"No place for fatalism"

Third sector contributions to improving older people’s experiences of declining health, bereavement and death
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1 Executive Summary

Declining health, death and bereavement are central features of later life. Providing good care to people whose health is in irreversible decline or whose lives are coming to an inevitable close is an important outcome of Reshaping Care for Older People and one of the major responsibilities of the health and social care system.

This report looks at the ways in which the third sector in Scotland contributes to improving older people’s experiences of declining health, death and bereavement.

This work was undertaken as part of the wider Stitch in Time? project exploring the contributions of the third sector to the Reshaping Care for Older People (RCOP) agenda.

This report looks at the types of activities that third sector organisations undertake to improve older people’s experiences of bereavement, declining health and death in Scotland. Activities are categorised using the Stitch in Time model headings:

- Activities to reach people
- Activities to inform other services
- Activities and provision for older people and carers

The report draws on a range of examples of activities, setting these in the context of the outcomes they contribute towards. As well as providing some illustrative examples of outcomes from each area of activity, the report provides three detailed case studies, and draws on wider evidence showing the positive impact of palliative and end of life care on people’s experiences.
2 Background

2.1 A Stitch in Time?

The aim of the Stitch in Time? programme is to show the contributions of the third sector to the *Reshaping Care for Older People* (RCOP) agenda. So far, the focus has been on third sector interventions designed to maintain the independence and quality of life of older people and to prevent deterioration, decline and loss of function.

However, whilst decline and death can often be postponed, they remain inevitable. Therefore, no model focusing on older people’s care would be complete without a corresponding focus on third sector interventions designed to improve older people’s experiences of declining health, death and bereavement.

Optimising the quality of the end of life is an important outcome of *Reshaping Care for Older People* and one of the major responsibilities of the health and social care system. This is recognised in NHS Health Scotland’s *Optimising Older People’s Quality of Life Outcomes Framework* which identifies optimising quality of end of life as one of four long term national outcomes.

The third sector is making important contributions which enable older people to live well with serious illness/decline and to experience better death, dying and bereavement. This publication explores those contributions.

2.2 Scope of this report

This report looks in general terms at the ways in which the third sector contributes to improving older people’s experiences of declining health, death and bereavement, focusing on categories set out within the Stitch in Time? model:

- Activities to reach people
- Activities to inform other services
- Activities and provision for older people and carers

A new theme was also added, given the important role played by the third sector in generating money and support for research and services.

- Activities to generate and harness resources

The scope of this report had the potential to be huge – firstly because of the breadth of issues encompassed by the terms ‘decline, death and bereavement’, and secondly because of the sheer number of individuals and organisations making contributions in this field.
Therefore, the report does not attempt to list all activities, or illustrate all outcomes of third sector contributions to this field. Rather, it draws on a range of illustrative examples of activities, setting these in the context of the outcomes they are intended to achieve. Similarly, it gives some illustrative examples of outcomes from each area of activity.

It was outwith the focus of this report to focus on contributions relating to dementia and other neurological conditions, as these are addressed within other Stitch in Time reports.

2.3 Experiences of declining health, death and bereavement

2.3.1 Experiences

The experiences of decline, death and bereavement are a central feature of later life:

- Around 55,000 people die in Scotland each year, 70% of whom are over 70 years old.
- Death is frequently preceded by a period of declining health.
- Approximately 220,000 people are bereaved each year and older people are more likely to be bereaved than younger people.
- Between 2012 and 2035 the numbers of people dying are expected to increase by 17%.

2.3.2 Palliative Care

Caring for people as their health declines and a cure is not possible is called palliative care. Historically, “palliative care” has been associated with hospices and with cancer care. However, in reality, palliative care is much broader than this – when a health or social care professional delivers care without the prospect of a cure, they are providing palliative care. It is palliative care regardless of whether someone has cancer, organ failure or “old age”, or whether they’re living at home, in a hospice, in a care home or in a hospital.

Though more specific definitions can be helpful (see Appendix 2), one way of thinking about “palliative care” is to talk in terms of providing “good care” to people whose health is in irreversible decline or whose lives are coming to an inevitable close. Palliative care can and should be delivered alongside curative care where that is appropriate. There is a focus on the relief of pain and other distressing symptoms, on good communication with the individual and their family, on the person’s psychosocial and spiritual needs, and on helping the
individual to focus on what is most important to them given the limited time they have left.

Therefore, in Scotland, much of the care that older people receive when their health is in decline could be termed general palliative care, being provided by health and social care professionals to older people living in the community, in care homes and in hospitals:

- Around half of all deaths currently occur in hospital\textsuperscript{vi}
- 29% of acute hospital beds are used by people in their last year of life
- Nearly 1 in 10 patients in hospital will die during their current admission – and the vast majority of these patients are older people\textsuperscript{vii}
- 22% of people die in care homes
- The main causes of death are cancer, organ failure and frailty/dementia

\subsection*{2.3.3 Creating supportive cultures}

Conventional approaches to improving palliative and end of life care have focused on activities aimed at influencing the health and social care infrastructure, for example training staff, providing guidance, and introducing systems and processes designed to improve care.

This work is hugely important and the third sector plays an important role in this.

However, there is growing awareness\textsuperscript{viii} that people’s experiences of declining health, death and bereavement are only partially determined in their interaction with traditional formal services. The social and cultural environment is a key influence on people’s experiences as well as being a limiting factor in service improvement.

In Scotland we have a cultural reluctance to think and talk about decline, death, dying and bereavement. This reluctance operates at the individual, organisational and policy levels: policies and strategies for older people often fail to mention death, dying and bereavement; organisations providing services for older people often fail to acknowledge explicitly that they work with people for whom death may be imminent; individuals and/or their families are often reluctant to discuss preferences and to plan for end of life care.

