Palliative and End Of Life Care Strategy

2019 - 2022

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Executive Summary

Death and dying, whilst a natural part of life, can be one of the most difficult times for everyone involved. Having a good death is just as important as having good quality of life. *'Whilst dying is inevitable, and universal, that is the only certain thing about it. So much else is unpredictable. It is therefore vital to offer people choice and control over the things that are important to them at this point of maximum vulnerability in their lives'.*[1]

A group of local people passionate about individuals having a good death has developed this revised strategy for Shetland. It takes account of the changing health and wellbeing needs of the Shetland population, in response to an increase of awareness and demand for good palliative and end of life care (PEOLC), particularly in relation to the move towards a more personalised approach. The aim was to create a strategy that focuses on what is important to people who are dying, their relatives and the carers/family who support them, a strategy that promotes respect, choice, dignity and safety for all regardless of age and of diagnosis.

The team of people that brought this strategy together came from a variety of professional and personal backgrounds and included health and social staff, carers and family members, individuals from the community and local organisations. Their purpose was to create a strategy that:

- Gives confidence in staff and service users that we will meet local outcomes and need.
- Raise awareness of and give confidence in, the valuable support that Health & Social Care staff, families, carers and communities do and builds on these strengths.
- Improves joint working relationships, where all key staff, carers, family and community members feel their contributions to the strategy are valued.
- Gives people with experience of palliative and end of life care a voice and opportunity to influence how we all work together to support people who are dying.

A local definition of palliative and end of life care was considered for this revised strategy. Whilst most definitions describe a formal approach to PEOLC by Health & Social Care services, what appeared to be missing is a community-based perspective. In addition, 'clinical' language does not acknowledge individuals roles in supporting loved ones/community members during this time. A recognition of the amount of support family members, carers and communities do in supporting people to die well had to be recognised within a local definition. The local ethos to work closely in collaboration with all involved to ensure individuals have a good death needed to be reflected.

Palliative care focuses on the person, not the disease, and applies a holistic approach to meeting the physical, practical, functional, social, emotional and spiritual needs of individuals and carers facing progressive illness and bereavement.
A local definition of Palliative and End Of Life Care:

"Palliative and end of life care is a supportive approach, (based on values of compassion, respect, and understanding), to improving the quality of life of individuals and their families/Carers, facing the problems associated with life-threatening illness , dying and death."

The ethos that underpins this definition:

Through good conversations, early identification and assessment/support planning, the prevention and relief of suffering and treatment of pain and other symptoms, (physical, psychosocial and spiritual support), we can work together in collaboration with the individual and those people that matter to them honour individuals' choice, control and dignity."

Introduction

Dying, death and bereavement are important parts of everyone's lives; they happen to us all and many of us will be affected by the death of people close to us.

There is predicted rise in the number of people living with long-term conditions and how we all need to respond to these changes is crucially important.

In terms of service provision, there will be an increased requirement to provide appropriate palliative and complex care, where people live longer and hopefully, healthier lives. Nevertheless, there will be new challenges, such as the increasing requirement to support people with dementia and other degenerative conditions, and children/young people living with complex disabilities. How palliative care services will adapt to meet changing population needs is fundamental.

The content of the strategy is based on contributions from patients/service users, health and social care professionals working in a number of settings, cancer and palliative care specialists, specialist nurses, children's occupational therapy and physiotherapy, community care services, public health, voluntary services and members of the public.

The importance of supporting choice and control for people with palliative and end of life care needs continues to be vitally important to individuals', families and carers.

There are a number of national frameworks that give guidance locally to Health & Social Care Partnerships on how they deliver this care:

Living and Dying Well, Strategic Framework for Action on Palliative and End of Life Care, Palliative and End Of Life Care – Enriching & improving experience and of course the new National Health & Social Care Standards. In summary, these frameworks promote a PEOLC strategy for Shetland that:

- Identifies individuals who may need support early.
- Offers person-centred holistic anticipatory care planning, supporting choice and control to the individual, their family and carers, engaging in timely, open and honest conversations that focus on quality of life outcomes.
- Promotes coordination of support across multi-disciplinary teams that provide appropriate care to meet physical, practical, functional, social, emotional and spiritual needs in the place of choice of the individual.
- Promotes confidence and opportunities to gain the appropriate skills to offer good PEOLC to all.
- Has a focus on involving and using wider resources in the community and promotes improved understanding of the importance of good palliative care.

Background

In Scotland, it is estimated that around 40,000 of the 54,700 people who die each year need some palliative care. That is 73%, equating to 129 people in Shetland per year (average number of deaths in Shetland is 212).

With the number of people dying in Scotland due to increase by 13% over the next 25 years we need to act now in order to ensure that access to palliative and end of life care is available to all who can benefit from it, regardless of age, gender, diagnosis, social group or location, by 2021.

Changing demographics, in terms of an ageing population, increase in complex conditions and a shift in the landscape of care provision, require us to look at how we support people to have more choice and control of the care and support they receive through an agenda of personalisation.

The following demographic information can help us determine where prevention and early involvement is best targeted. However, as previously mentioned, age and diagnosis are not used to determine how we respond to individuals; this must be done in a person-centred way.

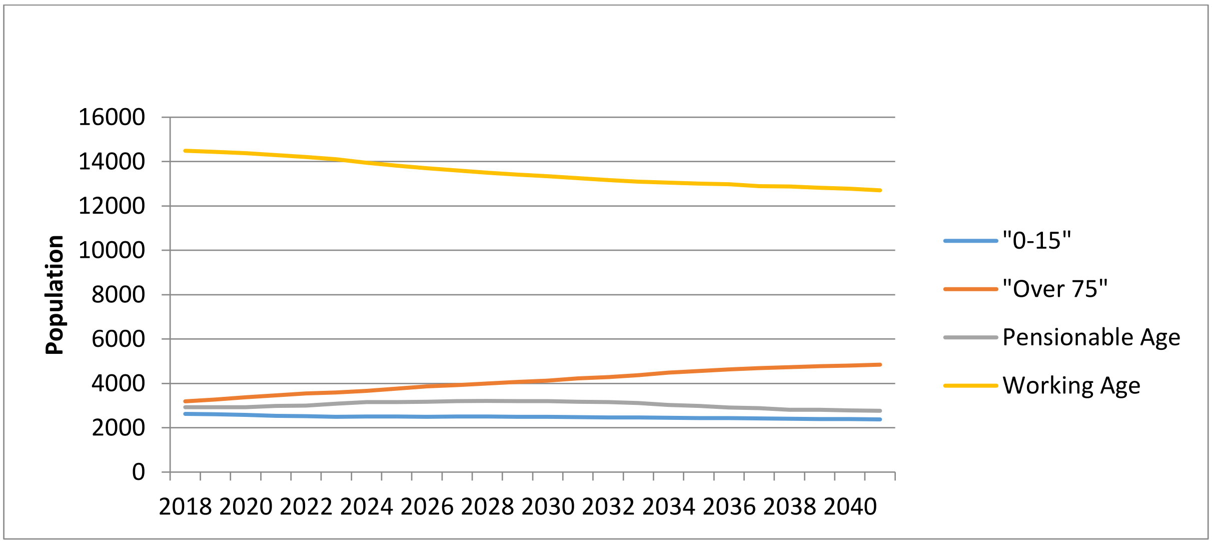
Percentage of the last 6 months of life, which are, spent at home or in a community setting:

Scotland		Shetland	
2016/17	87.% Average	2016/17	93.9% Highest rate in Scotland

Those living in more remote rural areas spend more time at home or in a community setting in the last six months of life compared to those living in urban areas.

The proportion of time spent at home or in a community setting towards the end of life provides a high-level indication of progress in implementation of the national action plan. It reflects both quality and value through more effective, person-centred and efficient end of life care.

