its actions relate and the intended outcomes.

| **Workstream no. and theme** | **Workstream Actions** | **Guideline 142 Recommendation** | **Island Plan Outcomes** |
|---|---|---|---|
| 2. Compassionate Isle of Man | Compassionate citizens are involved in and supported to care for people nearing the end of life. | 3 | *Compassionate citizens come together to offer each other support at the end of life.* |
| 3. Person centred and coordinated care | Ensure multidisciplinary agreement on holistic assessment, care plans and provision of information to support individuals and families to be involved in decision making | 2, 4, 5, 7, 8 and 9 | *My physical, emotional, spiritual and practical needs are met* |
| | Consider appointing a keyworker for those receiving end of life care. | 9, 10 and 11 | *I am at the centre* |
| 4. Much More than a Building | Enhance information to GPs and other practitioners about specialist Hospice services, who is eligible for them and | 4 and 11 | *Health and care professionals and carers are more knowledgeable about* |

|  |  |  |  |
|---|---|---|---|
|  | how to refer. |  | *palliative and end of life care* |
|  | Increase use of the Gold Standard Framework in general practice, hospital and care homes. | 1, 5 and 7 | *We work for my goals and the quality of my life and death* |
|  | Ensure the Community Model is available 24-hours, 7 day a week so Hospice or Hospice-influenced care is experienced by all Island residents who need it | 3, 5, 7, 10 and 12 | *I have responsive, timely support day and night* |
| 5. Developing our Workforce Together | Continue to expand the upskilling of those delivering palliative and end of life care in care homes, hospital and community settings | 1, 2, 3, 5, 9 and 10 | *Health and care professionals and carers are more knowledgeable and confident about palliative care and work together for the individual's goals and the quality of their life and death.* |
|  | Ensure carers and others who are important to people at the end of life are identified and recorded. | 1 and 3 | *The people who are important to me are at the centre of my support* |
|  | Ensure all professionals who manage people at the end of life are prepared to discuss treatment and care preferences with individuals and their chosen family members and encourage completion of an ACP. | 5, 6 and 7 | *I have honest discussions and the chance to plan* |
|  | Improve timely discussion of palliative care support and review of treatment options with patients in hospital and their families | 1, 3, 4, 5 and 6 | *Care is provided in the place of my choice* |
| 6. Monitoring Progress and Measuring Impact | Monitor information on the demand, capacity and quality of palliative and end of life care services |  |  |
|  | The services delivered are based on predicted population needs, informed by evidence and lived experience and prioritise what is important to local people, professionals and organisations |  |  |

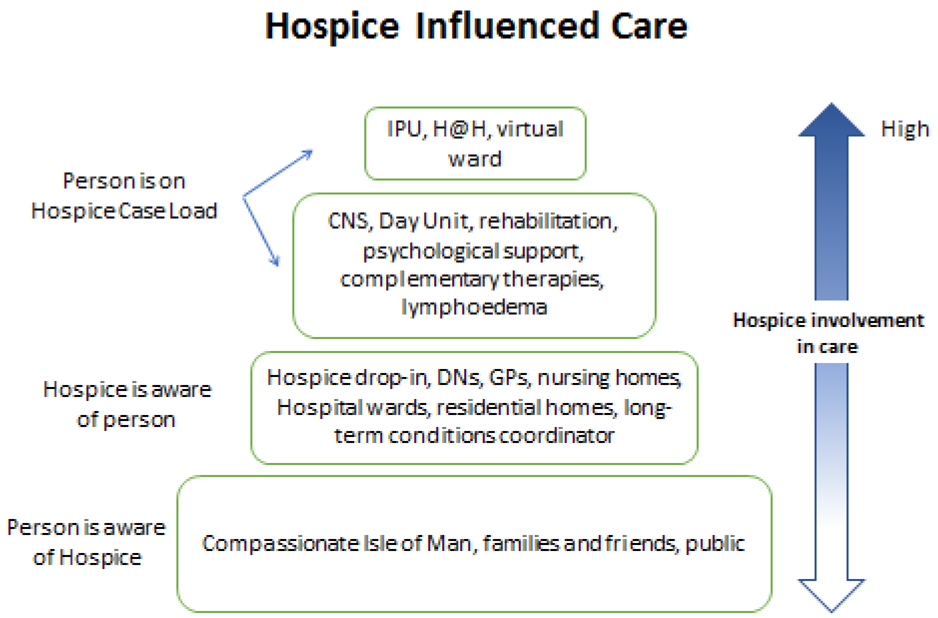
All of the NICE guidelines are, at least partly, addressed by one or more Workstreams. In order to address all of the sub-categories of some guidelines, wider action may be required. These are described in the table below:

| **Action required** |  | **Guideline 142 Recommendation** |
|---|---|---|
| Discuss further with Hospice partners | Fully implement the **Isle of Man Carers' Charter** to support carers for all who have palliative or end of life care needs, regardless of their condition, and consider the availability of respite services to support carers and avoid premature admissions to long-term care | 3 |

| | | |
|---|---|---|
| | Ensure **data-sharing agreements and improvements to electronic information-sharing** continue so that care plans and treatment plans can be shared and reviewed and ACPs bridge hospital and community services. | 6, 8 and 10 |
| | Improve communication and information transfer between **off-island providers** and islands services, residents and family members | 10 and 11 |

### How the recommendations might affect services

At present, Hospice IOM is the only specialist provider of palliative and end of life care on the Island. Hospice receives referrals of cases, some of which might be better managed within the community if relevant community services, e.g. 24-hour advice, urgent response team and more accessible care or respite, were available. The current arrangement could be an inefficient use of scarce, specialist resources. With the recommended improvements in community support and the implementation of the Hospice Community Model of Care (1), Hospice will be better able to deliver specialist services to all, rather than a proportion, of those who require them and could expand its support to those working in the community through what can be called 'Hospice-influenced care' (see Figure below).