It is recognised that promoting more openness about death, dying and bereavement can lead to:

- Policies which more adequately address this phase of life
- Services which are better aligned to meet people’s preferences for care towards the end of life
• Individuals and communities becoming more able to identify, build and harness skills, knowledge, networks, passions and resources to plan for and support each other with decline, death, dying and bereavement

More information about public health approaches, including international perspectives, can be found at [http://www.phpci.info/](http://www.phpci.info/).

### 2.4 Third sector organisations

The characteristics of third sector organisations working in this field mirror those featured in other Stitch in Time publications: they exhibit flexibility, responsiveness, innovation and are person-centred. These qualities are to be found in many of the examples of activity featured in this report.

Third sector organisations make diverse contributions to supporting older people in the final phases of life through a range of activities. They undertake many more activities than those mentioned within this report, and none have an exclusive focus on older people. However, declining health, death and bereavement affect far more older people than younger people, and so the bulk of the work the third sector does in this field is with "older people" (recognising that this is a broad term).

Organisations working in this field tend to fall into three categories:

- **Organisations with an exclusive focus on palliative and end of life care**

Some third sector organisations have an exclusive focus on palliative and end of life care. Good examples are Scotland’s twelve independent adult hospices, Marie Curie Cancer Care and the Scottish Partnership for Palliative Care.

- **Organisations with a focus on a specific medical condition**

Many third sector organisations focus on a specific medical condition, but include palliative and end of life care in their work. The scale and scope of their palliative care work varies greatly. For example all the work of an organisation like Motor Neurone Disease Scotland has a palliative care focus. For an organisation such as the British Heart Foundation palliative and end of life issues are just one part of a much wider portfolio.

- **Organisations with a focus on a specific issue**

Many third sector organisations focus on a specific issue, but encompass palliative and end of life care in their work. For example the Carer's Trust works to improve support, services and recognition for carers in communities across Scotland, and this includes providing support for people caring for someone approaching the end of life.
3 Activities to improve older people's experiences of bereavement, declining health and death

This and subsequent sections should be read alongside the logic model diagram in Appendix 1.

This section looks at the types of activities that third sector organisations undertake to improve older people’s experiences of bereavement, declining health and death. This includes

- Activities to reach people
- Activities to generate resources to support this work
- Activities to inform others’ services and
- Direct provision for older people and carers

Under each heading, key outcomes that come from these activities are identified. A few examples are given to illustrate how the activities contribute to the outcomes.

3.1 Activities to reach people

“If we are to reach people we need to take time to build referral pathways and to develop a relationship with potential referrers, users of our services and volunteers. This builds trust and willingness to use or contribute to our services” (Stitch in Time? model)

3.1.1 Outcomes

Third sector activities to reach people contribute to achieving the following outcomes:

- There is increased awareness of end of life issues
- More people plan for end of life/ or are able to make informed decisions
- Referrals between service providers in all sectors are improved

This leads to longer term outcomes around

- Talking about planning for decline, death and dying is perceived as normal and encouraged and supported within communities and families
- Families and communities are better equipped to help and support people in times of increased health need and decline
• Older people get the care and support they need from formal services and from their families and community

3.1.2 Public awareness raising activities

Many problems are caused because in Scotland we have a cultural reluctance to be open about decline, death and bereavement. Therefore, third sector work to engage and educate people in end of life issues is an important part of improving older people’s experiences.

The provision of public education on end of life issues supports older people to engage in joint decision making and planning with clinical professionals. Longer term, it also builds community and individual resilience to deal with the financial, emotional, practical, spiritual and medical challenges which come with death, dying and bereavement.

An example of activity in this area is Good Life, Good Death, Good Grief (GLGDGG) a charity-led alliance working to promote more openness about death, dying and bereavement.

Many of GLGDGG’s 200+ members are from the third sector, and contribute to its work to raise public awareness of ways of dealing with death, dying and bereavement, and promote community involvement in these areas. GLGDGG undertakes various national network activities to lead and support its membership, including:

• providing information and resources about public health and health promoting approaches to better death, dying & bereavement
• identifying & sharing good practice
• providing leadership, ideas, inspiration, practical tools & small grants
• generating media coverage/national dialogue
• influencing public policy

Example:

In November 2014, GLGDGG initiated To Absent Friends, a week of activities aimed at tackling the social isolation experienced by people who’ve been bereaved by creating a time when it is socially acceptable to share memories of dead loved ones. Third sector organisations across Scotland took part, and the initiative was successful in helping talking about death to be perceived as normal and encouraged and supported within communities and families. For example:
• People and organisations changed their profile pictures on Twitter and on Facebook to a picture of a dead loved one, including Parkinson’s UK and Marie Curie Scotland

• A "when someone dies" photo on Facebook went to 8.4K Facebook users, was shared 194 times, and was viewed by 15,112 people

• The Herald Saturday magazine featured a To Absent Friends photo competition run by Luminate: Scotland’s festival of creative ageing

The outcomes are also illustrated by feedback from members of the public:

“I saw this website through Facebook and have to say that I love what you are doing. My husband died 5 1/2 years ago and storytelling & remembrance for his friends, family and me is so important.”

“What a lovely initiative by @lifedeathgrief very respectful and touching.”

“It was so good having time to remember our loved ones while listening to some brilliant pieces of music.”

### 3.1.3 Activities marketing services

Third sector organisations help to reach older people who need support by:

• marketing their services to older people

• signposting and cross referring to other services thus extending the reach of others

• marketing their services to other providers to encourage referral

This supports the provision of a joined up experience for older people towards the end of life. For example, the Alzheimer’s Scotland website provides information and resources relating to dementia, and includes a search function to help people to find relevant local services.