Population predictions for Shetland 2018 – 2041:

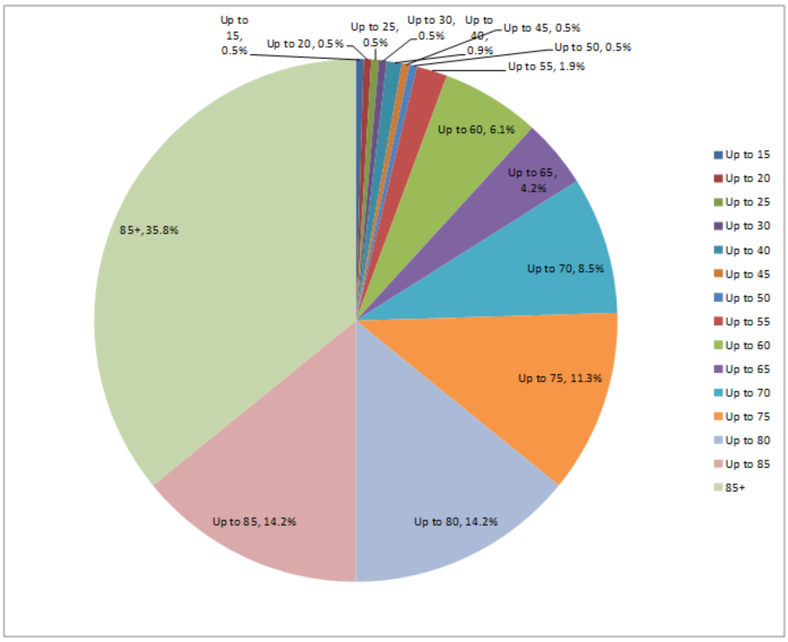


In 2017 there were 212 deaths in Shetland, detailed below are the demographics of deaths by age and condition.

Deaths in Shetland by age – a comparison between 2011 and 2017

2011 Percentage		2017 Percentage	
Under 60	11 %	Under 60	11.8%
60 – 65	7 %	60 – 65	4.2%
65 – 70	7 %	65 – 70	8.5%
70 – 75	10 %	70 – 75	11.3%
75 – 80	10 %	75 – 80	14.2%
80 – 85	15 %	80 – 85	14.2%
	39 %	85+	36.8%

2017 Data



Causes of Death in Shetland (2017)

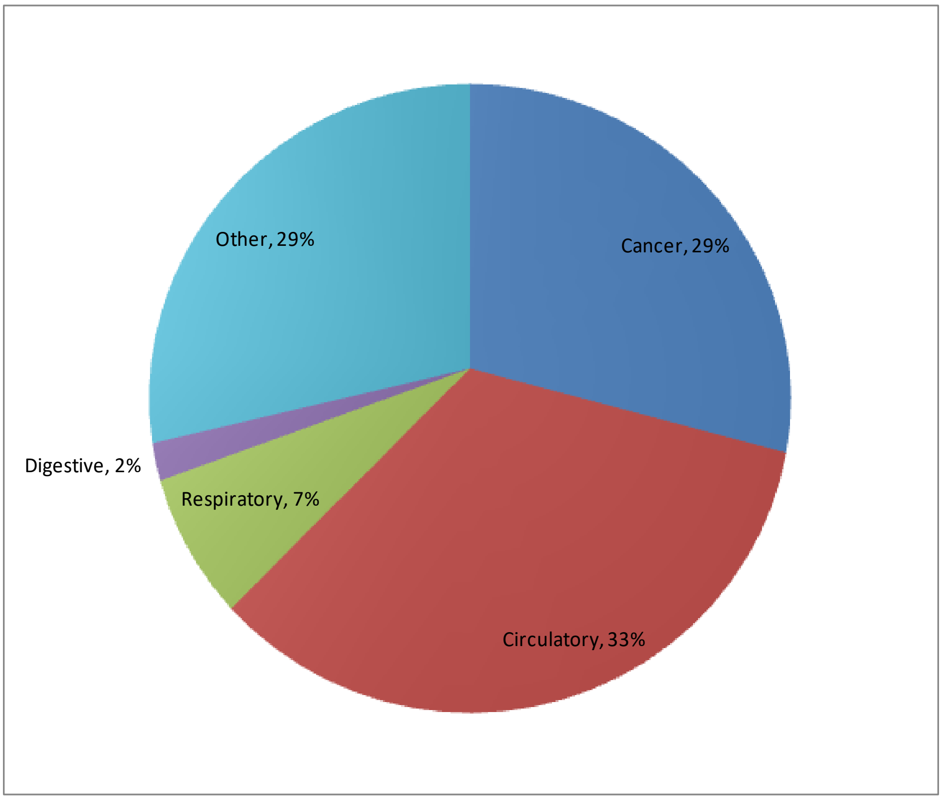
The main causes of death in Shetland are cancer, coronary heart disease, stroke and respiratory conditions, which is comparable with the figures for Scotland overall.

Pathways for palliative and end of life care related to cancer care are well understood. However, there is more work to do to ensure that there is effective communication, co-ordination of care between partner organisations, activation of anticipatory care plans and access to place of death for all dying people regardless of cause.

2017 Deaths in Shetland by cause:

2011 Percentage		2017 Percentage	
Circulatory	30%	Circulatory	33%
Cancer	30%	Cancer	29%
Other	30%	Other	29%
Respiratory	9%	Respiratory	7%
Digestive	1%	Digestive	2%

2017 Data



2017 Deaths by cause and age:

Age Group	Deaths from Circulatory	Deaths from Cancer	Deaths from Respiratory
85+	34.3%	27.4%	26.7%
80 – 85	8.6%	17.7%	20%
75 – 80	11.4%	19.4%	13.3%
70 – 75	14.3%	9.7%	6.7%
65 – 70	8.6 %	9.7%	
60 – 65	7.1 %	4.8%	
55 – 60	4.3 %	8.1%	
Under 60	11.1%	3.2%	

What do we want to achieve – outcomes and indicators

Personal outcomes for those people we care for, their loved ones and carers are to be the focus in PEOLC here in Shetland. Person-centred care supports people to develop the knowledge, skills and confidence they need to more effectively manage and make informed decisions about their own health and health/social care.

Whilst Person-centred care is not new, recently there has been greater emphasis on its importance in both Health and Social Care services and services and staff developing this approach further and in a more meaningful way.

'Over the past few years in particular, there has been a lot of focus on self-directed support as a central component of personalisation. Indeed, it was almost impossible to discuss the progress of personalisation without commenting on the numbers of personal budgets people had and how many of those were delivered as direct payments. But personalisation has always been a much broader concept.' 12

In order to ensure true personalisation happens, health and social care services too have to approach delivery, commissioning and procurement of services, in a way that provides personalised and flexible support; ready to adapt to the desires of the individuals who use them.

The overarching outcomes for this strategy are guided by the Strategic Framework for Action on Palliative and End of Life Care:

- People receive health and social care that supports their wellbeing, irrespective of their diagnosis, age socio-economic background, care setting or proximity to death.
- People have opportunities to discuss and plan for future possible decline in health, preferably before a crisis occurs, and are supported to retain independence for as long as possible.
- People know how to help and support each other at times of increased health need and in bereavement, recognising the importance of families and communities working alongside formal services.
- People access cultures, resources, systems and processes within health and social care services that empower staff to exercise their skills and provide high quality person-centred care.

The following Health Improvement Scotland PEOLC indicators are measured nationally and here in Shetland:

- **Increase in the number of people with palliative and end of life care needs who are identified**

Locally the Key Information Summary (KIS) is used to collect information about a patient, which is extracted from the patient's general practice record. A KIS has to be specifically created for each patient. This is a task normally carried out by a doctor, and with the consent of the patient or their carers. There are currently 700 patients with an eKIS in Shetland. However, having an eKIS does not necessarily mean someone is palliative or end of life (it can also be used for other conditions where appropriate) but anyone who is palliative should be offered an eKIS.

Planning ahead is one of the most important elements of good PEOLC. Understanding what individual's wishes and care plan is well in advance gives all involved the opportunity to plan and prepare themselves and ultimately makes the end of life more meaningful and pain free.

- **Increase in the number of people with palliative and end of life care needs who are assessed and have a care plan**

Using KIS formed part of the GP Contract requirements from 2012-2013 and GPs were encouraged to use KIS to create ‘Anticipatory Care Plans’ (ACPs) for vulnerable patients at risk of admission to hospital. The hope is that better information and planning for these patients can help keep them at home or in the community, reducing unnecessary hospital care.

- **Increase in the number of electronic palliative care summaries accessed**

The KIS information is shared by the GP’s computer system twice a day, making this information available to other people and services looking after the patient. For example, out of hours services, Scottish Ambulance Service or NHS24 may use the KIS to gain more information about people they are in contact with.

The Electronic Palliative Care Summary (ePCS) is a system which allows the automatic update and sharing of health records across community nursing, specialist nursing and GP teams. The sharing of information can be further extended to hospital based teams.

The ePCS system is in place in all ten practices and palliative care registers are in place in all of the practices. However, whilst communication was considered on the whole to be good, it still presented as one of the main areas for improvement, particularly the role of technology and eHealth systems in supporting communication between teams and partner agencies.

