



PALLIATIVE AND END OF LIFE CARE STRATEGY

2013-2016

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Executive Summary

Key priorities for palliative care and end of life care in Shetland 2013-16

This strategy has been revised to take account of the changing health needs of the local population, particularly in relation to the predicted rise in the number of people living with a long term condition and how we, as health and social care organisations will need to respond to these changes. In terms of service provision, there will be an increased requirement to provide appropriate palliative care and complex care, where people live longer and hopefully, healthier lives. But there will be new challenges, such as the increasing requirement to support people with dementia and other degenerative conditions and how palliative care services will need to adapt to meet changing population needs.

The content of the strategy is based on contributions from patients, healthcare professionals working in a number of settings, cancer and palliative care specialists, community care services, public health, voluntary services and members of the public. A wide variety of responses were received and they have been summarised into a series of broad headings which are set out in this document.

In summary, the feedback from the public and professional alike, noted the importance of supporting choice for people with palliative and end of life care needs continues to be highlighted.

Based on listening to this feedback the goals for implementation in relation to supporting choice are to support action to:

- Identify people who would benefit from palliative care, and to develop care plans with people that include establishing preferred place of care and preferred place of death;
- Maximise the time spent in people's preferred place of care (e.g. home or community setting);
- Minimise emergency admissions where these could be avoided through good anticipatory care planning;
- Support realistic choice of place of death (taking into account a holistic assessment of patient, family and carer needs). Responders to the consultation have made it clear to us that whilst more people would prefer to die where they live, rather than in an acute hospital setting, choices must be considered against a realistic assessment of circumstances, support, individual needs, and therefore feasibility of delivery.

Other key topics included the role of technology and the ehealth agenda in supporting the sharing of information and reducing duplication of effort. As well as the emerging role that technology will play in health improvement and self management models in the future to support people with long term conditions and palliative care needs.

There was also acknowledgement that there are cohesive, integrated systems to support palliative care pathways in place, particularly for cancer care, but that there

is more we need to do to support end of life care in the community setting. Consistency in terms of the skills and competencies of staff was seen as one of the enablers to this, particularly providing additional training and support to community based health and social care staff.

Communication between professionals and with patients and families was highlighted – 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 was considered to be an important factor to improve communication and provide responsive, flexible care for patients.

There was also a strong theme running through the 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.

This strategy and the action plan associated with it is ambitious, but we hope that through continued collaborative working with patients, families, the public, health and social care teams and partner organisations we will be able to continue to build effective services, which support people to maximise their health and wellbeing when living with a long term illness, complete their personal journey through life and die with dignity.

Kathleen Carolan, Executive Lead for Palliative & End of Life Care

October 2013

“Looking at the stars always makes me dream, as simply as I dream over the black dots representing towns and villages on a map. Why, I ask myself, shouldn’t the shining dots of the sky be as accessible as the black dots on the map of France? Just as we take a train to get to Tarascon or Rouen, we take death to reach a star. We cannot get to a star while we are alive any more than we can take the train when we are dead. So to me it seems possible that cholera, tuberculosis and cancer are the celestial means of locomotion. Just as steamboats, buses and railways are the terrestrial means. To die quietly of old age would be to go there on foot”.

Vincent van Gogh (date unknown)

1. Introduction

Palliative Care

The World Health Organisation (WHO) defined palliative care in 2004¹ as an approach that improves the quality of life of patients and their families facing the problems associated with any life-threatening illness and not just cancer, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Recent Palliative and End of Life Care national policy documents

In August 2008, Audit Scotland published a review of palliative care services in Scotland². Key findings that are relevant to NHS Shetland include recognition that people with a range of conditions need palliative care, but services remained primarily cancer-focussed; most palliative care is provided by generalist staff but increased skills, confidence and support are needed to improve palliative care; palliative care needs to be better joined up, particularly at night and weekends.

In October 2008, Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland³ was published and a summary of achievements against the original policy ambitions was produced in 2011⁴. It provided a focus for all Health Boards for planning palliative and end of life care services and included direction on assessment of people's palliative care needs; planning and delivery of care; communication and information sharing; and education and training and workforce development.

These national policy documents have been used to guide the actions we have taken forward to shape local services between 2009 and 2012, as well as the local feedback received from patients and service users, health professionals, partner organisations and the voluntary sector.

2. Demographics

The population of Shetland is ageing. Figure 1 below shows how we predict that this will continue, with the number of 75+ expected to more than double by 2035. A population who live longer are increasingly likely to be living with a range of long-term and progressive conditions. Currently, on average 213 people in Shetland die each year. The majority of people who die are over the age of 65 (87% in 2011) and 80% of these deaths are preceded by a period of illness or increasing frailty.

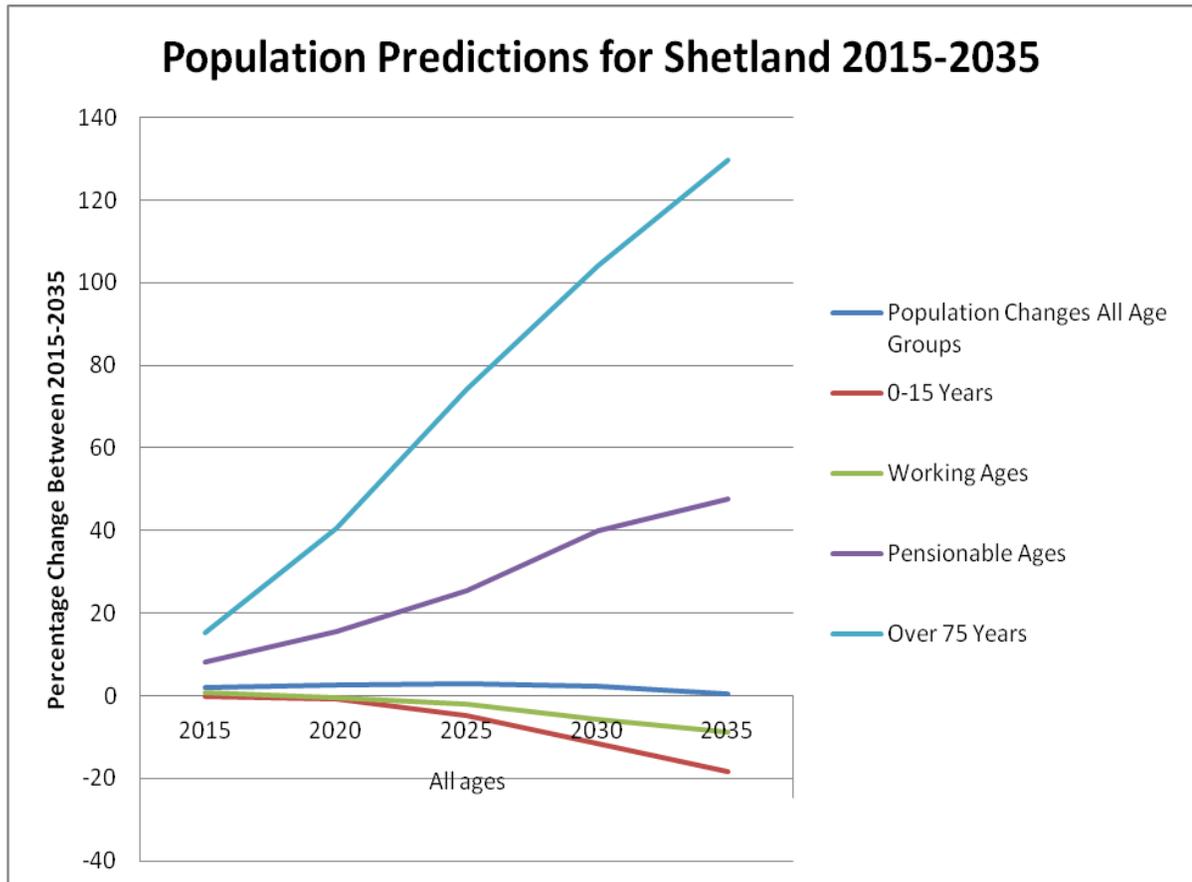
¹ WHO 2004 Twycross R (2003) Introducing Palliative Care (4th Edition). Radcliffe Medical Press, Oxford p.30

