# "TREES THAT BEND IN THE WIND":
## EXPLORING THE EXPERIENCES OF FRONT LINE SUPPORT WORKERS DELIVERING PALLIATIVE AND END OF LIFE CARE

# CONTENTS

## PREFACE

*Solace*
*[mass noun] Comfort or consolation in a time of great distress or sadness (Oxford English Dictionary)*

**Throughout Scotland today as you read these words there are hundreds of conversations taking place which are providing comfort, assurance and solace to someone who is living in a palliative or end of life situation. Most of these conversations will go unnoticed except by those involved, their words will never be recorded, their effect rarely noticed, but despite their hiddenness they provide a fundamental part of what we mean by good palliative and end of life care and support.**

This report seeks to describe the experience of those who work in care at home and care home services who day in, day out hold conversations with those who are dying or at the end of their life. The reflections contained here seek to give an insight into the experience of our solace givers, women and men who find themselves in situations where they provide a holistic approach offering physical, practical, social, emotional and spiritual support to both individuals and their family members who are facing progressive illness and bereavement.

So often the experience of these staff is hidden and unacknowledged. So often their contribution to meaningful end of life care and support is ignored. Scotland is committed to ensuring quality palliative and end of life care and support for all our citizens wherever they may live. I hope that the 'hidden' contribution of the thousands of women and men who work in care homes, care at home and housing support services will be increasingly recognised as a fundamental element in achieving that ambition.

But that will involve some listening and not a little action. It will involve both locally and nationally a re-prioritisation of focus on community settings, a greater resourcing of the care at home and care home sectors and critically a focus on equipping and enabling the frontline non palliative-specialist workforce who are today holding those hard conversations even if they feel they have not the 'right' words to offer. We owe it to our social care staff to ensure we listen to what they are saying to us in this report. It is they who are the 'hidden' carers, the 'palliative' care givers, it is their voices who console, whose hands offer the touch of comfort, and whose presence instils solace.

Dr Donald Macaskill
*Chief Executive, Scottish Care*

# 1. INTRODUCTION

*'Palliative care is the term used to describe the care that is given when cure is not possible.
The word comes from the Latin 'palliatus' (covered or hidden with a cloak) and is used to mean 'relieving without curing'.' (Scottish Partnership for Palliative Care)[1]*

In late 2016, Scottish Care began undertaking a programme of research relating to the delivery of palliative and end of life care in the independent sector. The aim of this research, entitled 'Supporting Solace', is to:

- Gain a better understanding of the level and range of palliative and end of life care support being delivered throughout the independent care sector, and any challenges associated with this delivery

- Identify the current skills, plus the training needs, of the front line care workforce in the independent sector

- Explore the emotional, psychological and spiritual impact on front line staff of delivering palliative and end of life care

- Identify any recommendations which would better support palliative and end of life care delivery within an integrated workforce environment

- Identify innovative and best practice around palliative and end of life care provision within the independent sector.

A key element of this programme of research was to engage directly with the front line workforce to better understand their experiences of delivering palliative and end of life care. It is the results of this element which form the basis of this report.

Scottish Care's commitment to front line engagement has been generously supported by the Office of the Chief Social Work Advisor (OCSWA) since 2014. Part of this commitment has involved creating a better understanding of the experiences of support workers working within the independent sector. Another aspect is to enable and support front line support workers to contribute to organisational, local and national policy discussions within an integrated health and social care landscape. Palliative and end of life care is one of the most crucial elements in which we need to engage with and listen to those with the experience and wisdom in care delivery if we are to continuously develop services and improve outcomes for individuals.

## Context

It is envisaged that the findings of this report will contribute towards achieving the vision of the Scottish Government's *Strategic Framework for Action on Palliative and End of Life Care 2016-2021.[2]*

The Scottish Government published this Framework at the start of 2016 and set its aims as ensuring that:

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

- *People, their families and carers have timely and focussed conversations with appropriately skilled professionals to plan their care and support towards the end of life, and to ensure this accords with their needs and preferences*

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

The Framework notes that:

*In Scotland around 54,000 people die each year and over 200,000 people are significantly affected by the death of a loved one. In general we are dying at older ages, sometimes accompanied by frailty, dementia and multiple other conditions. Driven by population growth,* the number of people dying each year will begin to rise from 2015. By 2037 the number of people dying each year will have gone up by 12% to 61,600. It is thought that up to 8 out of 10 people who die have needs that could be met through the provision of palliative care.