- **Place of death**

More people prefer to die at home, with Shetland achieving the highest rate of the last 6 months at home in Scotland at a rate of 94%. The proportion of time spent at home or in a community, homely setting towards the end of life provides a high-level indication of progress in implementation of the national action plan through meeting people’s wishes. It reflects both quality and value through more effective, person-centred and efficient end of life care.

Our Strengths:

- 94% of people in Shetland die in their own home or in a homely setting. (The highest rate in Scotland).
- Electronic Palliative Care Summaries are now in use.
- Palliative Care registers are in place.

Approaches to palliative and end of life care

Values, Principles and Human Rights

Shetland is a compassionate community, where support to people dying is based on a common set of values, a desire to give people choice; with formal services delivered by very experienced and dedicated staff; people who go 'above and beyond' to make things comfortable, dignified and person-centred.

Values are a set of beliefs or views that people hold about what is right or wrong and reflect a sense of what is good or bad. They have a strong influence on people's attitudes and behaviours and act as a set of rules or guidelines about how to behave in certain situations. Holding or developing values can be one of the greatest influences on peoples' experience of the care they receive.

The way we care for individuals who are dying is a measure of the values of the community in which we live. Attitudes such as kindness, caring, shared understanding, honesty, reliability, trust – the interpersonal parts of delivering care, are critical to people's perception of their own worth, something that is significantly important at the end of life. These values reduce fear and anxiety and revive hope and optimism. Hope and optimism have a valuable place in end of life care.

'Time spent with a person, a hand held, a small kindness, a caring act, honesty – any of these seemingly inconsequential actions have a critical impact well beyond their stand-alone worth. These critical but unmeasurable behaviours cannot be bought or commanded, they arrive with a set of values and thrive or wither as a function of organizational culture'.[2]

The importance of these attitudes and attributes are sometimes at risk of being neglected due to the preoccupation with systems, procedures and scientific medicine. Investment and access to care are important and only make a difference if an individual feels they are treated well. Value-Based care equates to efficient, high-quality, low-cost care to patients across the continuum. This means enhancing care coordination and improving communication between providers, as well as between providers and individuals. It also means finding ways of putting individuals at the centre of their care – viewing them holistically and treating more than an isolated acute episode.

Values play an enormous part in upholding the dignity of individuals. In a local staff survey the following values were seen as being vital to underpinning PEOLC:

- Compassion and Empathy
- Respect
- Comfort and Warmth
- Person-centred approach
- Kindness
- Understanding
- Sensitivity

Our Strengths:

- A staff group who are experienced, dedicated and compassionate about PEOLC.
- A Social Care model of assessment, support planning (WYFY) based on personal outcomes.

Protecting and promoting dignity – Choice and Control

Promoting and protecting dignity comes from supporting people who are nearing the end of life to maintain the best quality of life possible, to remain in control and to minimize suffering. This strategy aims to encourage dignity in PEOLC through:

- Supporting people to have as much control over decisions, care and treatment as possible
- Supporting people to die where they want and in a way that they choose
- Providing support to minimise pain and suffering
- Ensuring staff are open to talking to people who wish to discuss issues around their death and that they have the training and skills to respond appropriately
- Helping people to plan and to say goodbye to loved ones
- Allowing people time for reflection and provide professional support where needed
- Encouraging, as far as possible, meaningful activity and discussion to support a sense of self-worth and purpose
- Ensuring you are fully aware of people's cultural and religious preferences when providing end of life care
- Providing support for family and carers
- Providing support for those receiving care who may experience bereavement from the death of friends and peers [5]

Studies have shown that around 70% of people with terminal illnesses towards the end of life experience significant pain as well as other distressing symptoms such as anorexia, constipation, anxiety, lethargy, breathlessness, sleeplessness.

Symptoms may be caused by a variety of mechanisms such as progression of disease; side effects of treatments; debility or unrelated causes and each symptom responds to different approaches. People may have several different symptoms at the same time, which may need different approaches and treatments concurrently. Each requires careful history taking, physical examination, and appropriate investigations, if these investigations will alter the treatment plan and the outcome for the adult or child.

In Shetland we operate a generalist model for providing palliative and end of life care, and therefore we need to have easy access to specialists in Palliative Care for advice and help, as well as to other specialists who can undertake "palliative interventions" as necessary.

Priorities set in the 2009 strategy included the need to develop systems in the community to allow staff to be able to appropriately support symptom control, particularly pain management. The recent staff survey suggests that there have been improvements in staff confidence in managing symptoms with more work around the following required:

- Pain management plans
- managing anorexia
- bowel obstruction
- delirium/agitation and
- using syringe pumps

Other priorities included looking at ways of bringing together existing and potentially new services to provide appropriate psychological support for people who have palliative or end of life care needs.

We have been particularly successful in regard to the development of systems to ensure that the correct medications and equipment are available to respond to changing symptoms and provide good symptom control.

Work locally has continued to build services with all partners, to provide psychological support, including promotion of positive psychology and wellness through health improvement programmes and reducing isolation through work with community resilience initiatives. Kindness Cafes have started up in Shetland and a programme of training looking at isolation has been well attended.

Our Strengths:

- Holistic care delivered in local communities through collaboration between community nursing, pharmacy and care staff.
- Highly valued specialist McMillan nursing for individuals with cancer.
- NHS Spiritual Care- Dedicated Chaplain in post.
- Self-directed support – Offering individuals choice and control in how they receive social care.
- Just in case boxes.
- Shetland Bereavement Service – promoting awareness and good practice in bereavement care, psychological support, providing information, training and education.

Valuing and supporting staff.

Practitioners locally were asked what being involved in PEOLC meant for them and nearly all staff responded positively:

> *"Feeling like I have made a difference, and made this difficult time a bit less frightening."*
>
> *"Families remember the support and this has a direct impact on their grieving process."*
>
> *"It is one of the greatest markers of society if we provide good end of life care for the elderly frail and vulnerable."*
>
> *"Being part of a team that can help allow a person to die in comfort, in a place of their choice, surrounded by the people they want."*

Continuing to address education and training is a high priority for professionals from health, social care and voluntary organisations in Shetland. Having the skills and confidence to deliver consistently high quality care across all care settings is paramount. In a recent staff survey:

- 81% said they were either very or somewhat confident in PEOLC
- 39% said they'd had adequate or enough amount of training, with 36% receiving face to face taught and 32% on the job training
- 33% said individuals always have pain management plans in place, and 37% said these were in place most of the time
- Over 50% of staff said they were confident in managing mouth care, nausea & vomiting, sweating, weakness & fatigue, and other medication related to end of life care.
- Staff said they were least confident in managing anorexia, bowel obstruction, delirium and syringe pumps.

Training in regard to supporting social care workers in the community setting and maintaining an ongoing programme of training that is relevant to healthcare generalists at all levels of clinical seniority has begun locally.

Training framework:

NHS Education for Scotland (NES) has development a Knowledge and Skills framework for Palliative and End of Life Care for the health and social services workforce. Using this to map the skills and knowledge strengths and gaps across the Shetland workforce is vital in understanding what we need to do to ensure staff are confident in delivering PEOLC. The Strategic framework identifies 10 commitments with one commitment specifically focused on education, learning and training:

"We will support the workforce by commissioning NHS Education for Scotland and the Scottish Social Services Council to develop a new palliative and end of life care Educational Framework. This will address the needs of the whole workforce and will be focused on fostering an integrated and collaborative approach to educational provision."

The framework states that:

• A workforce that feels adequately trained and supported to provide the palliative and end of life care that is needed.

- All health and care workers require an appropriate level of knowledge and skill in palliative care and end of life to match level of involvement with people with PEOLC needs

Three sets of principles underpin the framework, which promote a person-centred, outcomes focused, human rights based approach to palliative and end of life care. These principles are at the centre of the integration of health and social care and wider public service reform.

- World Health Organisation Definitions of Palliative Care. Palliative care is internationally recognised as a basic human right, promoting person-centred care.

- The PANEL Principles (Participation, Accountability, Non-discrimination and Equality, Empowerment and Legality). These principles underpin a human rights based approach which empowers people to know and claim their rights.

- The National Care Standards Principles are integral to the standards which outline what everyone in Scotland can expect when using health and social care services, and how providers of care should deliver and improve services. These are based on a human rights approach underpinned by the PANEL principles

Within each domain, there are four levels of knowledge and skills. These outline what workers need to know and do, depending upon their degree of involvement in palliative and end of life care, and their role responsibilities in the care and support of people with palliative and end of life care needs, their families and carers. Some of the knowledge and skills are integral to all health and social care, and in the framework, are applied in the context of palliative and end of life care.

Informed level outlines the knowledge and skills required by all health and social service workers in relation to palliative and end of life care.