**Key to Figure:** IPU = Hospice inpatient unit; H@H = Hospice at Home; CNS = clinical nurse specialist; DN = district nurse; GP = general practitioner

## Future work

All of the evidence in this report was derived from the local needs assessment carried out by Hospice IOM from 2018 to 2019. At the start of this needs assessment the data available, from systems outside Hospice, were very limited. As further data become available it would be important to look in more detail at e.g. case mix at the different levels of the system to monitor the access to specialist care and ensure equity for the whole population. Better data would also enable regular, appropriate audits and the assessment of services against the NICE Quality Standards QS13 (4), QS14 (5) and QS15 (6) for End of life care, Care of dying adults in the last days of life and Patient experience in adult NHS services, respectively. This needs assessment a starting point for the development of appropriate plans and activities which are now being taken forward by the relevant SPSG workstreams.

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## References

1. Hospice Isle of Man. Community Model of Care: Delivering Care in the Community. 2019.
2. National Institute for Health and Care Excellence. End of life care for adults: service delivery (NG142) 2019. Available from: www.nice.org.uk/guidance/ng142. [2020 Feb 18]
3. The Isle of Man Carers' Charter: Isle of Man Government; 2013. Available from: https://www.gov.im/media/750345/carers_charter.pdf. [2019 Sept 9]
4. National Institute for Health and Care Excellence. Quality standard: End of life care for adults (QS13) 2017. Available from: https://www.nice.org.uk/guidance/qs13/resources/end-of-life-care-for-adults-pdf-2098483631557. [2019 Sept 6]
5. National Institute for Health and Care Excellence. Quality standard: Care of dying adults in the last days of life (QS144) 2017. Available from: https://www.nice.org.uk/guidance/qs144/resources/care-of-dying-adults-in-the-last-days-of-life-pdf-75545479508677. [2019 Sept 6]
6. National Institute for Health and Care Excellence. Quality standard: Patient experience in adult NHS services (QS15) 2019. Available from: https://www.nice.org.uk/guidance/qs15/resources/patient-experience-in-adult-nhs-services-pdf-2098486990789. [2019 Sept 6]
7. Isle of Man Government Cabinet Office Economic Affairs. Meeting our Population Challenges: Isle of Man Government; 2018. Available from: https://www.gov.im/media/1360674/addressing-our-population-challenges.pdf. [2018 Aug 20]
8. Hospice Isle of Man. Clinical Governance and Quality Report. 2019.

9. Hospice Isle of Man. Much More Than A Building: 2018-2023 Strategy: Hospice Isle of Man; 2018. Available from: https://www.hospice.org.im/assets/d525f5dcd6/2018-2023-Strategy-compressed.pdf. [2018 Oct 11]
10. Hospice Isle of Man. From Vision to Reality: Island Plan for Integrated Palliative and End of Life Care 2018-2023: Hospice Isle of Man; 2018. Available from: https://www.hospice.org.im/assets/News/Content/863d8ea97c/Island-Plan-for-Integrated-Palliative-and-End-of-Life-Care.pdf. [2018 Sept 14]
11. Isle of Man Government Department of Health. End of Life Care Framework and Implementation Plan for Adults 2012-2015: Isle of Man Government; 2012. Available from: https://www.gov.im/media/907693/endoflifecareframeworkandimple.pdf. [2017 June 19]
12. World Health Assembly 67. Strengthening of palliative care as a component of comprehensive care throughout the life course: Report by the Secretariat: World Health Organization; 2014. Available from: https://apps.who.int/iris/handle/10665/158962. [2019 Sept 9]
13. Hospice UK. Transforming hospice care: A five-year strategy for the hospice movement (2017 to 2022): Hospice UK; 2017. Available from: https://www.hospiceuk.org/docs/default-source/about-us-documents-and-files/hospice-uk-strategy-2017-2022.pdf?sfvrsn=6. [2019 Sept 9]
14. Isle of Man Government Economic Affairs. 2016 Isle of Man Census Report: Isle of Man Government; 2017. Available from: https://www.gov.im/media/1355784/2016-isle-of-man-census-report.pdf. [2019 Sept 9]
15. Isle of Man Government Department of Health and Social Care. Mortality Report 2017: Isle of Man Government; 2019. Available from: https://www.gov.im/media/1364519/ph09-0219-mortality-data-report-2017.pdf. [2019 Aug 27]
16. Etkind SN, Bone AE, Gomes B, Lovell N, Evans CJ, Higginson IJ, et al. How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Med. 2017;15(1):102.
17. Gomez-Batiste X, Martinez-Munoz M, Blay C, Amblas J, Vila L, Costa X, et al. Prevalence and characteristics of patients with advanced chronic conditions in need of palliative care in the general population: a cross-sectional study. Palliat Med. 2014;28(4):302-11.
18. Care Act 2014, (c.23) (2014). London: The Stationary Office [2020 Feb 18].
19. Children and Families Act 2014, (c.6) (2014). London: The Stationary Office [2020 Feb 18].
20. Mental Capacity Act 2005, (c.9) (2005). London: The Stationary Office [2020 Feb 18].