**Example:**

NHS Inform is a public information website hosted and managed by NHS Scotland. It includes a section called the “palliative care zone” which provides information relating to palliative and end of life care. The information on the palliative care zone is updated by third sector organisation the Scottish Partnership for Palliative Care, working closely with Macmillan Cancer Support.

Between 1 November 2013 and 31 October 2014, 23,971 people accessed the palliative care zone, illustrating that the website has a key role to play in increasing public knowledge and awareness of end of life issues. Web traffic
statistics show that four of the top ten referral sources to the palliative care zone website are from third sector-supported sources\textsuperscript{1}.

### 3.2 Activities to generate and harness resources

#### 3.2.1 Outcomes

Though not an area explored within the *Stitch in Time?* model, the activities undertaken by third sector organisations to generate and harness resources to improve a range of outcomes for older people are worth a specific mention. These outcomes include:

- A significant number of volunteers actively contribute to providing services for older people approaching the end of life
- Individuals and families are supported by a wide range and type of services

#### 3.2.2 Fundraising

The fundraising activities of third sector organisations lever significant resource into the care and support of older people approaching the end of life:

- In 2006/7 £59m was spent on specialist palliative care in Scotland and nearly half of this resource came from the third sector\textsuperscript{ix}
- In 2013-14 twelve independent adult Scottish hospices\textsuperscript{x} raised nearly £42 million (excluding income from government sources). The same hospices spent nearly £54 million in the same period

*Example:*

The successful fundraising of organisations such as Multiple Sclerosis Society Scotland, Motor Neurone Disease Scotland, Parkinson’s UK and Macmillan Cancer Support has been instrumental in funding the spread of a range of clinical nurse specialists.

#### 3.2.3 Volunteers

#### 3.2.4 Activities involving volunteers

Many third sector organisations in this field are involved in volunteer recruitment. Volunteers play key roles in both fundraising and service delivery towards the end of life. Across the UK it is estimated that the average hospice

\textsuperscript{1} alzheimers.org.uk, palliativecarescotland.org.uk, strokeforcarers.org and the Scottish Palliative Care Guidelines website (co-ordinated at the time by the Scottish Partnership for Palliative Care.)
has 240 volunteers\textsuperscript{xi}. St Columba’s Hospice (which features as a case study in this report) has over 700 volunteers.

Many of those who volunteer for hospices are older people. Volunteering provides a sense of purpose, the satisfaction of continuing to make a contribution to one’s community, and the opportunity to pass on knowledge and skills. Volunteering also helps to create and support relationships and combats loneliness.

In a recent study of Scottish voluntary hospices\textsuperscript{xii}, 98% of respondents stated that they would be unable to provide current services without volunteers. Findings suggested that volunteers:

- Are integral to professional team
- Are crucial to the quality and range of services
- Are important to care of patients
- Are important to the support of families
- Contribute significantly to financial success
- Play a key role in income generation
- Make services viable

\textit{Example:}

One example of the huge contribution that the third sector makes to volunteer engagement, recruitment and training, and the positive effects this has on outcomes for older people, is a joint project recently undertaken by Strathcarron Hospice and St Andrew’s Hospice. The project aimed to recruit, train and support volunteers to enable them to provide support to individuals and their carers facing the end of life. The volunteers received training on managing difficult conversations, moving and handling, dementia awareness and hand and foot massage. 31 volunteers have completed the training so far.

In the first six months of the project a total of 134 referrals were received from various sources. Reasons given for referral were often non-specific, identifying a need for emotional and social support. 37% of referrals related to befriending/reducing isolation. 45% related to carer respite/support, and 25% related to complimentary therapy. Outcomes from the project are illustrated by patient and carer feedback, for example:

"These couple of hours a week recharge my batteries." (Carer of a 71 year old man with cancer)

"I feel part of the human race again." (Housebound lady with progressive illness)
3.3. **Activities to inform other services**

“Some third sector organisations use their expertise and knowledge of a particular client group or community to influence the policy and practice of other organisations (statutory and non-statutory). They also enable those groups and communities to have a voice and shape services.” *(Stitch in Time? model)*

3.3.1 **Outcomes**

The third sector undertakes many activities to inform other services, influencing a range of outcomes:

- Organisational cultures are supportive of staff working with dying people
- Policies and services better reflect the needs and wishes of older people towards the end of life

This leads to longer term system changes around

- Care staff are more responsive to people’s psychological, social, practical and spiritual needs relating to decline, death, dying and bereavement
- People have more opportunities to discuss and plan for their decline and death
- Older people get the care and support they need from formal services, family and community
- More people have anticipatory care plans created in primary care and shared across health settings
- There are fewer inappropriate hospital admissions and more people are cared for and die in a place of their own choice

3.3.2 **Training and education activities**

Scotland’s hospices are very active in providing education and training in palliative and end of life care for staff working for local authorities, NHS Scotland, care homes and other independent providers. For example:

- The Care Commission identified that hospices are the major single provider of palliative and end of life education to the independent care sector\[xiii\]
- Macmillan Cancer Support run extensive educational programmes
- Many condition specific organisations such as Parkinson’s UK and Alzheimer Scotland run training and education programmes and provide
information for health and care professions, which include end of life care in their scope

Many third sector organisations have important links to further and higher education. Many hospices have very productive collaborations with colleges and universities which deliver benefits for old people through the contributions their staff make to research and to the training of professionals.