Skilled level outlines the knowledge and skills required by health and social service workers who by virtue of their role and level of responsibility regularly provide care and support to people with palliative and end of life care needs, their families and carers.

Enhanced level outlines the knowledge and skills required by health and social service workers who by virtue of their role and level of responsibility provide, co-ordinate and manage the care and support of people with palliative and end of life care needs, their families and carers.

Expert level outlines the knowledge and skills required by health and social service workers who by virtue of their role and level of responsibility play an expert specialist role in the care and support of people with palliative and end of life care needs, their families and carers.

The framework also confirms our local thinking around Palliative care being provided by a range of health and social care sectors and informally by families, carers, friends and communities. Training for families, carers and communities should also be considered if we are to enhance the considerable asset of this informal care.

Using our local knowledge and skills found in staff with experience is one of the best ways to use our assets and deliver local training. For example joint delivery of the MacMillan Foundations in Palliative Care course has started in community health & social care settings, by MacMillan Nursing and Workforce Development.

SSSC open badges in PEOLC are another way of accessing the basic knowledge. Fundamentals in palliative care (Informed level) is available to all social care staff and ought to be encouraged for all staff. The Enriching and Improving Experience Framework identifies the knowledge and skills required by all workers who might come into contact with people who have palliative and end of life care needs. The framework has five domains and this badge reflects the core knowledge and skills considered integral to the fundamentals to the delivery of high quality palliative and end of life care at the Informed level.

The University of Highlands and Islands in conjunction with Highland Hospice are in the process of developing a professional development award for PEOLC.

Our Strengths:

- Percentage of staff who feel supported by managers
- Percentage of staff who feel confident in their PEOLC practice
- 35% of staff who responded to the staff survey, have worked in their role for more than 10 years, demonstrating we have an experienced workforce. Local experience is crucial to promote and share. Using our own assets will strengthen our understanding of what works and when shared with less experienced staff, helps to ensure this valuable experience isn't lost.

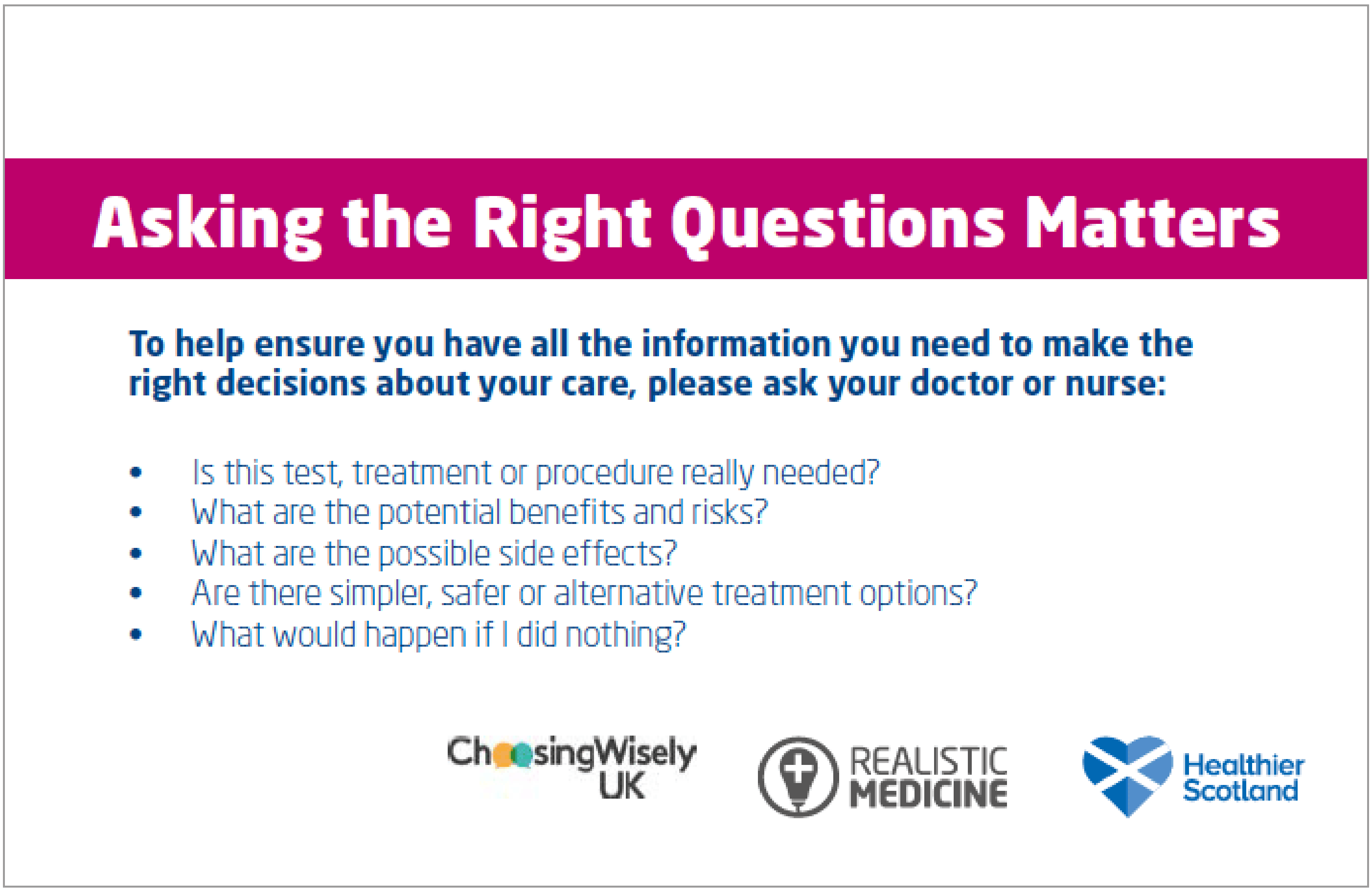
Realistic Medicine:

But in our attempts to defeat death, the question is this - are we over-medicalising death and the final years of life at the expense of providing better palliative care that would result in a better quality of life? Is it time to reset the system, and learn how to die a better death?’ [7]

In the Chief Medical Officer's third annual report, ‘Practicing Realistic Medicine’ there are a number of areas highlighted relevant to palliative and end of life care:

- Building Our Personalised Approach To Care With People Across Scotland
- Changing Our Style To Shared Decision Making
- Asking the Right Questions Matters
- Valuing Our Workforce
- Tackling Unwarranted Variation, Harm And Waste To Provide Value Based Healthcare
- A Realistic Approach To Population Health

Local practitioners are establishing a working group to look at the implementation of realistic medicine in Shetland. This group aims to ensure that professionals are realistic about prognosis and outcomes – including how they advise people about the benefits of ongoing treatments, and quality of life (as opposed to quantity of life) and how they record this.



Asking the Right Questions Matters

To help ensure you have all the information you need to make the right decisions about your care, please ask your doctor or nurse:

- Is this test, treatment or procedure really needed?
- What are the potential benefits and risks?
- What are the possible side effects?
- Are there simpler, safer or alternative treatment options?
- What would happen if I did nothing?

Locally we aim to implement Realistic Medicine in a number of ways:

- Listening to understand patients' problems and preferences
- Sharing decision making between healthcare professionals and their patients
- Ensuring that patients have all the understandable information they need to make an informed choice
- Moving away from the 'doctor knows best' culture to ensure a more equal partnership with people
- Supporting healthcare professionals to be innovative, to pursue continuous quality improvement and to manage risk better
- Reducing the harm and waste caused by both over-provision and under-provision of care
- Identify and reduce unwarranted variation in clinical practices.

'We want people working in health and social care and people who use services to think about the values and the behaviours that underpin good experience. Drawing on these values to have meaningful conversations with people to plan and agree care will support all staff and patients to base care around what matters most to people, with a shared understanding of what healthcare might realistically contribute to this. This is the ethos of Realistic Medicine.' [6]

There is also evidence that people are more likely to have greater confidence in decisions reached and less likely to regret their treatment choices. So good communication, listening to people, displaying empathy and asking the right questions all lie at the heart of practising Realistic Medicine'[6]

Our Strengths:

- Dedicated multidisciplinary team formed to take forward Realistic Medicine approach.

A strength based approach to palliative and end of life care:

Nationally and locally there is a cultural shift in care and support; away from a deficit led model of care to one that identifies and builds on the natural strengths of the individual, their family/friends and carers, the local community and the services/staff themselves.