Effective, high quality and locally delivered palliative care has never been as important as it is today. The Framework recognises that there needs to be an enhanced contribution of a wider range of health and care staff in providing palliative care. **In its aims, it highlights the importance of staff, wherever they are and whoever employs them having a sense of feeling adequately trained and supported to provide the palliative and end of life care that is needed.**

Over the last ten years there has been a growing recognition that for many citizens, a significant amount of palliative and end of life care and support is delivered by workers who are not palliative professionals. For many people today, their primary palliative care and end of life support is delivered by staff who work as support workers for care at home and housing support organisations, or staff who work in Scotland's care homes.

## What prompted the research?

The front line workforce is social care's greatest asset. Whilst elements such as adequate resource levels and positive commissioning practice are hugely important to the delivery of sustainable services, without a dedicated and skilled staff team, social care services could not deliver high quality care. However we know a lot is asked and expected of this workforce and that this is likely to increase in the coming months and years, not least in respect of palliative and end of life care provision.

The policy ambition to support people in their own homes for longer inevitably means that more people will be supported up until their death by home care services. It also means that individuals who move into care home services are likely to do so at later stages in their care journey, predominantly for the last 18 months of their life. Wherever an individual's palliative and end of life care is delivered, it is increasingly likely to be out-with hospital settings and this has significant implications for social care staff in terms of their roles, training, skills mix and support mechanisms. At present, we know that 100,750 people work in independent sector care home and home care services supporting over 63,000 people.[3]

This is a significantly higher number than those who are supported in hospital settings. Of these, nearly 83% are aged 65 and over.[4] A significant proportion of these individuals are likely to be receiving palliative and end of life care, or will require it in the near future.

At the same time, the social care sector is experiencing major recruitment and retention challenges across both care home and care at home services and for all categories of staff, including nurses. Scottish Care's latest reports put nurse vacancy levels at 28%[5], with 62.5% of organisations experiencing support worker vacancies and nearly three quarters of services having outstanding vacancies across their staff team.[6] Again, this has implications for the future of social care services, what they can deliver and what skills and capacity exists within the workforce, based on whether the recruitment and retention challenge can be overcome effectively. Furthermore the nature of social care and particularly palliative and end of life care means it is critical that the right people, with the right skills and values, positively choose to join and remain in the care sector. If palliative and end of life care continues and increases as a critical element of the support delivered to individuals, consideration needs to be given to how this relates to the workforce and some of the challenges currently being faced.

[1] https://www.palliativecarescotland.org.uk/content/what_is_palliative_care/

[2] Strategic Framework for Action on Palliative and End of Life Care (Scottish Government, 2015).
[3] Scottish Social Service Sector: Report on 2015 Workforce Data (SSSC, 2015).
[4] Care Home Census for Adults in Scotland: Figures for 31 March 2006-2016 (ISD Scotland, 2016).
[5] Voices from the Nursing Front Line (Scottish Care, 2016).
[6] In the Front Line: Social Care Providers Survey Report on Recruitment and Retention (Scottish Care, 2015).

## "We are the trees that bend in the wind" *(care worker, Dumfries)*

A lot of the facts and figures about the social care workforce and its role in palliative and end of life care may already be known. However, what is often overlooked or insufficiently understood is the human impact of delivering care at the end of someone's life, and of doing this in challenging conditions on a regular basis for multiple people. Palliative and end of life care involves delivering highly skilled, technical and practical interventions but also providing emotional support, a familiar face, a hand to hold, family liaison and so many more forms of care and support that cannot be captured in any job title. What's more, this is part of a wider remit and not in a specific palliative and end of life care role, therefore protected time and specialist training is often limited or even non-existent.

Additionally, the current commissioning and procurement arrangements for both care home and care at home services risk treating the care of individuals as homogenous and support as a serious of 'task and time' inputs. Whilst the picture is improving, there remains a danger that palliative and end of life care is seen as a process and merely a particular form of support, rather than a journey that affects not only the individual but their whole support network, including care staff, up to and beyond a person's death. At present, there is little understanding of this journey from the perspective of the support worker.

What's more, death and dying is one of the last remaining taboo subjects. As a society, we continue to struggle with having open conversations about this inevitable part of life, and often fail to see planning for a good death as an essential discussion to be had at an early stage with loved ones and professionals. This undoubtedly has implications for what support looks like for individuals receiving palliative and end of life care, and the decisions and challenges that surround this for the person, their family and care workers.

As a result of anecdotal evidence from members, Scottish Care was aware that palliative and end of life care forms an increasingly significant part of the day to day activity of the independent sector care workforce, and that the above elements hadn't been explored in detail from the perspective of this group.

The quote above was taken from one of the focus group participants, who referred to their need to adapt, change, bend and flex to the journey of palliative and end of life care, and to experience it with the supported person. In the same way as a tree bends in the wind, we wanted to explore how and to what extent pressure is put on our care workforce in the delivery of palliative and end of life care, as well as what support is available to them to support recovery and growth. This report not only hopes to shed some light on this but also to sow some seeds for further cross-sector development in this area.