*Example:*

Accord Hospice designed and delivered a series of specific education sessions aimed at carers working in care homes. After the training, participants expressed increased confidence in their knowledge of palliative care. As a result discussions took place with Renfrewshire Community Health Partnership (CHP) and Renfrewshire Council to consider a collaborative approach to delivering a palliative care training programme for the social care home care service. The initial project is now complete with 205 members of staff from Renfrewshire Council Home Care Service attending a palliative care training day at Accord Hospice over a 12 month period. Early findings from the project show that this collaborative and practical approach has been an effective model of training delivery for this group of staff. Home carers now have more knowledge of practical palliative care issues and have had the chance to enhance their communication skills. Some comments from participants:

"More confident to move someone with a syringe driver."

"This has changed the way I think about things - for the better!"

"Be inclined to listen more and not jump in with my solutions."

"I am now not so scared to go into someone who is very ill."

"Communication session was very helpful - really want to try it!"

As a result of third-sector led education and training activities such as these, the NHS, care homes and other independent providers are better equipped to provide care towards the end of life.

### 3.3.3 Public engagement, advocacy and research activities

Third sector organisations play an important role in enabling public engagement to inform the development and design of services and policy relating to end of life. For example, Marie Curie Cancer Care supports an Expert Voices group of carers for this purpose. A major project\textsuperscript{xiv} to identify the palliative care needs of people with non-malignant disease was led by the Scottish Partnership for Palliative Care with the support of Alzheimer Scotland, British Heart Foundation, British Lung Foundation, Cystic Fibrosis Trust, Multiple Sclerosis Society
Scotland, Muscular Dystrophy Campaign, Parkinson’s Disease Society, Scottish Kidney Federation, Motor Neurone Disease Scotland, Marie Curie Cancer Care and Waverley Care Trust (HIV/AIDS). The report remains influential on national policy and local practice.

A key part of the Scottish Partnership for Palliative Care’s work is to support and contribute to the development and strategic direction of palliative care in Scotland. It undertakes policy analysis, responds to relevant consultations, and produces a monthly digest of good practice, research, policy and practice which is widely disseminated.

Macmillan Cancer Support and Marie Curie Cancer Care are active in advocacy and lobbying for better end of life care. Both these organisations also work in partnership with the statutory sector to support service redesign processes.

The British Heart Foundation has been working in partnership with Marie Curie Cancer Care and NHS Greater Glasgow and Clyde to develop and evaluate new models of care for people with heart failure who are approaching the end of their lives.

Third sector organisations play an important role in building the evidence base for palliative and end of life care through research activities. For example:

- Marie Curie Cancer Care has a major research funding programme
- Multiple Sclerosis Society Scotland funds clinical research including research into symptom management
- Parkinson’s UK has an extensive research portfolio which includes research into quality of life and people’s experiences in care homes

As well as funding research, third sector organisations are also involved in recruiting to studies and disseminating findings. A collaboration led by Marie Curie Cancer Care recently identified what patients and carers see as the priorities for future research relating to end of life care.xv

Example:

In late 2013, Nanette Milne MSP initiated a debate on palliative care in the Scottish Parliament. This debate was prompted by the publication of researchxvi which asked the question How good is primary care at identifying patients who need palliative care? Published in the European Journal of Palliative Care, the paper is the result of a study led by Professor Scott Murray (St Columba’s Hospice Chair of Primary Palliative Care) and Dr Lilin Zheng at the University of Edinburgh in collaboration with representatives from Marie Curie Cancer Care and NHS Lothian.
Much of the publicity the research article received was due to the efforts of Marie Curie Cancer Care, and all of this was helpful in drawing attention to the need to identify people living in the community who are in need of palliative care in order that those needs can be met, and in highlighting that palliative care should be available to people on the basis of need not diagnosis.

This is an example of how third sector led research and advocacy work has an impact on enabling policies and services to better reflect the needs and wishes of older people towards the end of life.

### 3.4 Activities and provision for older people and carers

"The sector provides a wide range of activities, including some which can also be provided by other sectors." (Stitch in Time? model)

#### 3.4.1 Outcomes

The third sector undertakes a range of activities that work towards the following broad outcomes:

- **Staying positive and in control**
  - Older people and carers are more confident and able to make plans
  - Older people and carers maintain confidence and self-esteem as health declines

- **A more age friendly environment where**
  - Talking about death and dying is normal
  - People are better equipped to help and support older people in times of increased health need and declining health
  - Older people get the care and support they need from formal services, family and community
  - People have the information they need to make informed decisions

#### 3.4.2 Service provision

The third sector is an important provider of care home and care at home services for older people. 6% (110) of Scotland’s care homes for older people are provided by third sector organisations. Many of these services, particularly as eligibility criteria are tightened, are delivered to older people approaching the end of life - the median complete length of stay in a care home for older people is around 17 months xvii.
As well as care homes and care at home Crossreach provides dementia care, respite care, housing support, day care and community based creative arts projects. Day services provided by third sector organisations can have hugely beneficial effects on older people, including promoting physical activity and general wellbeing, enabling regular social contact, providing an early-warning system in the event of problems arising, and providing respite for carers.

Leuchie House is a provider of respite specialising in a service for people with advanced neurological disease and other long term conditions.

Scotland’s fourteen adult hospices are major providers of specialist palliative care services through inpatient, day care and community services:

- In 2006/7 the majority of specialist palliative care beds (250 beds) and 72% of day care places were provided by voluntary hospices
- Hospices provide specialist palliative care services through inpatient, day care and community services
- Much of the care provided by hospices takes place in the community through “hospice at home” and community nursing services
- Hospices also provide a range of care and interventions including physiotherapy, occupational therapy, complementary therapies, art therapy, music therapy, spiritual care, family support, counselling, support for end of life planning, carer support, bereavement support and general advice and information services

Other third sector organisations also provide services. For example CRUSE Bereavement Care Scotland provides bereavement information, support and counselling. Macmillan Cancer Support provides a wide range of information and support services, as well as financial grants.