Through a staff survey, interviews and the PEOLC event staff and individuals have identified what local strengths Shetland has in relation to PEOLC:

- A committed, confident & compassionate Health & Social Care workforce who go above and beyond their remit to provide care & support
- A workforce with lots of experience in working in PEOLC
- GP Palliative Care Registers
- High percentage of people dying at home or in a homely setting
- A smaller close community spirit, where we often know the person we are taking care of
- Working together in a multi-disciplinary – with strong relationships and willingness to share tasks
- A valued Specialist and Community Nursing Service

What are Asset/Strength Based Approaches?

In the context of health improvement assets may be defined as "the collective resources which individuals and communities have at their disposal, which protect against negative health outcomes and promote health status" [3].

Asset based approaches are contrasted with traditional approaches to the delivery of health care and other public services which tend to use narrow interventions which focus on deficits/problems/disease. Asset based approaches are not new but are currently enjoying a higher profile within a number of strands of Scottish Government policy for example:-

• The Chief Medical Officer makes use of assets as a concept in his analysis of Scotland's health inequalities and poor performance in international comparisons of health status

• Asset based approaches are highlighted in the Christie Commission on the Future Delivery of Public Services. Demographic and financial projections have placed an imperative on approaches which are not based on increasing the scale of existing formal services.

• Re-shaping Care for Older People emphasises the potential for strengthening informal community support and individual assets as a means to extend independent living in the community.

The National Alliance '*Good Life Good Death Good Grief'* promotes a strength-based approach to palliative, end of life care, and suggest the following positive outcomes:

- people are able to talk about death and deal with related issues in a constructive way
- children grow up treating dying as an inevitable part of ordinary life
- people are comfortable using words such as "death", "dead" and "dying", and are able to make choices relating to their own dying and death
- health and social care professionals and volunteers in all care settings feel able to have discussions relating to death, dying and bereavement with patients and families, and with colleagues
- communities of all kinds are empowered to provide effective support to those dealing with death, dying, bereavement and loss.

Our Strengths:

- Outcome focused strength based approach used in With You For You.
- Asset based community development currently being explored.

A greater openness about death, dying and bereavement in Shetland – having good conversations

One cultural challenge is how we all talk to each other about death and dying. The Scottish Government identifies encouraging greater openness about death, dying and bereavement as a pursuit on achieving the outcomes under the Strategic Framework for Action on Palliative and End of Life Care.

Timely conversations around death and dying can be both practical and emotionally supportive and can often prevent or reduce fear, confusion, distress and complicated grief.

'Having the chance to review the options properly, and get the care that's right for us is a really important part of all health care. But it's especially poignant in palliative and end of life care'. Marie Cure

The aim of having good conversations about death and dying is to put the person at the centre of their own care, taking into account their priorities and how they want to live and die. It's about having a sensible and practical idea of what can be achieved or expected, and representing things in a way that is accurate and true to life.

Whilst compiling this updated strategy we had open and honest conversations with family members who had recently lost a loved one. All of them without exception said that talking about a person's wishes for dying and death had been invaluable in both reducing the distress for their loved one but also in their own grief. Below is an extract of a conversation held with family member V.

V describes how close she became with her father during the hours they spent planning his funeral. She felt it was the best thing she could do for him, to support him have choice and control over the arrangements, this also gave him dignity. He picked his coffin and planned the service. V says this meant that when it came to his death she wasn't having to make arrangements, trying to guess what he would have wanted when her emotions and grief was so raw. V says she can't emphasis enough how this helped her in her own grieving process. She learnt how resilient she was and it strengthened her relationship with her father. Although she says she also learnt to ask for help, "you're not a failure if you ask.

Anticipatory Care planning, Ceilings of care, DNACPR and Power of Attorney.

Anticipatory Care Planning is about individual people thinking ahead and understanding their health. It's about knowing how to use services better and it helps people make choices about their future care. Planning ahead can help the individual be more in control and able to manage any changes in their health and wellbeing. Many people with long term conditions or chronic health problems can benefit from having an Anticipatory Care Plan.

'The moral questions about death that face not just the medical profession, but each and every one of us. The question of how we die is a question that all of us must face, and yet we avoid talking about it. Modern medicine is focused on saving lives. Amazing technical advances have increased doctors' ability to treat a wide range of life-threatening diseases, meaning many more people live longer lives. Life expectancy has surged, and we regard death as something to be battled. It is common for the medical system to throw everything into treating patients right to the very end.[7]

Increasing the uptake of ACPs amongst those on long-term condition registers, over 70 years old and those identified as higher risk to premature death i.e. those with multiple complex conditions is crucial to PEOLC. Having clear understanding of what is important to individuals and ensuring conversations that help prepare for dying and death will help us develop support that is personalised. In the PEOLC staff survey 48% said that sometimes individuals have an anticipatory care plan in place.

Promoting ACP is an area that is under development locally, with a recent introduction of the use of The Scottish Government & Health Improvement Scotland document 'My Anticipatory Care Plan'. Continued work to implement this would help promote the early identification for people who may need PEOLC and clear support plans can be put in place before individuals reach crisis point or their capacity to make choices deteriorates.

ACP's also incorporates the writing of wills or "Living Wills" now known as advance directives or advance decisions which can be done by the well person early on in life to plan for what **may** happen at the end of life. Anticipatory care planning is more commonly applied to support those living with a long term condition to plan for an **expected** change in health or social status. It also incorporates health improvement and staying well. Completion of a common document called an anticipatory care plan is suggested for both long term conditions and in palliative care.

The decision to give any treatment has to be made after weighing up potential benefits against potential risks and in collaboration with the individual. As a person's disease/illness progresses, the likelihood of benefitting from aggressive treatment decreases and the likelihood of side-effects and complications increase.

Having a conversation about a decisions not to attempt cardiopulmonary resuscitation needs to be discussed and recorded in an individual's anticipatory care plan.

Having timely, honest conversations with individuals allows them to have informed choice, is vital to care planning and can save needless distress for them and their family members. What care might be appropriate needs to be reassessed as the disease advances, in order to reduce the risk of harm and avoid excessive burden to the individual as a result of over-treatment.

Our Strengths:

- NHS Spiritual Care Lead in post
- What matters to You
- Introduction of The Scottish Government & Health Improvement Scotland document 'My Anticipatory Care Plan'.

Compassionate Communities – a Public Health approach

Compassionate communities are examples of the engagement of neighbourhoods in caring for others as a humanitarian practice, which includes palliative care and end-of-life care provision. Kellehear was the first to introduce the term “compassionate community”. He stated that compassionate communities are needed as a public health approach to palliative care. Kellehear also called all citizens to action by his statement: “end-of-life care is everyone’s responsibility.”

What it is	**What it is not**
Social Movement	A service
Involves ordinary people	About health professionals
Community development	A palliative care service
Needs based evolution, with no blue print development	Prescriptive

In early 2013, an online survey of over 200 UK palliative care services published in the British Medical Journal found that most of these services were prioritising ‘community engagement’ initiatives, most commonly adopting a ‘compassionate community’ model. This development embraces a public health approach including health promotion, community development and death education into a field that has previously focused primarily on the clinical care.

Compassionate communities are derived from the World Health Organisation concept of ‘Healthy Cities’ or ‘Healthy Communities’ and reinforces the move towards asset based community development (ABCD). Promoting the idea that ‘health and wellbeing’ is everyone’s responsibility – not just services.

The lack of death literacy is a common problem in many countries. Death literacy consists of four parts:1) skills, 2) knowledge, 3) experiential learning, and 4) social action. It is not enough to only talk about death—social action is needed. This underlines the fact that education alone is not the solution in improving palliative care in the community. Education must be accompanied by a reflection on attitudes, as well as action. Without reflection and action, there may be no change in practice and no practical improvement.

Opportunities to develop the strengths of community members to support each other in PEOLCis also central to this strategy. Knowledge in palliative care can be very limited or totally absent in most communities, and information about the effects of educational procedures in teaching non-professionals in basic palliative care is sparse. The ‘Last Aid’ course, described as an ingredient to compassionate communities, is a relatively new concept for teaching the public about palliative care.

Individuals, families and carers may lack knowledge about palliative care, and there is an urgent need to educate non-professionals in palliative care and end-of-life care. At present, the main source of citizens’ palliative care knowledge is often through personal experience. The experiences with Last Aid courses in different countries are overall very positive.

Last Aid courses are well-attended. The evaluation of questionnaires in a German pilot study has shown a favourable response. Last Aid courses may form the educational basis of compassionate communities, and are well-suited to inform the public about palliative care and end-of-life care

Our Strengths:

- SIC delivery of ‘Training’ to tackle loneliness
- The British Red Cross development of ‘Kindness Café’s’
- The British Red Cross Connecting Community Service

Working together

Key to a personalised approach to PEOLC, is communication and working collaboratively.