## Research objectives

It is hoped that the findings can be used constructively, and collectively, by employers, the Care Inspectorate, the Scottish Social Services Council, Health and Social Care Partnerships, the NHS, COSLA, Health Improvement Scotland and other key stakeholders.

It is our intention that the voices of a critically important workforce contained in this report will help to facilitate the changes required to ensure everybody in Scotland is enabled to have the best possible end of life experience. However, it is particularly relevant to the end of life experiences of our older citizens and the workforce who are involved in supporting them. It has been Scottish Care's assertion for some time that older people's care has been subjected to inequitable levels of resource allocation, a diminished focus on holistic care needs compared to other groups and a lack of recognition of the workforce due to inherent ageism. This report hopes to show that just because someone is old and nearing the end of life, their needs and wishes are just as important as any other individual.

We therefore expect a significant outcome of this report will be the way it articulates the experiences of front line support workers engaged in palliative and end of life care of older people in Scotland, and what is means for future commissioning contractual arrangements.

## Methodology

This report is based on focus group research with 50 members of care staff working across the independent social care sector.

Four focus groups were held across Scotland, in Dumfries, Inverness, Glasgow and Edinburgh. Each focus group lasted three hours and was based around a semi-structured group interview process exploring different elements of palliative and end of life care provision. Each session was led and facilitated by two or three researchers, with additional scribes supporting the data collection. The research questions which formed the basis for each focus group can be found in the Appendices.

Adopting a narrative methodology meant that the focus of the data collection was on the 'stories' of participants, allowing the researchers to interpret how care staff made sense of their palliative and end of life care experiences. This method was selected as it presented the best opportunity to explore people's attitudes, feelings, beliefs, experiences and reactions to delivering palliative and end of life care in a sensitive way. It enabled the researchers to maintain a level of consistency and structure, whilst allowing what were often emotional and challenging discussions to develop around the participants in a flexible way, and be led by them.

This method and the size of the study mean the findings reflected in the report do not seek to present a fully representative picture of the experiences of staff delivering this form of care. However, we believe they strongly highlight the importance of not only listening to but hearing the views and experiences of our workforce in relation to delivering palliative and end of life care. It is the only way to really understand and therefore improve the picture, not only for staff but for the individuals receiving support at the end of their lives.

In order to achieve widespread, inclusive participation, expressions of interest for taking part in the focus groups were sought from across Scottish Care's membership. The researchers selected the four areas to ensure a geographical spread of experience and thereafter information about the research was communicated via email to services operating in those areas, in addition to direct engagement with organisations through Independent Sector Local Integration Leads working in the relevant locations.

Ultimately, 50 members of care staff participated in the four focus groups, consisting of a mix of care home and care at home workers. Overall, 27 people took part from care home services, 22 from home care services and 1 student nurse. Of these, 44 were female and 6 male. This gender split is largely reflective of the fact that more than 82% of the workforce in independent sector care home and home care services are female[7]. A further breakdown of the focus group composition is as follows:

**Dumfries**
11 participants - 9 female, 3 male
13 participants – 12 female, 1 male

8 from care home services
4 from care at home services

**Inverness**
13 participants - 12 female, 1 male

6 from care home services
7 from care at home services

**Glasgow**
11 participants – 9 female, 2 male

8 from care home services
3 from care at home services

**Edinburgh**
14 participants – all female

5 from care home services
8 from care at home services
1 student nurse

Each focus group contained individuals with varying degrees of experience and with a range of job roles. Whilst information about job roles and length of service were not formally collected, often this emerged during the focus group discussions.

Throughout this report, variable terms are used to describe the care workforce represented in the research. These include 'care workers', 'support workers', 'carers' and 'care staff'. This reflects the lack of consistent terminology in the social care sector, with different groups preferring different titles. In this report, the terms are used in their most general sense to describe all individuals working in paid roles within the independent care sector, from those new to caring roles to those in senior positions with supervisory and managerial responsibilities. This reflects the range of people who deliver palliative and end of life care, which was mirrored in focus group participation.

[7] Scottish Social Service Sector: Report on 2015 Workforce Data (SSSC, 2015).