² Audit Scotland (2008) Review of Palliative care services in Scotland. http://www.audit-scotland.gov.uk/docs/health/2008/nr_080821_palliative_care.pdf

³ Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland. Edinburgh, October 2008

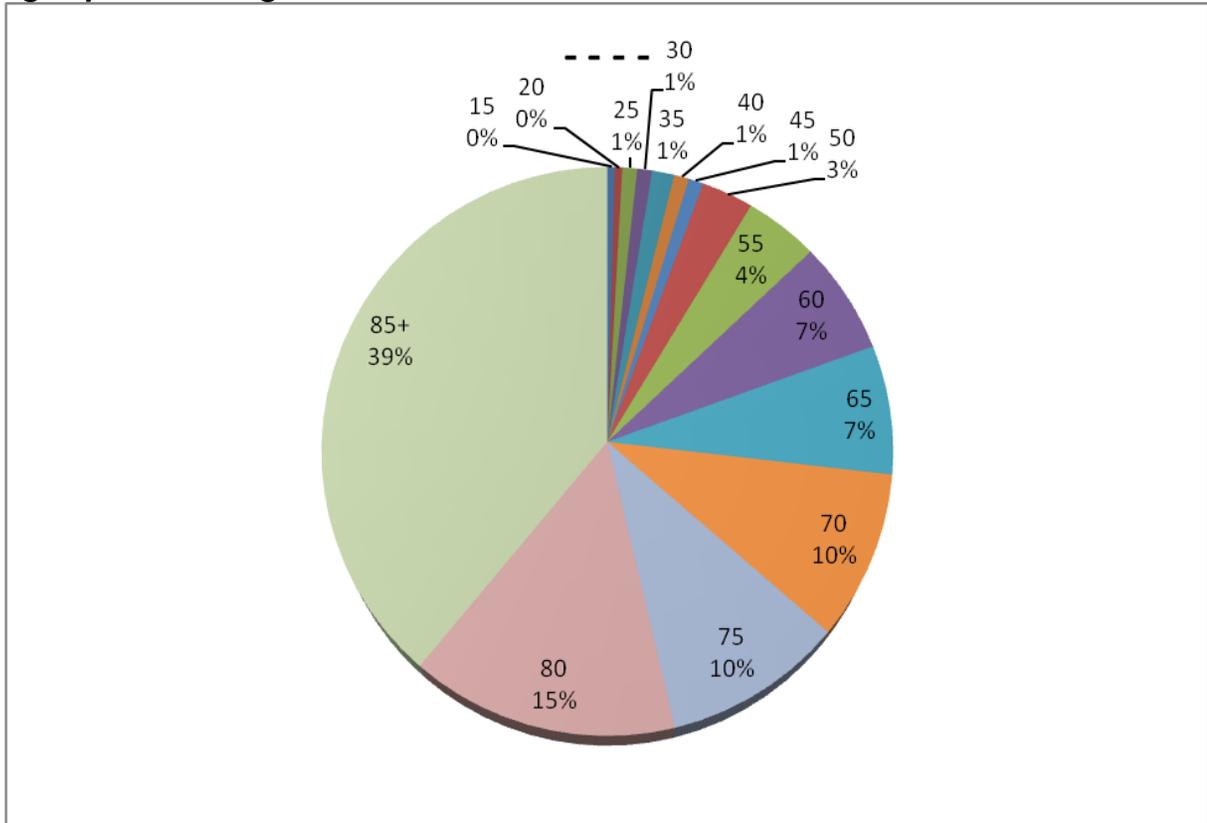
⁴ Living and Dying Well: Building on Progress. Edinburgh, January 2011

The number of younger adults and those of working age will fall in parallel with the increase in the number of older and very old adults. Changes to the population profile need to be considered as part of the work we do in the next five years to develop sustainable, palliative care and end of life care services in Shetland and how we work with the public, families, carers and the voluntary sector to achieve this.



Deaths and Age Specific Death Rates

Figure 2 A pie chart to show the proportion of deaths in Shetland, in 2011, by age specific categories



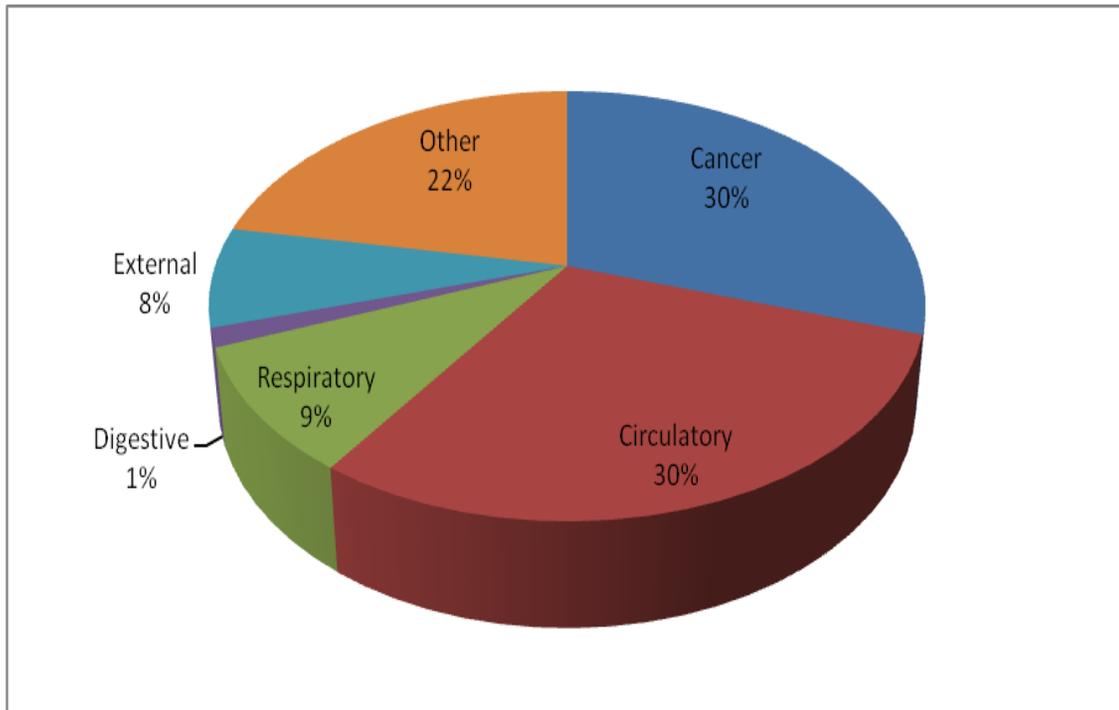
The increase in the number of older and very old people in the Shetland population will mean that people will be accessing palliative care services for longer and potentially with more complex health and social care requirements.