Communication between professionals and with individuals and families was highlighted as crucial by the local people who took part in our PEOLC event and staff survey – particularly in relation to discussing treatment choices, future planning and end of life care and how this is then translated into an appropriate, shared anticipatory care plan. Strengthening communication between specialist (sometimes off island services) and local teams is considered an important factor to improve communication and provide responsive, flexible care for patients.

There continues to be a strong theme running through staff feedback which noted the importance of positive psychology, self-management and public awareness raising regarding „living a healthy life and having a good death‟. There was an emphasis on how we need to work together to support people to have conversations about „life and death‟ in a positive way, in an attempt to change the societal culture and taboos, which are associated with talking about death and dying. Providing appropriate psychological services, counselling and information for people who need additional support to manage their grief and loss following the death of a loved one, was also considered a key aim to be incorporated into this strategic plan.

Evidence-Based remains at the core of informing best practice and guidance, but for it to truly take place, we must use best available evidence, clinical/professional judgement and individuals' preferences together.

In the recent staff survey 44% said that communication between health & social care staff is adequate most of the time.

Consultation with staff continues to demonstrate the need to have a particular focus on anticipatory care to support people with long-term conditions, as there is a predicted increase in the prevalence of people who will be living with complex health needs who will also access palliative care services, over the next five years and beyond. As part of this work, we will also need to consider the changing pattern of diseases (epidemiology) and the death trajectory (rapid or slow decline) associated with common long term conditions such as Dementia, which can have an uncertain prognosis (Mitchell et al, 2009).

The Gold Standards Framework (GSF) is a tool which has been developed to facilitate effective communication, co-ordination and continuity as well as emphasising the need for assessment and review of those people with palliative and end of life care needs. This includes the use of a palliative care register to enhance communication about patients between healthcare professionals.

In terms of death trajectory, staff would benefit sharing knowledge and understanding through the consistent use of a palliative indicator tool such as SPICT. Supportive & Palliative Care Indicators Tool (SPICT™) is used to help identify people at risk of deteriorating and dying with one or multiple advanced conditions for holistic, palliative care needs assessment and care planning. Sharing these with all those involved in supporting a person will enhance the

The Gold Standards Framework (GSF) is a tool which has been developed to facilitate effective communication, co-ordination and continuity as well as emphasising the need for assessment and review of those people with palliative and end of life care needs. This includes the use of a palliative care register to enhance communication about patients between healthcare professionals.

The Electronic Palliative Care Summary (ePCS) is a system which allows the automatic update and sharing of health records across community nursing, specialist nursing and GP teams. The sharing of information can be further extended to hospital based teams.

The ePCS system is in place in all ten practices and palliative care registers are in place in all of the practices. However, whilst communication was considered on the whole to be good, it still presented as one of the main areas for improvement, particularly the role of technology and ehealth systems in supporting communication between teams and partner agencies.

Communication was also noted concerning the individual conversations with patients and their families about planning for the future and their wishes in relation to end of life care and how we can effectively support people who are dying and the professionals providing care and treatment, to manage these difficult and emotional discussions.

Much work has been taken forward to revise and improve the single shared assessment process for adults (known as With You For You) and for children (known as Getting it Right for Every Child) across Shetland, it has been noted in the feedback that we need to continue to prioritise the development of a co-ordinated approach to support people who need to access a wide range of services (e.g. specialist, local hospital, community based and voluntary sector). Particularly where additional support might need to be provided to ensure that a person can remain at home (if that is a preferred place or care and/or death) and support timely discharge from hospital.

With You For You (WYFY) - Staff were divided on the clarity of a main point of contact for coordination with 32% saying it was always clear, 32% saying most of the time it was clear and 32% saying it was sometimes clear. As discussed above having a collaborative approach to PEOLC is crucial in meeting the needs of individuals, family members and carers. This is particularly crucial with ‘fast track’ care needs. The WYFY process aims to offer a coordinated approach to supporting someone, where they have one point of contact. During the writing of this strategy, we spoke to many family members and carers who stressed how important this was to them. Improvements and quality assurance for the WYFY process is vital in understanding how well we coordinate our care.

Getting It Right For Every Child (GIRFEC) – Providing care for children who are dying (their families & carers) can be one of the most difficult journeys anyone takes.

The 2016 NICE ‘End of life care for infants, children and young people with life-limiting conditions: planning and management’ guidance sets out the following general principles which are considered within the child’s plan:

- Recognise that children and young people with life-limiting conditions and their parents or carers have a central role in decision-making and care planning.
- Discuss and regularly review with children and young people and their parents or carers how they want to be involved in making decisions about their care, because this varies between individuals, at different times, and depending on what decisions are being made.
- Explain to children and young people and to their parents or carers that their contribution to decisions about their care is very important, but that they do not have to make decisions alone and the multidisciplinary team will be involved as well.
- When difficult decisions must be made about end of life care, give children and young people and their parents or carers enough time and opportunities for discussions.
- Be aware that continuity of care is important to children and young people and their parents or carers. If possible, avoid frequent changes to the healthcare professionals caring for them.
- Be aware that siblings will need support to cope with:
    - their brother's or sister's condition and death

    - the effects of their parents' or carers' grieving.

  This may include social, practical, psychological and spiritual support.
- Be aware that other family members (for example grandparents) and people important to the child or young person (for example friends, boyfriends or girlfriends) may need support. This may include social, practical, emotional, psychological, and spiritual support.
- When developing plans for the care of the child or the young person with a life-limiting condition, use parallel planning to take account of possible unpredictability in the course of the condition.

As with PEOLC to all ages, the NICE guidance highlights the following areas as crucial to children and young people and their family and carers:

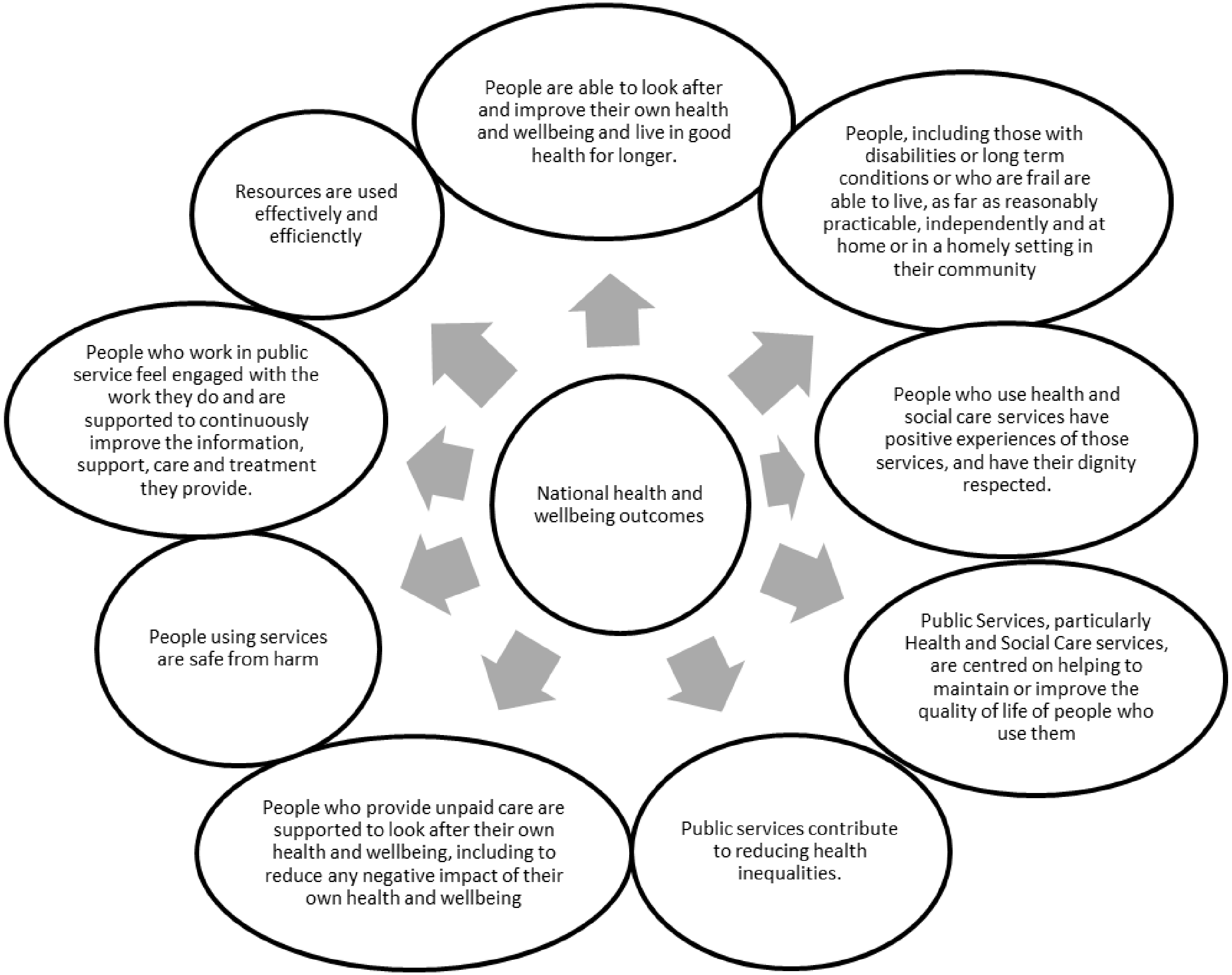
- Communication
- Providing Information
- Care planning and advanced care planning
- Emotional and Psychological support
- Social and practical support
- Religious, spiritual and cultural support
- Preferred place of care and death
- Managing distressing symptoms - pain, agitation, seizures, respiratory distress, hydration and nutrition
- Recognising that a child or young person is likely to die within hours or days
- Care and support for parents, carers and healthcare professionals in relation to the death of a child or young person