> *"You relearn it every time. Deaths are all uniquely different."*
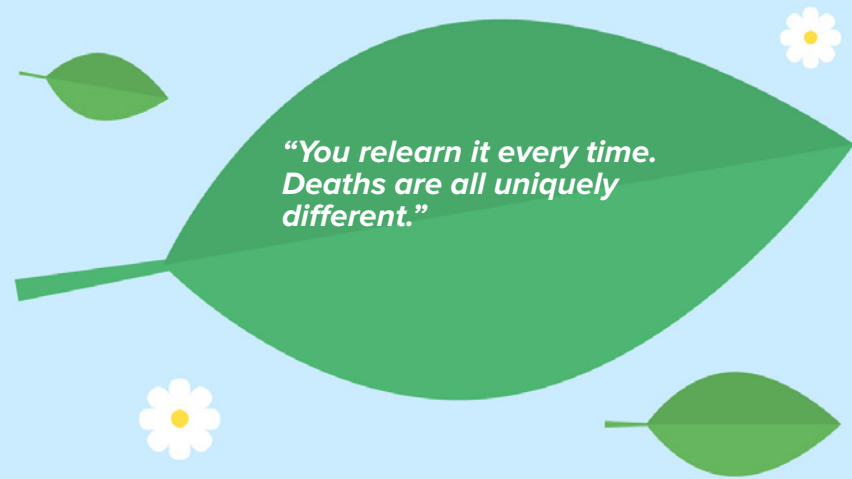
# 2. THE DYING JOURNEY

**In the course of conducting this research, the most immediate and prevailing theme that emerged was the fact that no two experiences of palliative and end of life care are the same – for an individual, for a care worker or in a care setting. Instead each instance of support is both distinct and constantly changing.**

The palliative and end of life care delivered by care staff is vast, both in terms of the number of people supported and the lives, needs and circumstances of these individuals. Some people will be supported by the independent sector for the last weeks, days or even hours of their lives. Others will receive support for a much longer period of time, including many who develop palliative care needs whilst already in receipt of care services. Regardless, each individual will go through a unique journey of palliative and end of life care upon which care staff and families will accompany them. The individuality of that journey will have implications for both the care they require and the people delivering that support, on practical, relational, emotional and spiritual levels.

Furthermore, that dying journey will vary in length depending on individuals and their circumstances. This journey won't just be from a palliative care diagnosis to the point of death, but will often begin long before this and almost certainly extend far beyond for the individual's loved ones. What this report seeks to highlight is that this equivalent journey is experienced by care staff and has a profound impact on their professional and personal lives.

## The individual's journey

*"Everyone is an individual, as much when they're dying as when they're healthy."*

In all of the focus groups, the importance of respecting individuality came through strongly and particularly the need for this to continue throughout palliative care up to and beyond death, into treatment of the body and funeral planning.

In relation to care staff, this has significant implications for their role, particularly when considering they are likely to supporting multiple individuals with unique needs and wishes. Participants spoke of the fact they could be supporting the palliative and end of life care needs of individuals in their 20s right through to those over 100 years old, often simultaneously. Respecting the individuality of this range of people is reflected in staff's approach to providing care.

*"We go down the same route as the service user – if they are deteriorating, we adapt with them and change our approach."*

Staff placed high value on empathy and a person-centred approach to palliative and end of life care, very closely aligning themselves with the people they support in terms of responding to changing needs. In order to do this they spoke of continuously evolving and adapting their delivery of care to respond to individuals' needs and wishes; a complex task which involves them being constantly tuned in to verbal and non-verbal cues. It also involves ensuring care plans are adapted and kept up to date and communicating new changes and needs to colleagues and wider health and social care professionals as appropriate. As one participant said:

*"We're a link with healthcare to report any changes."*

These practical elements are similar across both care home and care at home settings. What is particular about palliative and end of life care as opposed to other forms of support is the pace at which changes can take place. Participants spoke about the challenges of ensuring individuals' needs and wishes were understood, communicated and fulfilled in circumstances whereby needs and wishes could alter dramatically on a daily basis.

## Guardians of the journey

Participants reflected that they were often the people best placed to recognise changes in a person receiving palliative and end of life care, given the intimacy and frequency of the care provided.

*"We know these people... the district nurse only sees them 2-3 times a week, we see them 2-3 times a day. It's important that we can express what they want."*

It was clear in the course of the research that staff often perceive themselves as "guardians" of a positive dying journey for individuals and shared that experience with them. Participants frequently used language such as *"fighting for"* and *"being a voice for"* the individuals they support, in relation to upholding their needs and wishes.

Where this responsibility becomes challenging is in managing the uncertainty of the journey alongside supporting an individual in the most person-centred way, often when communication is difficult.

## Predicting the unpredictable

Furthermore, the changeable nature of the palliative and end of life care journey can place considerable strain on all those involved, including care workers. The broad range of conditions that staff encounter through palliative care can affect how that journey looks and feels, with a number of participants remarking on the particularly upsetting and unpredictable experience of supporting those with dementia at end of life.