Clinical nurse specialist roles funded by the third sector play a vital role in co-ordinating care and support and providing hands on care towards the end of life.

**Example:**

Ardgowan Hospice runs a drop in and day support service called Access @ Ardgowan. Access aims to provide a supportive, caring and friendly environment that focuses on the Hospice being informative and reassuring for those people coming to terms with the diagnosis of a life limiting illness, which can be frightening, confusing and overwhelming for individuals and their families.

The services provided include peer support groups, relaxation groups, breathlessness management, drop in, 1/1 sessions, bereavement support, complimentary therapies, day support and rehabilitation. The services are nurse-led with a support team of key workers and complimentary therapists.
Evaluations of this service show that it has a genuine impact on outcomes for individuals:

“Look forward to my days in ACCESS, helps me cope with things”.

“No regrets, feel I have a quality of life. Get frustrated at times, but in perspective I’m not in pain. Know the support is there. Talking and therapies help.”

“Overall the hospice has been a great support to myself and my family and I am so grateful for everything.”
4 Evidence

4.1 Describing outcomes

Section 3 sets out just a few examples of where attempts have been made to quantify the outcomes of third sector work in this field. As illustrated in Appendix 1, the short and medium term outcomes outlined above in turn influence longer term outcomes:

- More older people live well as their health declines
- More older people "die well"
- Quality of end of life care is optimised

Capturing and evidencing outcomes is always a challenge. However strong the logical constructs of cause and effect appear to be, it is difficult to prove that activities such as awareness raising, public engagement, advocacy and information provision have a specific positive effect on the unique individual experiences of older people and their families. There are also particular challenges in evidencing outcomes towards the end of life, when relational and spiritual concerns are often of particular importance.

An alternative way of thinking about outcomes of third sector activities is to imagine the gaps that would be created if all third sector work in this field suddenly ceased. Imagine a world without:

- Voluntary hospices providing specialist palliative care, advice, therapies and day care
- Marie Curie, Macmillan\textsuperscript{2} and hospice specialist nurses providing end of life care to people in their own homes
- Charity services, advocacy, support and public information
- Volunteers raising money and helping out with services
- Third sector/volunteer- run informal community support
- Free bereavement services provided by Cruse Bereavement Care and voluntary hospices
- Charity-led and charity-funded research

\textsuperscript{2} Macmillan nurses are usually employed by the NHS and their posts are funded by Macmillan for a set time, often for the first three years.
Training and education resources developed and provided by the third sector

4.2 Key evidence relating to the impact of palliative and end of life care

This section summarises some of the key evidence available on the impact of palliative and end of life care. Though not all of it was gathered specifically in relation to older people’s experiences, or specifically in relation to third sector activities, this evidence is relevant to building an understanding of the potential impact of third sector activities in this area.

4.2.1 Quality of care in third sector settings

There is evidence that the quality of care in hospices (as rated by bereaved relatives in a major survey across England) is higher than that in other settings, for all causes of death\(^\text{xix}\).

4.2.2 Advance care and anticipatory care planning

Anticipatory care planning has been found to produce statistically significant reductions in unplanned hospitalisation for a cohort of patients with multiple morbidities\(^\text{xx}\). The study also concluded that this “demonstrates the potential for providing better care for patients as well as better value for health and social care services. It is of particular benefit in managing end-of-life care.”

4.2.3 Identification of people with palliative care needs

Early identification of people who need palliative care is important in ensuring that people get the care they need at the right time. A recent study\(^\text{xxi}\) found that most non-cancer patients were identified as requiring palliative care too late to fully benefit – on average only eight weeks before dying. A palliative care approach should be used as appropriate alongside active disease management from an early stage in a disease process\(^\text{xxii}\). There is one study which suggests that early access to palliative care can extend life as well as improving quality of life\(^\text{xxiii}\).

4.2.4 Community palliative care

There is evaluation evidence to suggest that home-based nursing services (for example as provided by Marie Curie Cancer Care) help more people to die at home (in line with their preferences) and reduces hospital use and costs at the end of life\(^\text{xxiv}\).
4.2.5 Preferred place of death

Whilst on average people say they wish to die at home this may be less true for some groups than others, including older people\textsuperscript{xxv xxvi}.

4.2.6 Impact of third sector support of care homes

There is evidence to support improved outcomes for older people as a result of third sector interventions to build and sustain the skills, confidence and knowledge of care home staff\textsuperscript{xxvii}.

4.2.7 British attitudes towards death and dying

There is evidence from the British Social Attitudes Survey about public beliefs, attitudes, preferences and behaviours around end of life issues. Sub-analysis of Scottish data shows findings consistent with the UK picture. Few people have discussed and planned for end of life issues, including a significant proportion of people aged 75+\textsuperscript{xxviii}.

4.3 Case studies

This section provides three case studies exploring the impact of specific activities undertaken by third sector organisations working to improve older people’s experiences of declining health, death or bereavement.

4.3.1 Leuchie House

http://leuchiehouse.org.uk/

Background

Leuchie House provides person centred short breaks for people with long term conditions and their partners. Many guests at Leuchie have advanced neurological conditions, complex needs and are older people. Leuchie provides person centred care which integrates social care and health care in a single service which is responsive to individual preference, supports carers, anticipates and assesses needs often preventing crisis.

Enhancing quality of life even with advanced disease

The role of respite care in enhancing quality of life, preventing carer crisis and costly hospital admission is well established. As a respite care provider Leuchie House is unusual and innovative in two key ways.