Our Strengths:

- Intermediate Care Team – multi-disciplinary approach to helping people remain at home.
- WYFY & GIRFEC – process for assessing, support planning that are based on a collective approach to care.

Appendix 1 Outcomes Framework

The Palliative and End of Life Care strategy is in line with the general Health and Wellbeing Outcomes for Integration.



National health and wellbeing outcomes

People are able to look after and improve their own health and wellbeing and live in good health for longer.

People, including those with disabilities or long term conditions or who are frail are able to live, as far as reasonably practicable, independently and at home or in a homely setting in their community

People who use health and social care services have positive experiences of those services, and have their dignity respected.

Public Services, particularly Health and Social Care services, are centred on helping to maintain or improve the quality of life of people who use them

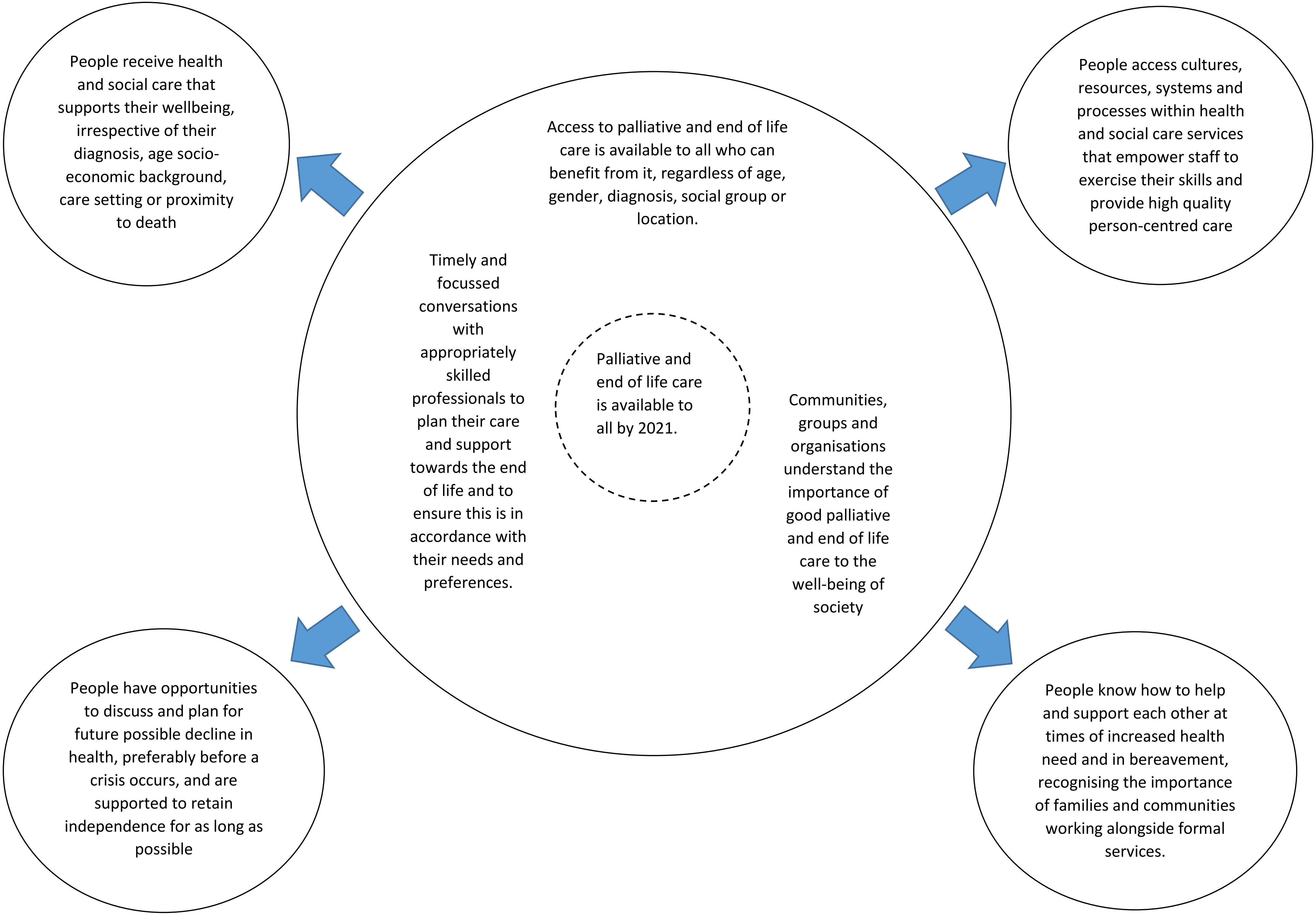
Public services contribute to reducing health inequalities.

People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their own health and wellbeing

People using services are safe from harm

People who work in public service feel engaged with the work they do and are supported to continuously improve the information, support, care and treatment they provide.

Resources are used effectively and efficienctly



People receive health and social care that supports their wellbeing, irrespective of their diagnosis, age socio-economic background, care setting or proximity to death

People access cultures, resources, systems and processes within health and social care services that empower staff to exercise their skills and provide high quality person-centred care

Access to palliative and end of life care is available to all who can benefit from it, regardless of age, gender, diagnosis, social group or location.

Timely and focussed conversations with appropriately skilled professionals to plan their care and support towards the end of life and to ensure this is in accordance with their needs and preferences.

Palliative and end of life care is available to all by 2021.

Communities, groups and organisations understand the importance of good palliative and end of life care to the well-being of society

People have opportunities to discuss and plan for future possible decline in health, preferably before a crisis occurs, and are supported to retain independence for as long as possible

People know how to help and support each other at times of increased health need and in bereavement, recognising the importance of families and communities working alongside formal services.

Appendix 2 Action Plan

Outcome	Output	Process	Lead & Input	Timescale
People have opportunities to discuss and plan for future possible decline in health, preferably before a crisis occurs, and are supported to retain independence for as long as possible.	Improved identification of people who may benefit from palliative and end of life care and conversations about PEOLC start earlier in an individuals' Care. Increased and timely use and promotion of the 'My Anticipatory Care Plan' to encourage good conversations and care planning.	Each Health Centre identifies a list of individuals, promotes ACP, and offers documentation for self-completion to all those on long-term condition registers, over 70 years old and those identified as higher risk to premature death i.e. those with multiple complex conditions. Nurse Specialists routinely offer ACP tools to patients on their caseload to discuss at home with their families. Identify groups at higher risk of premature death and encourage GP practices to offer ACP to these groups. Promote ACP as part of WYFY and signpost individuals to their health centre. Offer documentation for self-completion. Audit and monitor the DES returns across primary care	All - WER Primary Care - WER Long-term Conditions Specialist Nurses - WER Health Improvement Manager - Public Health - WER Senior Social Care Workers	

		services feeding back performance data to MCN PEOLC.	Social Workers Assistant Social Workers Care Coordinators – All WER Primary Care - WER	

Outcome	Output	Process	Inputs	Timescale
People receive health and social care that supports their wellbeing, irrespective of their diagnosis, age socio-economic background, care setting or proximity to death.	24-hour support is available for end of life care in the community for those that need it.	Investigate a 24/7 response service to further support care@home and out of hours arrangements based in Lerwick. This will involve exploring partnership arrangements with other statutory and 3rd sector partners.	£311,379. Executive Manager for Community Care	
	An enhanced contribution of a wider range of health and care staff in providing palliative care.			
	Enhanced community support that prepares people for death and dying.	Explore the use of Volunteers for compassionate companionship service.	NHS Spiritual Chaplain – WER British Red Cross – Community Connectors Service	