*"With dementia, it can be like they die twice. At least that's certainly how the family perceives it."*

*"Residents with dementia seem to go downhill quickly, it's so distressing."*

In 2016, nearly 20,000 residents in care homes had a formal or informal diagnosis of dementia and the figure is likely to be higher for those supported by homecare services[8]. Given that many of these individuals will be receiving palliative and end of life care or will do so in the future, this has a substantial and growing impact on the role of care staff.

What's more, this period of intensive practical and emotional support can continue over a significant length of time, often unexpectedly.

*"Doctors said it would be a week, but the lady lived for 5 months. The carers found this difficult."*

It is in part testament to the high quality of holistic social care that people are living longer, even if that extension is days or weeks rather than years. However it is important to recognise the emotional outlay of this for care staff who can find it difficult to know what support, communication and preparation should be offered when and to whom, particularly recognising that

*"Every death is different. I feel anxious because I want to make it right for them."*

Participants felt a strong sense of obligation on behalf of the individual to ensure they experience a "good death", which often leads to a degree of emotional strain whilst carrying out their professional duties. A lack of clarity around the complexities and changes within the dying process (which could differ significantly for each person), as well as not knowing an individual's explicit wishes or a fear of not being able to meet these wishes, contributes to a significant degree of anxiety in the workforce delivering this care. Conversely, all staff felt calmness should be paramount at this time. This indicates disjointedness between what staff feel should be experienced by the individual through palliative and end of life care, and what they themselves experience in that process.

this is an extremely difficult time for families. Staff also spoke of the negative effect this uncertainty can have on their working lives in terms of confidence levels and apprehension about what they are likely to experience when going in to support someone's end of life care needs.

Conversely, staff also highlighted that they found unexpected and sudden deaths to be amongst the most difficult to cope with.

*"I didn't know she was going to die that night. I found it really hard."*

*"I hadn't realised that death can happen so quickly."*

They attributed this to a lack of time to "prepare", both in terms of their own emotions and ensuring the person had the right support at the end of life. This was true for both care home and care at home workers. For care homes, this was challenging if someone they had supported died when they were not working and they only found out about it upon returning to work. For homecare staff, these unforeseen deaths were sometimes encountered when entering someone's home to provide care.

We recognise that there will never be a science of certainty attached to the time and nature of someone's death and nor should there be. What is important is that the person receives the highest quality support over whatever period of time that is required, up to and beyond eventual death. However it appears that the intensive period of time, whether long or short, in which someone receives palliative and end of life care can look extremely different for every individual and proves difficult for staff to manage both practically and emotionally.

[8] Care Home Census for Adults in Scotland: Figures for 31 March 2006-2016 (ISD Scotland, 2016).

## Journey preparation

Despite the fact that almost all had had direct experience of deaths in their work, around half of the 50 staff members who took part in the research indicated that they had received little or no specific training on palliative and end of life care.

*"I don't know when somebody is dying and what the signs are. Why don't I know?"*

Some had touched on this form of care as part of other courses or had been given an introduction to it within their employers' induction processes. Nevertheless, staff across all four focus groups emphasised their need to know more about death and dying in order that they could better support people at the end of their lives.

More specifically, participants highlighted the necessity of understanding the practical and technical elements of dying and what happens to a person during the process:.

*"It can be challenging to be professional if you're still learning about the death process. It would be helpful to have enhanced technical knowledge as the body closes down, so we know what's happening."*

It was felt that more in-depth knowledge about this would have a range of benefits, not least enabling staff to feel more confident and informed in supporting someone well. Participants felt it would also improve their ability to recognise the signs that someone is nearing end of life, therefore aiding support to families and communication with other professionals.

*"I want to be able to explain to someone exactly what's going to happen. I want to be able to stop someone being afraid."*

Furthermore, staff stressed the importance of effective care planning in order to ensure that the palliative and end of life care journey can be as positive and person-centred as possible for individuals and their families. Each end of life experience is different and a good end of life experience is different depending on a person's wishes. It is therefore imperative that an individual's requirements and requests are recorded and shared effectively so that care staff can honour these as far as possible.

It is clear that staff see it as their duty and indeed a privilege to meet these wishes, but this becomes difficult and distressing when there is a level of uncertainty or conflict about a person's end of life wishes, ranging from what music they want to be played to whether a DNACPR is in place.

*"I want to be the person that can ask these detailed questions. I want to know, "Do you want the sun on your back?"*

Care workers play a crucial role in someone's palliative and end of life care journey. They are often the people that know the needs and wishes of individuals best, and who can recognise and communicate changes to the rest of the person's professional and personal support network. They can make the difference between someone having a "good" death or a "bad" death through the solace they offer, whether for a few hours or a few years. However, this role could be more effective and better supported through additional learning opportunities and more proactive, holistic and anticipatory care planning and recording.