Causes of Death in Shetland (2011)

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 (see figure 3 below).

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 people dying of care.

Figure 3 A pie chart to show the main categories⁵ of the cause of death (all deaths in Shetland), in 2011⁶



It was also noted in the consultation exercise that there needs to be 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).

From the feedback that we have received from families and carers we understand that more people want to die in their own home and we need to develop services to better support that. Although more people die in their own homes in Shetland than in the rest of the UK, over the last 3 years the place of death shows that up to 49% die at home or in care homes.

⁶ Examples for the categories: circulatory e.g. heart conditions, other e.g. dementia, external factors e.g. accidents or sudden deaths such as suicide

3. Communication

What we have achieved since the publication of the Palliative & End of Life Care Strategy in 2009

Effective communication between professionals about adults and children with palliative and end of life care needs especially across organisational boundaries is a vital component of high quality palliative care services.

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 in regard to 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.

In addition to this, it was suggested that there would be merit in exploring options for 'hand held' patient records which would allow for a more seamless flow of information between professionals and patients, as well as reducing duplication.

In the following section, there is a summary of the progress which has been made to improve communication between professionals and with patients.

Priorities set in 2009

- Participate in the national roll out of the '**electronic Palliative Care Summary**' (ePCS) [estimated winter 2009, but dependent on national development].
- Implement the **Gold Standards Framework** Shetland-wide ensuring that each GP practice has a Palliative Care Register

Current Position (2013)

- The '**electronic Palliative Care Summary**' (ePCS) was implemented in 2010 – 90% of Practices are using this system
- Each Practice has a palliative care register and has assessed the service they provide against the **Gold Standards Framework**
- The single shared assessment process – known as '**With You For You**' has been implemented

Going Forward (2013 - 2016)

Communication was described as a central issue in a number of the consultation responses and include the need to:

- Ensure that the ePCS system is enabled to support sharing of information between professionals and across the health and social care partnership. Whilst the system is in place, information is not routinely available outwith the Practice team (because it isn't electronically linked). Various case studies were offered which set out examples of where routinely available information was not easy to share and so contributed to making discharge planning and/or supporting someone in the community more difficult.
- Explore options for developing 'hand held' records that can be used to keep key information in one place which is readily accessible to the patient and the professionals supporting their care (e.g. for everyone who has an anticipatory care plan).
- Ensure that individuals and their families have enough time to discuss their wishes and be part of the palliative and end of life planning arrangements. Particularly, in relation to the dying phase and bereavement care, where our audits have shown that this is an improvement area (e.g. DNACPR in the community, recording bereavement care requirements on the care plan etc). Along with a process for evaluating how we assess how well we do this.
- Ensure that as professionals, we are realistic about prognosis and outcomes – including how we advise people about the benefits of ongoing treatments, and quality of life (as opposed to quantity of life) and how we record this.
- Look at ways in which we can develop models that support 'strengthens based approaches' to help people living with long term conditions to focus on 'ability', 'self management' and positive conversations about living with a life limiting or palliative condition.
- Work with the public to promote awareness of death, dying and managing loss. Including how this can be sensitively delivered to young people and children.

- Work with partners to ensure that there is a smooth transition for patients who may be moving between specialist, hospital and community based services and how we will improve communication across the whole pathway to achieve this.

4. Co-ordination

What we have achieved since the publication of the Palliative & End of Life Care Strategy in 2009

One of the priorities set out in the last iteration of the strategy was the need to improve the co-ordination of palliative and end of life care. The recommendation was that once a diagnosis of a life-threatening illness or a long term condition is made, consideration needs to be given to nominating an appropriate co-ordinator (from within the multi-disciplinary team) to oversee all aspects of the adult or child's care, and act as a point of contact to ease communication paths and help provide a consistent approach.

Whilst 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.

The refreshed strategy reinforces the need for us to focus on developing models of health and social care that support 'care at home', promoting options and choices for people that are alternatives to institutional settings such as hospitals. The valuable role of the GP and wider primary care team in the provision of joined up long term conditions management, palliative care and end of life care was emphasised in the feedback.

Priorities set in 2009

- Formalise how the **co-ordinator role** is determined and what the role entails which will include elements of planning and co-ordination of care and ensuring timely and relevant information is communicated to all other professionals involved, particularly when a patient is transferred between care settings and between health boards.

Current position (2013)

- **Revised models of the singled shared assessment and GIRFEC for children have been implemented.**

- The **Liverpool Care Pathway (LCP) and other models of structured, individualised care planning have been implemented** (see section nine).

Going Forward (2013 - 2016)

- Develop a model of intermediate care, which supports the availability of ‘hospital at home’ services and time limited, intensive input to people with long term conditions
- Develop a model which identifies named practitioners to take the lead role in the overall co-ordination of care for people who have palliative and end of life care requirements. The practitioners will be GPs, District Nurses and Specialist Nurses who will have a specific remit for working with community nurses, social care teams, therapists and specialist services.
- Develop a ‘case management’⁷ approach which clearly identifies practitioners who will act as care co-ordinators for people who have palliative care and subsequent end of life care needs. The approach will emphasise the role of the community nurse in providing practical, day to day advice and care as well as the supervision of input from social care and healthcare support workers.

A fictional example of case management to support a person with palliative care needs:

“Mary is 76 years old and she lives at home with her husband. She has been diagnosed with bowel cancer and has recently been told that no further active treatment is available to her, so the plan is to help her manage her symptoms and keep her pain under control.