Firstly, Leuchie provides the opportunity for the carer’s guest to stay too and enjoy the break, whilst carer duties are taken on by the staff team. This, combined with an elegant non-institutional setting and ethos, affords people an
opportunity to experience a holiday together. This is a basic thing which many of us take for granted but which can be difficult to achieve for people with advanced neurological disease. Carers often worry about the quality of care provided when they leave the person they care for. The Leuchie model provides reassurance for the carer – they can witness the excellent care – and this makes the break even more restorative. Secondly, Leuchie is unusual in having staff with the knowledge and skills to meet the complex needs of this group of guests. Historically NHS acute and rehabilitation services may have afforded periods of respite for people with high support needs but this is no longer the case (and care homes for the elderly do not generally have the requisite skills and staffing levels required to provide high quality care).

Leuchie House provides 600 short breaks a year along with additional day respite services. Since its launch as an independent charity a little over 3 years ago Leuchie House has provided nearly 22,000 respite days. Had this respite been provided in an NHS step-down bed, estimated at £3k per week, the cost to the NHS would have been in the region of £9m and more if acute provision is taken into account.

Every guest at Leuchie has a full assessment and access to physiotherapy and other services. Every guest is weighed and monitored over the period of the break. In addition every guest is seen by a physiotherapist, a wheelchair assessment is carried out and repairs are done if necessary. Postural alignment training is given and for 24/7 for the time they are at Leuchie House all physical and emotional requirements are assessed. Weighing, wheelchair assessments and repairs are extremely difficult and time consuming to do for local NHS services. Anecdotally a wheelchair assessment can cost in the region of £120 and this is not including repairs or the time involved with travelling and having staff for hoisting. In 2014 Leuchie carried out in excess of 270 full wheelchair assessments and repairs, saving the NHS at least £30k, excluding travelling time.

Joining up the health and care system through assessment and cross referral

Assessments made during the short break often result in onward referral to NHS and local authority services. Referrals are routinely made to district nursing, general practice, dietetics, social work and wheelchair services. In 2014 there were 693 such referrals. These referrals and advocacy input improve access to those services. Without the assessments by Leuchie House the issues requiring referral would either not have been picked up, or would have been picked up at a later stage, with lost opportunity for anticipatory, preventative or early stage intervention.

What people affected by long term conditions and their carers say about Leuchie House

Leuchie carries out evaluations with every guest and carer. Below are some comments received in one month during 2014:
Guest Comments:

“I give the staff 10/10 — nothing is too much trouble. Incredible shepherd's pie! Justine (physio) — cannot praise her enough, she has saved my life and cleared my chest.”

“I just love it here!!! I can’t get enough of the physio!”

“Leuchie is Scotland's best-kept secret.”

Carer Comments:

“Very pleased with the professionalism of the staff, John well catered for.”

“Extremely likely to recommend Leuchie due to the professionalism of the staff — they are friendly and approachable and John looked happy and content.”

“Staff look after my husband — he always looks rested and relaxed when he comes home.”

Inputs levered by Leuchie House

The work of Leuchie House is supported and enabled by a busy team of locally recruited volunteers. Since its inception in July 2011 Leuchie House has raised £1.5 million from charitable sources. In addition Leuchie House is a significant local employer securing 80 jobs and playing a role in the training and development of local young people. Leuchie regularly hosts student nurses and staff of other organisations who come to learn about and develop skills relevant to the care of people with advanced neurological conditions.

4.3.2 Marie Curie Cancer Care

www.mariecurie.org.uk

Marie Curie is a major charity providing care to people with a terminal illness in their own homes or in their two hospices in Scotland. Marie Curie’s ethos is listen to people living with terminal illness and their families about their experiences, what their life is like and what care and support they want to help them through difficult times.

Marie Curie nurses provide patients and their families with free hands-on care and emotional support at home, right until the end. In Scotland Marie Curie runs hospices in Edinburgh and Glasgow, which provide free specialist medical care for those with a terminal illness, and emotional support for their families, giving them the best possible quality of life. Last year, in Scotland Marie Curie
supported nearly 5,000 patients with its nursing service and over 2,000 patients through its Scottish hospices.

Many of Marie Curie’s services work in an integrated way with local NHS Boards and councils as well as other local partners. Below are two examples of such services; our out of hours service in Forth Valley and its fast track service in North Glasgow.

In NHS Forth Valley, the Marie Curie service is now operating as part of the Out of Hours nursing team based in Forth Valley Royal Hospital, and working as a complement to the existing team. It helps provide weekend and evening support enabling a more effective coverage and further consistency as part of the out of hours partnership. The service is now supporting District Nurses as well as care homes and community hospitals across Falkirk CHP. To date it has supported over 490 patients in Falkirk CHP, achieving up to 97% preferred place of death / actual place of death in 2014/15. The lead nurse for out of hours is looking to further develop the work of the team in out of hours, with greater relationships with front door services at Forth Valley Royal, and the community settings.

The fast-track discharge service in North Glasgow is a partnership between Marie Curie, NHS Greater Glasgow and Clyde and other local providers which has been jointly funded by Marie Curie and Reshaping Care for Older People Change Fund. It has assisted almost 700 people with palliative care needs between February 2012 and September 2014. It was shortlisted for the prestigious Health Service Journal Care Integration Awards 2013.

The fast-track discharge services in North Glasgow help terminally ill people spend their final weeks at home rather than in hospital or a hospice. The services facilitate patients’ safe and timely discharge from hospice or hospital to their homes, as well as providing a short package of care post-discharge.

In Glasgow, the fast-track discharge liaison nurses are based at the Marie Curie Hospice, Glasgow. They assess the patient’s care needs, make discharge arrangements and organise support for the period immediately after discharge.