## What does 'good' look like?

*"For the person to die where they want, how they want and in the place they want knowing that what they wished for is followed and respected."*

As part of each focus group, participants were asked to reflect on the elements that constituted a positive experience of death and dying, both for the supported person and for the care worker. These elements will be reflected throughout the various sections of this report. What emerged was that these elements were often inextricably linked; the journey cannot be positive for care staff if it is not experienced as such by the individual they are caring for at end of life, and vice versa.

*"TLC, observe, hear, pain control, pressure care, oral hygiene, fluids, being alongside colleagues who can't cope, recording, involvement with families... It really is an enhanced technical and emotional role."*

# 3. THE ROLE OF THE CARE WORKER

**The challenges presented by staff's limited capacity and emotional strain can be better understood by examining the complexity of the role they undertake in relation to palliative and end of life care.**

*"The role is actually quite endless, you have to wear 10 different hats."*

Discussions around what tasks staff currently undertake around palliative and end of life care provision were extensive, reflecting the vast array of support they offer. In fact the consideration of tasks transferred quite quickly to the exploration of roles, since in essence what care staff offer is far more complex and more comprehensive than a series of inputs. One may even argue that what they deliver is wider than what should reasonably be expected of one person or one workforce.

Staff saw their role as four-fold:

- Supporting the dying person
- Supporting families
- Supporting other staff, and
- Updating information (such as care plans and medication charts).

Behind these sit an immeasurable number of ways in which they carry out their multi-faceted role on a daily basis.

Even within each of these four aspects, there are layers of complexity and variation which require a mix of technical competence and emotional intelligence.

## Practical interventions

In terms of practical support for individuals nearing the end of life, this includes a significant degree of personal care, pain management, nutrition and hydration assistance, monitoring signs and symptoms, reviewing care plans and communicating needs to other people.

*"Making them comfortable, doing what you can... TLC, mouth care, turning them, nursing them in bed, socialising.... Whatever makes them comfortable."*

These applied interventions were similar across both care home and care at home services, and across varying levels of exposure to the palliative and end of life care journey. Even those who hadn't yet seen a dead body or been intensively involved in supporting someone at the end of life, had participated in supporting the practical needs of those receiving palliative care, particularly around personal care. It was acknowledged that personal care needs intensify significantly towards end of life.

Interestingly, a significant number of individuals referred to these elements of support as "basic" care and didn't see their role in delivering that as especially significant. On some level, the fact that these interventions are fundamental to life and therefore elementary may be true. However, the level of skill and knowledge required to deliver all of these to someone at a time of intense need, fragility and reduced communication is extraordinary. What's more, to be able to deliver these fairly autonomously given the reduced availability of co-located health and care professionals in most care services means what these individuals deliver is nothing short of remarkable.

## Comfort through kindness

Practical inputs form part of the wider holistic support that care staff provide to individuals, and to their families. In all four focus groups, one of the most frequently used words when discussing end of life care was "comfort". This term was used to extend beyond someone feeling physically comfortable into them feeling comforted on an emotional and spiritual level. This is the essence of giving solace – working with all the senses at a point of life when the senses are both intensified and diminishing.

*"As a carer we make sure they are comfortable in bed, nice smells, nice lighting and you sit and hold their hand or read to them."*

These efforts were seen as equally if not more essential to palliative care provision than clinical or 'care' interventions. However, it is in the ability to deliver this 'softer' support that practical tensions were identified by participants. This was especially true for care at home staff whose time limitations within people's own homes often mean they cannot positively influence the environment and offer companionship as much as they want to, despite their affirmation that this is just as critical an element of quality care as making sure someone is clean and safe. However it is also a challenge for care home staff, who recognise the additional time and physical presence required for an individual at the end of life in order that they have support beyond personal care but the difficulty in balancing this against the pressures of a small staff team with multiple individuals to support.

## Key communicators

That isn't to suggest that providing assurances is inherently easy for care staff. In fact, communication was one of the areas that staff felt most apprehensive about and least equipped to deal with.

Staff expressed this challenge in different ways and in relation to different people. Many talked of a difficulty knowing what to say to the person as they are supporting them:

*"I don't know what to say... it can be overwhelming. We try and say what we think is right. It just comes out".*

*"You feel like you're apologising all the time."*

Others felt the issue of communication most keenly in relation to family liaison and breaking bad news, either in relaying a prognosis or in the event of a death:

*"It's hard to discuss with families that the end is approaching."*

This was common across both care home and care at home services:

*"Hospitals don't tell families bad news. They expect care homes to tell it."*

*"Someone should be there 24/7 – it can be very difficult. You still have medications to do, still have other people to consider."*

Regardless of setting, above all staff articulated the importance of having high levels of emotional intelligence to support people at the end of life. Unsurprisingly, they did not use this term nor did they necessarily recognise the fact that they possessed this but it clearly emerged in all the discussions.