The District Nurse is her ‘case manager’ and she contacts Mary once a week by phone and visits once a month. The District Nurse helps to support Mary’s physical and psychological needs by providing equipment to make her more comfortable at home, monitoring her health needs and pain control, providing time to listen to Mary’s concerns and that of her husband about the future and liaising with other health and social care professionals to provide advice and support as required. For example, the District Nurse makes a referral to the Occupational Therapist and Physiotherapist to assess Mary’s mobility now that she is becoming frailer and finding using her bath more difficult. The District Nurse also keeps in close contact with the Oncology and Palliative Care Nurses as well as the GP – when the District Nurse is not on duty, then he/she ensures that someone from the nursing team who also knows Mary is available to provide home visits or provide support over the phone to anticipate any issues that might arise, particularly at night and over the weekend”.

⁷ Case management is an umbrella term to describe the assessment, planning, implementation, co-ordination and monitoring of a person’s care requirements. It often refers to the care that is provided in a community setting, where a person may be getting support from a number of different health and social care practitioners.

5. Control of pain and other symptoms

What we have achieved since the publication of the Palliative & End of Life Care Strategy in 2009

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 iteration of the strategy included the need to develop systems in the community to allow staff to be able to appropriately support symptom control, particularly pain management.

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.

The following section summarises in more detail the priorities that we set and some of the new and emerging recommendations from the recent consultation.

Priorities set in 2009

- **Holistic care** needs to be provided by a multi-professional team where there is a wide range of generalist skills. The core community team of GP, District Nurse and Social Care Worker may need to include others e.g. therapists and spiritual advisors, in order to respond to the needs of adults and children at the end of life.
- Develop **spiritual care** through the Board’s soon to be appointed Chaplain so that professionals feel confident to support people’s spiritual needs towards the end of life

- Develop awareness of how to identify **loneliness and isolation** and work with others to develop different types of support for people who are lonely and isolated
- At any stage of the illness, the right medicines must be available when needed. Early on in a life-threatening illness, where the progression of the illness is fairly slow it is possible to supply the right medicines at the right time to meet the patient's need, but towards the end of life, especially in the last days, when the pace of change is faster it is harder to have the medicines available as needed. This is particularly difficult "out of hours" and in a rural situation. For this purpose medicines that are likely to be needed may usefully be prescribed in advance and then stored at the patients home, for the patient to use as needed and directed, or to be there for the doctors and nurses to use as appropriate. These can be located in **just in case boxes** which can be left in an adult or child's home at the appropriate time, with drugs prescribed by GPs and administered by healthcare professionals
- There needs to be easy **access to palliative care specialists** who can provide advice and specialist interventions, to support teams and services on Shetland. All professionals need to know how to contact specialist services.

Current position (2013)

- **Clear pathways are in place** to support the delivery of holistic care through the multi-professional team and these pathways, such as LCP are working effectively. However, more work is required to ensure that the systems are in place to provide care in the place of choice (this includes working with other health partners such as NHS 24). This has been noted as a particular issue in relation to people who have non cancer related palliative care needs.
- **National guidelines are available** to clinicians to ensure that symptom control and management are undertaken in a consistent manner. Guidelines are available to support the treatment and care of both adults and children.
- **A dedicated Chaplain post was in place from 2010 to 2012**, in that time additional pastoral support was provided to patients and their families through the chaplaincy service. We also have a number of people who are active volunteers and provide spiritual and pastoral support in hospital. We are reviewing the model for spiritual care in light of the current vacancy and the feedback we have received from the consultation exercise.
- A number of **voluntary sector services have been put in place aimed at providing opportunities for social inclusion** and they include activities provided by Alzheimer's Scotland, Shetland Befriending Scheme, Shetland Carers Groups and existing support groups such as Shetland Stroke Support Group. In addition to this, we include within the holistic assessments for patients and carers an assessment of psychological wellbeing which is there to help identify early, if more formal psychological support is required.

- **‘Just in Case’ boxes have been successfully implemented** and have been very positively evaluated.
- NHS Shetland has **strengthened the links with NHS Grampian and Roxburgh House, to ensure that appropriate access to specialist palliative care advice** is in place. This includes input for individual patients to their palliative care plans as well as opportunities for clinicians to discuss clinical pathways and access specialist education sessions.

Going Forward (2013 - 2016)

- Continue 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. One responder described the need to reflect on the importance of ‘human kindness’ which was expanded with subsequent feedback to consider this in relation to ‘neighbourliness’.
- Review the current arrangements for spiritual and pastoral care (perhaps moving away from one post) to look at how we can make better links with faith groups, increase volunteering in hospital and the befriending scheme access and resources for basic counselling and support. This was also considered in relation to the needs of children and young adults.
- Continue to build links with specialist services based in Aberdeen, particularly in relation to shared treatment pathways (i.e. an individual is under the care of specialists and local clinicians). And supporting the clinical team as generalists, to access updates on changes to the evidence base and new technologies/interventions for palliative care through multi-disciplinary meetings, education sessions and 1:1 clinical advice.

6. Continuity of Care In and Out of Hours

What we have achieved since the publication of the Palliative & End of Life Care Strategy in 2009

We know from patient and carer feedback as well as published research that the majority of patients want to be cared for in their own homes towards the end of life. However, we also understand that carers and families need help to achieve that aim otherwise people might be admitted to hospital particularly when their GP practice is closed because they can’t cope at home.

We currently operate a Fast Track Palliative Care Procedure for people who need support quickly in order to be cared for at home in the last weeks of life. This procedure works well for patients with cancer. Through the Community Healthcare

Partnership (CHP) we need to develop a procedure that allows more flexible access, particularly for people with a non-cancer diagnosis.

Tools such as Advanced or Anticipatory Care Planning and Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) policy; promote greater choice, control and communication of people's preferences about their future care. They enable discussions to take place with people about particular choices such as their preferred place of care and preferred place of death, towards the end of life.

In 2009, we did not have robust systems in place to record advanced or anticipatory plans in a consistent way. Each practice and locality had its own forms and interpretation of the key information to be held in shared plans.

In addition to this, we did not have waking 24/7 community nursing cover, so providing care at home could be more challenging and logistically difficult to put in place.

However, over the last three years we have implemented the electronic palliative care summary (ePCS) which is an electronic anticipatory care plan and this is now in place in 100% of locality areas.

The Scottish Government published a CEL in 2012, which describes the direct enhanced service (DES) for palliative care and primary care medical services. We have looked at the DES and applied the principles to support the availability of appropriate anticipatory care plans (cancer and non cancer diagnosis) and sharing information across health and social care teams, particularly in the out of hours period.

Since April 2012, we have been piloting 24/7 community nursing services to support more choice and opportunity for care at home to meet palliative and end of life care needs. The model has included the extension of the evening shift to 9pm and a nurse based in Lerwick overnight who can be directed to provide nursing input on a planned or emergency care basis.

We are also in the process of looking at how we can implement anticipatory care plans for people with long term conditions who are not in a palliative or end of life phase, but who would benefit from regular surveillance and proactive support from the health and social care team.