A team of senior Marie Curie health and personal care assistants are also available to support patients for up to three days. Additionally, the service takes referrals to prevent avoidable admissions of patients with palliative care needs to hospital or hospice.

In 2013/14, 210 patients were discharged from Glasgow hospitals and the Marie Curie Hospice, Glasgow and 99 admissions were prevented.

4.3.3 St Columba’s Hospice

http://www.stcolumbashospice.org.uk/

St Columba’s mission is to improve the quality of life for people with progressive, far advanced disease and to provide support for their families.

St Columba’s care is based on need and not diagnosis and, whilst we work with adults of all ages, in practice the average age of our patients is around 70. As people are living longer with their illnesses, an important part of St Columba’s
work is in ensuring that its patients have the best quality of life possible for as long as possible. St Columba’s takes a multidisciplinary team approach to caring for its patients, and work hard to support them to live independently with their illnesses for as long as possible.

St Columba’s Hospice first opened its doors in 1977, with just three months’ running costs and 15 beds. It has since developed and expanded to provide a modern, comprehensive range of services for people in Edinburgh and the Lothians. Following a successful £26million Rebuild Campaign, the Hospice moved from its temporary base back home to 15 Boswall Road, overlooking the Firth of Forth, in May 2014.

St Columba’s has a 30 bed inpatient unit which admits 450-500 patients every year. Patients are admitted for management of specific symptoms, assessment of complex needs and care at end of life. As well as care for the patient St Columba’s support family and friends at a very difficult time and offer an open visiting policy to allow family and friends to be with the patient when they need to be.

St Columba’s have a nurse-led Day Hospice service which provides holistic care and symptom management three days a week for up to 15 patients each day. These are patients who are still able to be at home, but need support with pain, symptom management and psychosocial issues. Staff talk to patients, families and carers about their wishes for care as their disease progresses and support them with the choices that they make. Referrals come from the hospice multidisciplinary team, GPs, district nurses and clinical nurse specialists.

The hospice also have a Community Team of six palliative care nurse specialists who complete over 3,000 visits each year to patients in their homes in North Edinburgh. The team support patients and families with specialist palliative care needs (symptoms, psychological support and advice) in their home and work closely with primary care teams.

St Columba’s new outpatient department is allowing the development of an outpatient service which will enable patients to see members of its clinical team without the need for admission to the inpatient unit or to other clinical services.

There are over 150 staff at the hospice, all of whom provide essential medical, clinical and support services to ensure the smooth running of the Hospice. The multidisciplinary team consists of physiotherapists, occupational therapists, counsellor, social worker, chaplain, pharmacy team and complementary therapists, and the hospice’s Education Centre runs a programme of in-service education and practice development for its own staff and volunteers, delivering a wide range of multidisciplinary courses in partnership with local universities.
St Columba’s Hospice also has over 700 volunteers who support all aspects of its services to patients and families. Volunteer drivers bring patients to and from the Day Hospice. Volunteers greet visitors at reception, top up water jugs, and spend time with the patients. Volunteers organise social activities such as arts and crafts in the Day Hospice and serve in the café and shops. Volunteer chaplains, counsellors and complementary therapists support the psychological and spiritual wellbeing of patients and families, whose emotional wellbeing is also of paramount importance.

**Bereavement Counselling**

The Counsellor’s role in the hospice is to offer psychological and emotional support to patients, families and carers. This includes the Inpatient Unit, Day Hospice and community. Each patient and family go through a unique transition from diagnosis to the patient’s end of life - they face and experience many internal and external stresses, which can present as a mixture of emotions like depression, anxiety, anger and fear. Having someone to talk to and be listened to may not change the situation, but it can help put thoughts and feelings into perspective and offer strategies to enable both patients and families to cope and deal with their situation.

**Chaplaincy Service**

The chaplaincy team provide spiritual care, available to all, whether they have a religious faith or none. The chaplaincy team’s role is about being with people as a fellow human being – in conversation (and indeed in silence) – and to be open to what emerges. Spiritual care is a crucial part of the hospice’s multidisciplinary approach to care.

**Physiotherapy/Occupational Health Team**

Physiotherapy is available to all patients under the care of St Columba’s Hospice at any stage in their illness. People with progressive illnesses often feel they are not able to do all the activities they used to and the hospice aims to help people to move around and stay as active and independent as possible. The team can teach techniques to make symptoms like breathlessness and fatigue more manageable, provide guidance on appropriate types of exercise and work on specific things like strength and balance.

Occupational therapy is also available to all patients and provides practical support to enable people to overcome physical and psychological
difficulties that prevent them from doing the activities that matter to them. This can include assessing their home environment to ensure patients are enabled to stay in their own homes, assessing for carer support and arranging equipment to aid everyday tasks.

Social Work

The hospice’s social worker works collaboratively with members of the multidisciplinary team to assess and address the psychological, practical and social needs of patients and of their families and carers. She works in partnership with other multidisciplinary team members and patients and their carers to enable them to make informed choices and provide advice and information on financial issues and discharge planning.

Complementary Therapies

Complementary therapy is an integral part of the holistic multidisciplinary care offered to patients and their loved ones at St Columba’s. A comprehensive range of massage therapies, including therapeutic massage, reflexology, reiki, Indian head massage and craniosacral therapy is offered. These can help to relieve stress, aid relaxation, promote a sense of wellbeing and help develop coping skills. The therapies are provided free of charge by a team of six complementary therapists, each trained in massage techniques appropriate for palliative care.