*"What's needed is talking... valuing the person... reassuring them when they are frightened."*

This emotional intelligence is demonstrated in support workers' ability to interpret an individual's words, actions or demeanour to establish what exactly it is they need, often when traditional communication methods are limited. The palliative and end of life care journey forces people to consider their own mortality. It can raise very personal and existential questions and fears about death. Staff spoke of the tactile and verbal ways in which they provide security, reassurance, companionship and solace to individuals, families and colleagues at the most emotionally challenging of times. It cannot be underestimated how important but how difficult this is to do well, yet care staff do it on a regular basis.

*"If I go in and someone is dead, I call the police, then the office, then my colleague to come. But there's times when I'm asked to call the family. That's hard. I say, 'I think you should come over to your mum's'."*

Some did have good experiences of other professionals, such as GPs, communicating comprehensively but what generally emerged was that care staff tend to be the main point of contact for the individual and their family, regardless of what other services and professionals may be involved in supporting that person near the end of their life:

*"The nurses and the GP pop in and out but we are the ones who are there. It is us who have to be with them and care for them and answer the family's questions and try to calm them."*

*"We are often supporting the families, communicating with the GP and doing whatever is needed at any given time. It's difficult with families at times, especially if they don't know what is happening. Families look to you to tell them what to do."*

This highlights a reality of substantial expectation and responsibility being placed on care staff, whereby they are assumed to not only be experts on all elements of death and dying but to be able to impart that knowledge to a wide range of people clearly and sensitively at a time of heightened distress. It may be reasonable to expect staff to undertake this role given they are often the most involved and informed about an individual and the most regular point of contact for their families. However, there is a danger that both employers and other professionals fail to support people to manage the emotional burden of this by just assuming that this is a given in palliative care provision and another 'part of the job'. Without providing sufficient learning opportunities – and time - around this process there is a risk that this communication will be done, at best, in an ad hoc way and at worst, incorrectly with very negative outcomes for all involved. At either end of this scale, the current norm of assumption and expectation is contributing to care workers' feeling a sense of inadequacy, incompetence and anxiety in their role and how they do it.

*"People think that carers are medically trained and it is hard as it makes you feel inadequate."*

In fact, we should be reinforcing the high value and complexity of their role through support, learning and 'walking the talk' around good communication.

## Partnership working

The current weight of expectation and responsibility on care staff highlights the need to further explore their role in the wider palliative and end of life care landscape, particularly at a local level. In this area, there was clear divergence between care home and care at home workers' experiences.

Most participants from care homes felt a sense of community and mutual support with their colleagues both within and outside of their organisation when it comes to supporting someone's palliative or end of life care journey:

*"In care homes, we work as a big family... we understand each other."*

*"Macmillan nurses are really important, especially in helping with pain relief."*

*"We get good support from the GP, but our role is more complex now... everyone needs to be aware of palliative and end of life care."*

In care homes with nursing provision, nurses make up part of the core staffing and staff value feeling part of a team containing a range of knowledge and skills. Participants also remarked on the proximity of senior and more experienced staff in a care home, who can be drawn on for advice and guidance almost immediately. This was deemed important in enabling staff to feel more confident and informed in delivering palliative and end of life care.

In terms of external support to care homes, this was largely positive. There was a recognition that due to the increased palliative and end of life care needs that care homes are now supporting, it is an area that all staff regardless of rank or workplace need to be knowledgeable about. A couple of instances were highlighted whereby care staff didn't feel that their contribution was valued or listened to by other professionals which caused distress. Workers struggle with making their voice heard with other professionals, but did feel relatively confident that the individuals they were supporting would receive input from external colleagues where required. They also felt able to draw on other internal colleagues, such as nursing staff in care homes, whenever these were needed.

However, care at home staff had very different perceptions of how their role is viewed within the wider care network:

*"The external palliative care team are just another set of instruction givers – we don't feel any more included or valued."*

*"There is no support... no team around you."*

Almost all participants from homecare backgrounds remarked on a sense of isolation in delivering palliative and end of life care. Whilst this often referred to physical isolation as a result of lone working practices and delivering care in rural locations, it also related to feeling professionally isolated within the care landscape. Given that care at home services generally do not employ nurses, clinical interventions tend to be delivered be district nurses or specialist palliative care teams from other organisations. Whilst this should operate as an effective partnership approach to delivering person-centred palliative and end of life care, participants relayed a distinct sense of disconnection between themselves and external nursing staff. This was reflected in examples of communication breakdowns, the use of different and inaccessible recording mechanisms and misunderstanding of roles and skills.