Priorities set in 2009

- Develop different **community nursing models** that support people with life-limiting conditions in the **out of hours** period
- Understand how we could **work with the voluntary sector** to better support patients at home (e.g. Crossroads, Marie Curie Cancer Care)
- Introduce **Advanced or Anticipatory Care Planning** to facilitate discussions about place of death towards the end of life.

Current Position (2013)

- **Community nursing 27/4** model is currently being piloted.
- **ePCS is in place across 100% of localities** and other work is being taken forward to implement anticipatory care plans for other people with long term conditions.
- **Work continues with the voluntary sector** to build appropriate support systems of patients at home.

Going Forward (2013 - 2016)

- Further develop the 24/7 community nursing model to include 'hospital at home' and look at ways of utilising the nursing capacity as effectively as possible (e.g. activity is low but referrals to hospital for end of life care continue to happen which are not always driven by patient choice).
- Look at models with the voluntary sector for increasing the number of overnight carers or 'sitters' who can support families at home, which is complementary to the nursing, medical and social care package.
- Identify ways in which electronic records such as ePCS can be more readily shared in the out of hours period through the implementation of portal software which can be accessed in a variety of places, including the hospital.
- Look at ways of fully implementing the palliative care DES across primary care and sharing information about the number of people who receive care as per the DES which is based on the Gold Standards Framework.
- Develop clear protocols for palliative care planning to support health and social care staff to deliver care at home in a consistent way with clear access points into specialist care and advice as required.

7. Continued Learning

What we have achieved since the publication of the Palliative & End of Life Care Strategy in 2009

Addressing 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.

NHS Shetland recognises that generalist staff undertake the vast majority of palliative care in Shetland. Living and Dying Well (2008) provided a renewed focus and framework to put in place sustainable education and training for the mainly generic, multi-agency workforce in Shetland.

An original aim of the strategy was to develop a prioritised education plan that is flexible, sustainable and available to all staff across all care settings. The programme was to include refresher days, workshops, online learning and more formal courses where needed e.g. training to support chemotherapy.

In the last three years, successive training plans have been put in place to support staff to develop and maintain skills in palliative and end of life care. This has included training to support the implementation of the Liverpool Care Pathway and online training such as the NHS Education Scotland (NES) work based learning materials about palliative care in practice. In addition to this, additional training for community nurses is in the process of being rolled out to support more complex care in the community setting, thus promoting more choice of place of care. The training includes non medical prescribing, specific skills such as managing intravenous infusions and clinical assessment skills (so people changing symptoms and care needs can be reassessed immediately – right place, right clinician, and right time).

There is however, further work to do to assess specific training needs particularly 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. This will include further work to secure input from specialist services at NHS Grampian and a programme of educational opportunities that they will deliver in relation to specific topics.

Priorities set in 2009

- Undertake a **training needs analysis** across agencies for staff and volunteers who care for people with palliative and end of life care needs
- Develop **sustainable and accessible training** that is supported by palliative care specialists and meets the needs of all professionals working in primary and secondary care.

Current position (2013)

- A **sustainable and accessible training** plan is in place.
- Structured, individualised care planning (e.g. LCP) is being rolled out with appropriate training.
- Online training has been implemented.
- Specialist training and education is being sourced in conjunction with colleagues from NHS Grampian.

Going Forward (2013-16)

- Review training needs across health and social care staff (level 2-5 on the NHS Career Framework and equivalent for social care).
- Put appropriate training resources in place to meet those training needs – (focussing on staff at career framework levels 2-4).
- Ensure that there is at least an annual conference or workshop which meets the needs of senior nursing and medical staff, support by specialists from NHS Grampian.
- Develop specific training to support staff who work with people with dementia, including learning needs in relation to supporting palliative and end of life care.
- Bring all of the training resources together on the website, so they are easily accessible to health and social care staff.
- Improve access to the palliative care and end of life care resources available (e.g. pathways and guidelines) so they are available across agencies.
- Continue to prioritise skills development which supports long term conditions management and more complex care in the community 'e.g. hospital at home'.

8. Carer Support

What we have achieved since the publication of the Palliative & End of Life Care Strategy in 2009

People who care for someone with a life-limiting or terminal illness have to deal with many issues such as a sudden diagnosis may mean they take on a caring role with little time to consider what it involves. The condition of the person they are caring for will change overtime, and this is sometimes difficult to predict.

A review of the research evidence shows that carers' needs include "practical, financial, technical nursing assistance, etc, but the psychological and information needs are the most pressing"⁸.

Members of the public told us how important it was to have information about available services for patients and carers, including financial information, such as Direct Payments Support run by the Citizens Advice Bureau. This service is appropriate for people who qualify for community care services as it gives them

⁸ Harding R, Higginson IJ. What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Medicine* 2003; 17(1):63-74.14

greater control over all aspects of their care. We do not currently have one source of information that brings together services, equipment and resources.

Priorities set in 2009

- Develop a **carer's assessment tool** so that the needs of people who care for someone towards the end of life can be identified
- Understand the **support needs of carers** caring for people with life-limiting or life threatening conditions in Shetland and work in partnership with the voluntary sector to support carers to care for people at home
- Work with partners to further develop **respite services** in local communities
- Continue to assess **carers bereavement support needs**
- Develop **information** for carers, patients and staff about available services, equipment and resources

Current position (2013)

- A **carers assessment tool** has been developed and included in the single shared assessment document, known as Understanding You;
- A number of **new carers support groups and services** have been established with support from the voluntary sector including the Shetland Befriending Scheme, Alzheimer's Scotland and Chest Heart Stroke Scotland
- **Respite services** have recently been reviewed by Community Care services and a new strategy is under development which will set out how respite services will work along a more flexible model to enable rapid provision of respite for people who have palliative care needs (supporting alternatives to hospital and residential care);
- We have developed a **Bereavement Care Strategy** (published in 2013) which sets out how we will work together to support carers and families following the death of a loved one – which includes assessment of needs and services that are available;
- **Information materials** have been further developed and made available through health, social care and the voluntary sector services (e.g. Carers Group and Citizens Advice Bureau)

Going Forward (2013 - 2016)

A local survey of carer's views on access to services and being a carer, which was undertaken in 2013, corresponds with the results of the consultation to update the palliative care strategy in that there continues to be concerns raised about:

- Access to transport
- Access to respite
- Being heard
- Access to personal time

- Access to Care at Home

Whilst much work has taken place to develop resources and services which support carers, we know that there is further work to do, to consistently assess needs and signpost individuals to appropriate support services, particularly where carers and families are accessing input from healthcare teams (in hospital and the community). Many people do not perceive themselves as having a caring role and one of the key aims of the Carer's Group is to promote the support that is available.