	Clear written guidance on roles and responsibilities for Care Coordination in PEOLC.	Using the With You For You process for those with social care/support needs and via community/specialist nursing.	Executive Managers in Adult Social Work and Community Resources Senior Social Workers Care Coordinators	
	Consistent joint process in place for fast track palliative referrals/hospital discharge.	Update With You for You guidance regarding use of WYFY Referral tools for fast track palliative support.	Executive Managers in Adult Social Work and Community Resources Senior Social Workers Care Coordinators Community Nursing	
		Develop a pathway for palliative fast track referrals.	Hospital discharge group	
		Introduce a palliative discharge checklist for ward staff.	Hospital discharge group	
	Consistent use of Palliative Care Indicator Tool shared across Health & Social Care Staff	MCN to decide which tool to use and members to promote shared use within their service areas.	PEOLC MCN Executive and Service Managers	

Outcome	**Output**	**Process**	**Lead & Inputs**	**Timescale**
People know how to help and support each other at times of increased health need and in bereavement, recognising the importance of families and communities working alongside formal services.	Training delivered for both health (Community and Acute) and all social care staff, unpaid carers and Personal Assistants on the following:	Promote resilience amongst those that support and care through supervision and training.	Managers and Supervisors within Services	
	• Person Centred PEOLC practice. • Pain & Symptom management	Joint delivery of the MacMillan Foundations in Palliative Care course	SIC Workforce Development	
	• Having good conversations about death and dying		Public Health/Health Improvement	

People access cultures, resources, systems and processes within health and social care services that empower staff to exercise their skills and provide high quality person-centred care.	• Ensure that professionals are realistic about prognosis and outcomes • Staff have wider range of skills and knowledge development opportunities in PEOLC	Promotion of Health Literacy and 'teach back' techniques.	Team Leaders / Service Managers / Supervisors	
		Multi-disciplinary debriefs following deaths where there are shared learning opportunities.	PEOLC MCN	
	A sense among unpaid carers and health/social care staff of feeling adequately trained and supported to provide the palliative and end of life care that is needed, including a better understanding of how people's health literacy needs can be addressed	Sharing evidence based practice and local stories about good outcomes.	Team Leaders / Service Managers / Supervisors	
		Advise people about the benefits of ongoing treatments, and quality of life (as opposed to quantity of life) and record these conversations.	Team Leaders / Service Managers / Supervisors	
	An information guide/leaflet on practical tasks, realistic expectations of dying and death, managing symptoms and other useful local signposting information.	Promotion of stress and distress management through supervision.	MCN PEOLC	
		Sharing staff experience and encouraging staff to be involved with PEOLC across all social/health care.		
	GP's, Acute medical and social care staff will be confident and skilled in talking about death and dying.	Professional development award developed by UHI and Highland Hospice Training on 'Having Good Conversations' focusing on: • Promoting ACP's	UHI, Shetland College and Workforce Development Workforce development	

		• Breaking bad news’ Debrief and supervision of staff involved in PEOLC		

Outcome	Output	Process	Lead & Inputs	Timescale
People, their families and carers have timely and focussed conversations with appropriately skilled professionals to plan their care and support towards the end of life, and to ensure this is in accordance with their needs and preferences.	A greater openness about death, dying and bereavement in Shetland.	Community Conversations about death and dying will be promoted through existing groups.	Health & Social Care all staff Voluntary Sector Community Groups Spiritual and Faith groups	
	Strength based self-management conversations are had with people with long-term health conditions	Continue to develop ethos and principles that focuses on the strengths of staff, individuals in receipt of PEOLC, their families, friends, carers and the communities in which they live.		

Outcome	Output	Process	Lead & Inputs	Timescale
Communities, groups and organisations of many kinds understand the importance of good palliative and end of life care to the well-being of society.	A guide on practical tasks, realistic expectations of dying and death, managing symptoms and other useful local signposting information.	Promote resilience amongst those that support and care. Through community based training.		
	An asset based map of community support that supports PEOLC.	Gather information on relevant community groups that could support PEOLC	Community Development	
	Community based training such as ‘Last Aid’ course delivered.	Develop community interest and ownership of a good citizen approach to PEOLC,	Health Improvement Workforce development VAS	

	Recognition of the wider sources of support within communities that enable people to live and die well.	through encouraging existing groups to reach out. Look after carers’ welfare through Adult Carer Support Plans and Young Carers statements. Encourage a space for peer support.	Senior Social Care Workers Social Workers Assistant Social Workers Care Coordinators Neil Brice	

Outcome	**Output**	**Process**	**Lead & Inputs**	**Timescale**
Greater emphasis in strategic plans, research activities and improvement support programmes on enhanced access to and quality of palliative and end of life care.	Quality assurance framework across PEOLC implemented.	Develop a QA framework for PEOLC and gather data	PEOLC MCN	
	Clearer understanding of areas of improvement in service delivery.	Collect and evaluate individuals’ experience of dying at home; focusing on dignity, choice and control, management of pain and distress, and on the individuals wider support needs.	All Service areas	
	SIC/NHS policy/procedure for use of PEOLC indicator tools.	Presented to MCN PEOLC twice a year.	PEOLC MCN	
	Clear procedure regarding individuals with incapacity and the role of significant others (POA, Guardians, non-instructed advocates)	Explore use of most appropriate tool locally and write procedure for use across all service areas.	Mental Health Officers	

	to ensure preferences are heard.	Produce procedure or explore existing guidance and share with all staff		
	Opportunities for community based ‘Hospice’ care are researched.		Executive managers of Community Nursing & Support@Home	
	Explore opportunities to introduce a model of care in the community across all PEOLC similar to the MacMillan service.	Encourage small test for change projects that look at personalised, community approaches to PEOLC. Adequate investment in supporting communities in their role in PEOLC.	PEOLC MCN	

Appendix 3 – Last Aid programme

The Last Aid course contents (version May 2018). Last Aid Care for seriously ill and dying people at the end of life.

Topic Course Content	
Module 1 Dying as a normal part of life	Welcome and introductions First Aid and Last Aid What you can do to care The process of dying
Module 2 Planning ahead	Networks of Support Making decisions Medical and ethical aspects Advance care planning Advance Directive Power of Attorney
Module 3 Relieving suffering	Typical problems and symptoms Caring/relieving suffering Nutrition at the end of life How to comfort
Module 4 Final goodbyes	Saying good bye/final fare-well rituals Funeral and various forms of burials Grieving is normal Grief and ways of grieving Questions, Comments

References

1. *'What's important to me. A Review of Choice in End of Life Care'*; The Choice in End of Life Care Programme Board; February 2015

2. '*The importance of values in healthcare'*; Aidan Halligan; J R Soc Med 2008: 101: 480–481.

3. Asset based approaches for health improvement: redressing the balance Glasgow Centre for Population Health October 2009

4. Last Aid Course. An Education For All Citizens and an Ingredient of Compassionate Communities. Healthcare 2019, 7(1), 19;

   https://doi.org/10.3390/healthcare7010019

5. Dignity in Care, SCIE, Specialist Care, End of Life.

   www.scie.org.uk/publications/guides/guide15/specialistcare/endoflife/

6. Realistic Medicine; What realistic medicine is and what it isn't.

   https://realisticmedicine.scot/about/

7. We need to talk about Death, BBC Horizon, 2019.

   https://www.bbc.co.uk/programmes/b0c10f7h

8. Compassionate communities: end-of-life care as everyone's responsibility. A.Kellehear. QJ Med 2013; 106:1071-1075

9. Chief Medical Officer's Annual Report 2016-17. Practising realistic Medicine.

10. Strategic Framework for Action on Palliative and End of Life Care – Executive Summary. The Scottish Government.

11. Why a realistic approach to health and social care is best for patients. 15 November 2017 Richard Meade, Head of Policy & Public Affairs, Scotland

    https://www.mariecurie.org.uk/blog/realistic-medicine-and-palliative-care/170099

12. What's the difference between personalisation and self-directed support? Think Personal Act Local; 2014; Tim Collins Lead for Self-directed Support and Personal Budgets & Regional Co-ordinator for for Yorkshire and Humber Association of Directors of Adult Social Services (ADASS)

    https://www.thinklocalactpersonal.org.uk/Blog/Whats-the-difference-between-personalisation-and-self-directed-support/