Education

St Columba’s Education Department has provided an extensive educational resource to Lothian, and beyond, for many years. As well as in-hospice education and practice development role, they also provide a variety of multidisciplinary courses and modules at certificate and Masters level. Staff working in a variety of hospital, community and care home locations benefit from studying and take their palliative care learning back to benefit their own patients.
Appendix 1: Logic model

Key providers
- Care homes
- Home care providers
- Independent hospices
- Macmillan Cancer Support
- Marie Curie Cancer Care
- Other health care providers e.g.
  - Alzheimer’s Scotland
  - British Heart Foundation
  - British Lung Foundation
  - Cystic Fibrosis Trust
  - Multiple Sclerosis Society
  - Scottish Kidney Federation
  - Motor neurone Disease Scotland
  - Waverly Care Trust
  - Independent sector care providers

Activities to reach people
- Public awareness/education on end of life issues
- Marketing of third sector services
- Other service providers

Activities to generate resources
- Volunteer recruitment and training
- Fundraising activities

Activities to inform others’ services
- Training/education
- Advocacy and information sharing based on research, development, evidence gathering and policy analysis

Activities and provision for older people and carers
- Increased awareness of end of life issues
- More people plan for end of life
- Referrals between service providers in all sectors are improved

Medium term outcomes for older people and carers
- Advice and information service (talks, leaflets, enquiries, signposting, advocacy)
- More ready and able volunteers
- Able to deliver a wider range of services/research

Long term outcomes
- Staying positive and in control
  - Older people and carers are:
    - Are more confident, able and willing to plan and make informed choices about their care as health declines
    - Older people and carers are supported by their families and communities to maintain their confidence and sense of self-worth as their health declines
- Physical and social environment is age friendly
  - Talking about plans for decline, death and dying is normal and encouraged
  - Families are better equipped to help and support older people in times of increased health need and decline

Go to assumptions on page 10
Go to external factors on page 11
Appendix 2: Definitions

Palliative care

Palliative care is the term used to describe the care that is given when cure is not possible. The word comes from the Latin “palliates” (covered or hidden with a cloak) and is used to mean “relieving without curing”.

Palliative and end of life care are integral aspects of the care delivered by any health or social care professional to those living with and dying from any advanced, progressive or incurable condition. Palliative care is not just about care in the last months, days and hours of a person's life, but about ensuring quality of life for both patients and families at every stage of the disease process from diagnosis onwards. A palliative care approach should be used as appropriate alongside active disease management from an early stage in the disease process. 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 patients and carers facing progressive illness and bereavement.

The World Health Organisation (WHO) defines palliative care thus:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, 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. Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient’s illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”
Specialist palliative care

Specialist Palliative Care focuses on people with complex palliative care needs (e.g. complex pain management or psychological support) and is provided by a team of professionals who specialise in palliative care (e.g. consultants in palliative medicine and clinical nurse specialists in palliative care).

General palliative care

General palliative care forms part of the routine care of patients and support for carers. It may be part of the work of a range of health and social care practitioners including GPs, district nurses, care assistants and hospital staff.

Common misconceptions and confusions about palliative care

Palliative care is not just terminal care, and also is not just care for people with cancer and is mostly provided by people and services which are not called “palliative care”.

The phrase “access to palliative care” can cause confusion. Most palliative care is not specialist palliative care and is not provided by specific services branded “palliative care”. Whether or not someone is able to “access palliative care” is likely to depend on factors such as whether their particular GP is comfortable and confident to initiate conversations exploring end of life care issues and whether the team on a particular hospital ward to which a person is admitted happen to have the relevant skills, knowledge, attitudes and behaviours to support someone approaching the end of their life.

End of life care

Palliative care includes, but is not exclusively about, end of life care. End of life care is that part of palliative care which should follow from the diagnosis of a patient entering the process of dying, whether or not he or she is already in receipt of palliative care. There can be uncertainty involved in identifying when someone is dying – illness can be unpredictable, and change can occur suddenly and unexpectedly. The term “end of life care” is used by different people to mean different things, since this phase could vary between months, weeks, days or hours in the context of different disease trajectories.

Within this report the phrase “end of life” is used to mean “when the team caring for the person agree that death is expected within hours to days and a natural death is occurring with all possible reversible causes having been considered”.

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Appendix 3: References


iii General Register Office for Scotland: Table 5.4: Deaths, by sex, age, and ethnic group, Scotland, 2012 http://www.gro-scotland.gov.uk/statistics/theme/vital-events/general/ref-tables/2012/section-5-deaths.html

iv A figure often used by the Grief and Bereavement Hub, which estimates the number of people bereaved by multiplying the number of people dying by 4.


x Figures exclude the 2 Marie Curie hospices


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http://www.nuffieldtrust.org.uk/publications/marie-curie-nursing
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A Stitch in Time? is a partnership project to support the third sector to collect and present evidence about its contribution to Reshaping Care for Older People (RCOP). The programme runs from April 2013 to March 2015 and focuses on third sector organisations working with older people and carers in Lothian.

**A Stitch in Time? publications**

- A model to explain the third sector contribution to Reshaping Care for Older People
- Indicator Bank for third sector outcomes for older people
- Focus on third sector interventions that make the physical and social environment more age friendly
- Focus on third sector interventions to enable older people to keep or be more socially connected
- Focus on third sector interventions that allow older people to stay positive and in control
- Focus on third sector interventions to enable older people to keep or be more financially and materially secure
- Focus on third sector interventions that make the system work better for older people
- Focus on third sector interventions that ensure healthy and active ageing

To accompany this series there are evaluation case studies and a number of evidence reviews. To see all publications associated with A Stitch in Time please see Evaluation Support Scotland website.

Evaluation Support Scotland (ESS) works with voluntary organisations and funders so that they can measure and report on their impact.