Within the scope of this strategy we will focus on ensuring that carers needs are central to the development of palliative and end of life services. Furthermore, we will place particular emphasis on:

- Increasing the number of joint assessments of carers needs and monitoring how well we meet those needs
- Working with partners to provide support to carers, including respite and information
- Increasing the number of assessments of individuals needs in relation to bereavement care and monitoring how well we are meeting those needs
- Involving carers in the development of local services through voluntary sector representation on planning groups and the Public Participation Forum (PPF)

9. Care of the Dying Phase

What we have achieved since the publication of the Palliative & End of Life Care Strategy in 2009

As a person's life limiting condition progresses, the pace of change increases towards the end. Difficulty is sometimes experienced in recognising where we are in the patient's journey so that professionals can give appropriate care at that time.

The needs of the dying patient and his or her family are on many levels – physical, mental, social, emotional, and spiritual – and a multi disciplinary team best meets these.

Because of the complexity and the speed of what is happening at the end of a patients life, it is helpful to have a clear pathway, which gives direction to staff about the needs of the patient and family at different stages in the last days, and how these may best be met by the team.

In addition, policies should be in place which helps to support people to make choices about symptom control, future treatment, refusing treatment and how to give someone the legal right to make choices if they no longer have the capacity to make those decisions. We have focussed on implementing a range of policies and

pathways which support individuals during the 'dying phase' of their lives and the work we have done is summarised in the section below.

Priorities set in 2009

- Implement a localised **Integrated Care Pathway for the dying** based on the 'The Liverpool Care Pathway' for the Dying Patient' (LCP) which facilitates regular re-assessments towards the end of life
- Ensure that all professionals know how to access **equipment** for adults and children at the end of life and arrange for its delivery
- Develop the skills of professionals to recognise when a patient might be nearing the end of life
- Develop and implement a Do Not Attempt Cardio-pulmonary Resuscitation (**DNACPR**) Policy to support the process of making resuscitation decisions.

Current position (2013)

- A localised **Integrated Care Pathway for the dying** based on the 'The Liverpool Care Pathway' for the Dying Patient' (LCP) was introduced in 2011 and is monitored on a regular basis
- **Training has been put in place to support the LCP** and to ensure that there is a consistent approach when using the pathway and recognizing when someone might be nearing the end of life
- **Inventories of equipment have been put in place** so all professionals know how to access and arrange delivery of equipment
- The **national DNACPR Policy has been implemented**, with regular review of compliance with the DNACPR assessment process being undertaken by medical staff. Other policies with training for staff have also been implemented to support individuals to understand their rights and make decisions about their ongoing treatment e.g. through the Adults with Incapacity (Scotland) Act 2000 and the Resuscitation Planning Policy for Children and Young People (2010)
- There has been an **increase** in the number of Non Medical Prescribers (e.g. nurses and pharmacists) who **can independently prescribe medicines** making it easier and quicker to provide appropriate medicines for people with long term conditions or palliative care needs. Symptom control has also been improved through the availability of the 'Just in Case Boxes'

Going Forward (2013 - 2016)

- Continue to implement integrated approaches to support people who are in the dying phase of their life, including the LCP or other structured, individualised care plans as appropriate.
- Continue to implement systems to review and monitor the care standards set out in the integrated pathways so that improvement ideas can be identified

and implemented (e.g. quality of record keeping, undertaking case reviews in the primary care setting and the hospital, undertaking significant event analysis when needed, monitoring patient and family inclusion in care planning, monitoring the DNACPR assessment process etc).

- Implementing all of the other recommendations and principles in this strategy which come together to make a holistic plan to support people at the end of their life.

10. Palliative Care Performance Indicators

Palliative care performance indicators were published in 2013 by Healthcare Improvement Scotland, which provides a clear set of outcome measures for the provision of palliative and end of life care in Scotland.

The intention is that the data to demonstrate performance against these outcome measures will be taken from routinely available information already provided to Information Statistics Division (ISD) and the results will be represented to Health Boards to be included in the clinical governance arrangements and future planning of services.

The indicators are shown below and will form part of our local performance scorecard for palliative care and end of life care.

- Indicator 1: Increase in the number of people with palliative and end of life care needs who are identified
- Indicator 2: Increase in the number of people with palliative and end of life care needs who are assessed and have a care plan
- Indicator 3: Increase in the number of electronic palliative care summaries accessed
- Indicator 4: Place of death

11. Monitoring the Implementation of the Strategy

The strategy sets out the agreed aims across health, social care and voluntary services. As such, the action plan will be monitored through the CHCP Strategic Group and the assurance on the delivery of the strategy will be undertaken by the CHCP Committee.

The working group that has developed the strategy will continue to meet to bring stakeholders together to shape and support the progression of the action plan. The actions will be owned by the respective services (e.g. health, social care and voluntary sector partners).

The CHCP Strategic Group will receive a monitoring report twice a year and the action plan will be refreshed annually and received by the CHCP Committee.

The executive lead roles for all joint services will be reviewed as part of the work to develop closer partnership working and service integration. At the time of publication, the Executive Lead for Palliative and End of Life Care for the partnership is the Director of Nursing, Midwifery & AHPs.

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Appendix 1 – Actions Agreed to Support the Implementation of the Shetland Palliative & End of Life Care Strategy (13-16)

Topic	Action Required	Person Responsible	Status (Review Annually)
Communication	Audit the completion of palliative care and end of life care planning twice a year and present results to multi-agency groups and the clinical governance committee.	Assistant Director of Nursing (Community)	Audit completed in June 2013 – reported back to practitioners
Communication	Organise/facilitate training for staff in 'strengths based approaches' to support positive conversations about living with a life limiting condition and end of life care wishes/expectations	Assistant Director of Nursing (Community)	Strengths based approaches training delivered to community nurses and HV in April 2013.
Communication	Implement the Key Information Summary (KIS) system to enable electronic sharing of information about palliative care needs and other health requirements	Primary Care Manager	KIS system is 'live' in the Health Centres. Work planned to review palliative care plan quality and communications.
Communication	Deliver training to staff to promote person centred care e.g. Caring Behaviours Assurance System (CBAS)	Director of Nursing, Midwifery & AHPs	Training delivered in July & October 2013.
Communication	Extend the DNACPR audit into the community setting and review the results twice per year	Medical Director	To be progressed
Co-ordination	Increase the availability of 'hospital at home' care through the community nursing, GP and social care teams	Director of Community Care	To be progressed – will form part of the Reshaping Older Peoples Care Action Plan
Co-ordination	Develop a case management model across the community nursing team which focuses on people with long term conditions and includes a 'named practitioner' arrangement to promote continuity of care	Assistant Director of Nursing (Community)	To be progressed – will form part of the Reshaping Older Peoples Care Action Plan

Topic	Action Required	Person Responsible	Status (Review Annually)
Pain and symptom control	Work with community resilience initiatives to promote activities which reduce social isolation and promote psychological support for people living with long term conditions and palliative care needs	Health Improvement Manager	To be progressed
Pain and symptom control	Work across all agencies to ensure that there is access to appropriate spiritual care services, through faith groups, volunteers and statutory services	Director of Pharmacy (lead for spiritual care)	Spiritual care group established mid 2013 to review spiritual care provision across agencies.
Pain and symptom control	Develop a tailored programme of evidence based updates and education for specialist and generalist practitioners in conjunction with specialist services based in Aberdeen, through an annual conference/symposium	Medical Director Director of Nursing, Midwifery & AHPs	To be progressed
Continuity of care in and out of hours	Work with the voluntary sector as part of the Reshaping Older Peoples Care programme to look for opportunities to provide more overnight carers who can support families at home	Director of Community Care	To be progressed – will form part of the Reshaping Older Peoples Care Action Plan

Topic	Action Required	Person Responsible	Status (Review Annually)
Continuity of care in and out of hours	Identify ways of fully implementing the palliative care DES across primary care services (and evidence through the national performance indicators)	Director of Clinical Services	To be progressed
Continuity of care in and out of hours	Develop clear protocols for palliative care planning and support for social care staff so that care at home is delivered in a consistent manner	Director of Community Care	To be progressed
Continued learning	Review training needs for health and care staff (level 2-5 on the NHS Career Framework and equivalent for social care)	Director of Nursing, Midwifery & AHPs/Head of Staff Development	To be progressed
Continued learning	Put appropriate training resources in place for HCSWs and Social Care Workers as per the training needs analysis	Director of Nursing, Midwifery & AHPs/Head of Staff Development	To be progressed
Continued learning	Bring all of the policy, procedures, guidelines, protocols and learning resources together on one website so they are easily available to all agencies and the public	Director of Nursing, Midwifery & AHPs/Head of IT	To be progressed
Continued learning	Prioritise skills development to support self management, long term conditions management and more complex care in the community	Assistant Director of Nursing (Community)	To be progressed
Carers support	Implement the joint respite care strategy	Director of Community Care	To be progressed
Carers support	Implement the refreshed carers strategy	Director of Community Care	To be progressed

Topic	Action Required	Person Responsible	Status (Review Annually)
Carers support	Audit the completion of carers assessments and review how well these needs have been met with the CHP Operational Team	Chief Executive - VAS	In progress
Carers support	Audit the identification of bereavement support needs and review how well these needs have been met with the CHP Operational Team	Director of Community Care	To be progressed
Care of the dying	Roll out integrated approaches to support people who are in the dying phase of their life e.g. LCP in all care settings	Medical Director Director of Nursing, Midwifery & AHPs	In progress
Palliative care performance indicators	Undertake a scoping exercise to review the data currently available to evidence each of the performance indicators ahead of national reporting in 2014-15	Medical Director Director of Nursing, Midwifery & AHPs	To be progressed

Appendix B – Stock take of the Actions Completed Against the Shetland Palliative & End of Life Care Strategy (2009)

Topic	Action Required	Person Responsible	Status of the Actions in October 2013
Communication	Participate in the national roll out of the „ electronic Palliative Care Summary “ (ePCS).	Information Services & Primary Care Manager	Partially 9/10 Practices have ePCS in place. Work is ongoing to look at ways of sharing this information out of hours, across teams as required (under data sharing agreements).
Communication	Implement the Gold Standards Framework Shetland-wide ensuring that each GP practice has a Palliative Care Register	Palliative Care Nurse and Primary Care Manager	Partially All GP Practices have a palliative care register in place. Not all aspects of the Gold Standards Framework implemented/evidenced.
Co-ordination	Formalise how the co-ordinator role is determined and what the role entails including elements of planning and co-ordination of care and ensuring timely and relevant information is communicated to all other professional involved, particularly when a patient is transferred between care settings and between health boards.	ADN (C) & Palliative Care Nurse & Assistant Manager Community Care Resources	Completed Definitions are set out in the “With You For You”, single shared assessment procedure.
Control of Pain and Other Symptoms	Holistic care needs to be provided by a multi-professional team where there is a wide range of generalist skills. The core community team of GP, District Nurse and Social Care Worker may need to include others e.g. therapists and spiritual advisors, in order to respond to the needs of adults and children at the end of life.	Lead Cancer Nurse & Lay Representative Palliative Care Nurse & Chaplain Nurse Director & ADN (C) & Lay Representative	Completed Clear arrangements are in place to provide multi-disciplinary care. There has been input from spiritual advisors into local services and steering groups. There has been input from the voluntary sector into local services and steering groups. Good links are in place with specialist services for children and adults.

Topic	Action Required	Person Responsible	Status of the Actions in October 2013
Control of Pain and Other Symptoms	Develop spiritual care through the Board's soon to be appointed Chaplain so that professionals feel confident to support peoples spiritual needs towards the end of life	Lead Cancer Nurse & Lay Representative Palliative Care Nurse & Chaplain Nurse Director & ADN (C) & Lay Representative	Partially Chaplain was in post between 2010-12 (post vacant at present). Spiritual Care policy still requires updating. Links in place with local spiritual leaders. Staff are able to access online training which includes supporting peoples spiritual needs and other NES resources.
Control of Pain and Other Symptoms	Develop awareness of how to identify loneliness and isolation and work with others to develop different types of support for people who are lonely and isolated through the Shifting the Balance of Care Project	Lead Cancer Nurse & Lay Representative Palliative Care Nurse & Chaplain Nurse Director & ADN (C) & Lay Representative	Completed Voluntary sector are active in providing befriending programmes across Shetland. This includes a range of activities e.g. reminiscence, music, meals and other group/individual activities.
Control of Pain and Other Symptoms	Implement just in case boxes which can be left in an adult or child's home at the appropriate time, with drugs prescribed by the GPs and administered by members of the multi-professional team.	Nurse Director and Director of Clinical Services	Completed JICBs are in place across Shetland and are being actively used to support people at home by GPs and Nurses.
Control of Pain and Other Symptoms	There needs to be easy access to palliative care specialists who can provide advice and specialist interventions, to support teams and services on Shetland. All professionals need to know how to contact specialist services.	Nurse Director and Director of Clinical Services	Completed Good links in place with specialist palliative care services in Grampian. Multi-disciplinary meeting and training provided as well as advice regarding specific treatment plans.

Topic	Action Required	Person Responsible	Status of the Actions in October 2013
Continuity of Care in and out of hours	Develop different Community Nursing models that support people with life-limiting conditions in the out of hours period	ADN (C)	Completed 24/7 Community Nursing service is currently being piloted.
Continuity of Care in and out of hours	Understand how we could work with the voluntary sector to better support patients at home (e.g. Crossroads, Marie Curie Cancer Care, CLAN, Red Cross etc)	Nurse Director & Lead Cancer Nurse	Partially Ongoing work with the voluntary sector to look at ways in which we can support patients at home. Looking at specific projects which can be supported as part of the Reshaping Older Peoples Care plan.
Continuity of Care in and out of hours	Introduce Advanced or Anticipatory Care Planning to facilitate discussions about place of death towards the end of life	ADN (C)	Partially ACPs have started to be developed in small numbers (less than 150), including plans stored on the ePCS. A project is being devised to look at how ACPs can be rolled out across all localities.
Continued Learning	Undertake a training needs analysis across agencies for all staff who care for people with palliative and end of life care needs	Lead Cancer Nurse	Completed Training needs assessed on an annual basis and included in the Board training plan. Online resources are available via local palliative care website.

Topic	Action Required	Person Responsible	Status of the Actions in October 2013
Continued Learning	Develop sustainable and accessible training that is supported by palliative care specialists and meets the needs of all professionals working in primary and secondary care.	Lead Cancer Nurse	Completed Online resources are available via local palliative care website. Other training sessions facilitated by the Voluntary Sector and Palliative Care Specialists are organised as part of a rolling programme.
Carers Support	Develop a carer's assessment tool so that the needs of people who care for someone towards the end of life can be identified	Palliative Care Nurse	Completed Included in the WYFY, single shared assessment process.
Carers Support	Understand the support needs of carers caring for people with life-limiting or life threatening conditions in Shetland and work in partnership with the voluntary sector to support carers to care for people at home	Palliative Care Nurse	Completed Good links in place with the Carers Group and various services are in place to support carers through the voluntary sector. Provision of services to meet carers' needs are monitored as part of the WYFY assessment process.
Carers Support	Understand the support needs of carers caring for people with life-limiting or life threatening conditions in Shetland and work in partnership with the voluntary sector to support carers to care for people at home	Palliative Care Nurse	Completed Good links in place with the Carers Group and various services are in place to support carers through the voluntary sector. Provision of services to meet carers' needs are monitored as part of the WYFY assessment process.
Carers Support	Work with partners and in particular the local authority to develop respite services in local communities	Head of Community Care	Completed Review of respite services completed in 2012 along with the development of a Respite Strategy

Topic	Action Required	Person Responsible	Status of the Actions in October 2013
Carers Support	Continue to assess carers bereavement support needs	Palliative Care Nurse	Completed Liverpool Care Pathway in place. Multi-agency Shaping Bereavement Care group in place – which has developed a Bereavement Strategy, information resources, training and audited practice.
Carers Support	Develop information for carers, patients and staff about available services, equipment and resources	Palliative Care Nurse	Completed Information for carers is in place.
Care of the Dying Phase	Implement a localised Integrated Care Pathway for the dying based on The Liverpool Care Pathway for the Dying Patient (LCP) Ensure that all professionals know how to access and transport equipment for adults and children at the end of life Develop the skills of professionals to recognise when a patient might be nearing the end of life Develop and implement a DNAR Policy to support the process of making resuscitation decisions.	Lead Cancer Nurse Palliative Care Nurse/ AHP"s/ Community Staff Lead Cancer Nurse Resuscitation Committee	Partially LCP is currently being rolled out. Extensive staff training has been provided at the launch of the LCP A fast track discharge document setting out access to equipment and transport has been developed Training concerning the management of patients nearing end of life has been provided and continues to be available via specialist training sessions. National DNACPR policy implemented and monitored.

Abbreviations - ADN (C) = Assistant Director of Nursing (Communities), AHPs = Allied Health Professionals (i.e. therapists)

Appendix 3. Rapid Impact Checklist

<p>Which groups of the population do you think will be affected by this proposal?</p> <ul style="list-style-type: none"> • minority ethnic people (incl. gypsy/travellers, refugees & asylum seekers) ✓ • women and men ✓ • people in religious/faith groups ✓ • disabled people ✓ • older people, children and young people ✓ • lesbian, gay, bisexual and transgender people ✓ 		<p>Other groups:</p> <ul style="list-style-type: none"> • people of low income ✓ • people with mental health problems ✓ • homeless people ✓ • people involved in criminal justice system ✓ • staff ✓ <p>Voluntary Sector</p>
<p>N.B. The word proposal is used below as shorthand for any policy, procedure, strategy or proposal that might be assessed.</p>		<p>What positive and negative impacts do you think there may be?</p> <p>Which groups will be affected by these impacts?</p>
<p>What impact will the proposal have on lifestyles? For example, will the changes affect:</p> <ul style="list-style-type: none"> • Diet and nutrition? • Exercise and physical activity? • Substance use: tobacco, alcohol or drugs? • Risk taking behaviour? • Education and learning, or skills? 	<p>The Strategy will positively impact on the lifestyle of people at the end of life, by raising awareness, and delivering individualised care at the end of life. Specific initiatives such as the Liverpool Care Pathway will support this.</p>	
<p>Will the proposal have any impact on the social environment? Things that might be affected include</p> <ul style="list-style-type: none"> • Social status • Employment (paid or unpaid) • Social/family support • Stress • Income 	<p>The Strategy will positively impact on all groups as each of these areas will be identified with individuals and addressed. Specific initiatives such as working with the voluntary sector are included within the strategy.</p>	
<p>Will the proposal have any impact on</p> <ul style="list-style-type: none"> • Discrimination? • Equality of opportunity? • Relations between groups? 	<p>The Strategy aims to negate discrimination and promote equality by identifying all palliative care patients and treating them as individuals.</p>	
<p>Will the proposal have an impact on the physical environment? For example, will there be impacts on:</p> <ul style="list-style-type: none"> • Living conditions? • Working conditions? • Pollution or climate change? • Accidental injuries or public safety? • Transmission of infectious disease? 	<p>Living conditions for all groups should be positively impacted on as this strategy aims to support people to die in the place of their choice.</p>	
<p>Will the proposal affect access to and experience of services? For example,</p> <ul style="list-style-type: none"> • Health care • Transport • Social services • Housing services • Education 	<p>Yes, an enhanced response for people at their time of need for health care and social care. Certain client groups, eg children, patients with heart failure will have better symptom management and therefore continue to have access to education/housing/transport as appropriate to their level of ability and need.</p>	

Rapid Impact Checklist: Summary Sheet	
Positive Impacts (Note the groups affected)	Negative Impacts (Note the groups affected)
<p>Lifestyle – all groups through individual care.</p> <p>Social environment – all groups through individual care and specific initiatives with the Voluntary Sector.</p> <p>Aims to negate discrimination and promote equality by formally identifying all palliative care patients.</p> <p>Living conditions – positive impact for all groups.</p> <p>Enhanced access and experience of services for all groups.</p>	<p>NI</p>
Additional Information and Evidence Required	
<p>From the outcome of the RIC, have negative impacts been identified for race or other equality groups? Has a full EQIA process been recommended? If not, why not?</p> <p>No</p>	

Manager's Signature: Kathleen Carolan, Director NMAHPs