*"The district nurse sometimes doesn't even tell us they are going in."*

*"The nurses have no idea of what it is we do – they still think of us as home helps and treat us as such... It feels like nurses and us."*

This is compounded again by the fact that strict rostering of visits means that care staff may not be present when others are providing alternative support, so are neither able to impart their knowledge of the person and their condition nor able to obtain accurate and up to date information about their holistic care needs. This contributes to homecare staff feeling that their contribution to the care effort is not valued despite their close relationships with clients and families.

# Information sharing

The provision of correct and timely information is absolutely crucial in order that care staff can deliver the highest quality, person-centred care to individuals requiring palliative or end of life support. Unfortunately, the quality, appropriateness, accessibility and promptness of receiving information about individuals' needs is proving to be a significant issue for both care home and care at home staff at present.

*"We are given very basic information... it's all about sharing."*

Staff from both types of service emphasised the importance of being fully informed before delivering palliative care to an individual, and of agencies working together, in order that care can be planned and coordinated effectively:

*"Sometimes we are not even told that the person is coming home to die. I think that's bad... you need to be aware, the staff need to be aware... you need to plan for palliative care."*

*"You can get a phonecall on a Friday afternoon saying they don't have time for a handover and that you just need to work to the care plan. That's not enough when you are going in on a Saturday into the house of someone who might be dying."*

However, participants' experiences were that the imparting of this information was often rushed or liable to significant omissions which negatively impacted on both the practical and emotional preparedness of staff. Many spoke of the apprehension and even fear they felt at the start of care packages at home or supporting new care home residents because they did not have enough information about the person and their needs.

*"I get really anxious because I don't feel prepared and this transfers to the person."*

This was felt to be most problematic in relation to hospital discharges. Staff recognised the strain that hospitals are under around delayed discharges and the difficulties that both care services and hospitals share around meeting the positive ambition to support people, particularly towards the end of their life, in a homely setting. One person revealed the pressure on care services, resulting in pressure on hospital discharges, meant individuals' positive choices around end of life care were being completely restricted:

*"We get a list from the hospital every Monday with 30 to 40 people who need care packages, many of them for palliative or end of life care. There's not enough support to be able to deliver these packages and we have to say no, so people aren't able to choose to go home to die."*

However, the answer to this pressure is not in striving to discharge people quickly with very little accompanying information. This is often to the detriment of the individual and their care, and can even lead to them being unnecessarily readmitted to hospital if a failure to share information results in a lack of appropriate support being in place.

This information transfer failure carries through into the delivery of care by independent sector services too, whereby a lack of timely information leads to communication breakdowns.

*"Trying to coordinate palliative and end of life care is difficult. We don't know who is making decisions. For example if a syringe driver arrives, no one tells us. Communication is really bad."*

*"We can drive miles to discover someone has been taken into hospital. No one has told us".*

*"All staff need the total amount of information in palliative situations... It's terrible when you have to repeat the same questions to families who are already upset. They shouldn't have to do that more than once."*

These examples show the negative impact of poor information sharing and communication, not only on care staff and their workload but on the care that can be delivered to the person requiring it at the end of life. With how quickly their journey can change, it is imperative that support, whether human or clinical, can be introduced quickly and efficiently. Responsive support becomes almost impossible when the chasing or rediscovering of information causes delays, and is also not the best way of utilising this skilled workforce. It impedes care staff from delivering critical support at the time it is needed and from supporting the wider health and social care sector as effectively as they could be, including through supporting hospital discharge and preventing hospital admissions. Finally, the knock-on effects of information deficits are realised by families and other contributors to the palliative and end of life care journey, who end up having to have the same conversations with multiple professionals; this is not an outcomes-focused approach to care and support.

Participants highlighted the introduction of consistent and compatible information recording mechanisms across health and social care services as one way of overcoming this considerable barrier to delivering the best palliative and end of life care. This applies to everything from practical documentation such as medication administration records and 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) forms to holistic care plans capturing individuals' likes, dislikes and values. Linked to this, participants stressed the need for a common understanding of systems and interventions. This would help to ensure that all health and social care professionals are informed and have a shared appreciation of the impact of decisions and information recording on the individual and the people supporting them. At present, participants felt that the conferring of different information to individuals and their families on elements of care and support was leading to confusion and fear, and creating impediments in positive decision-making processes. These include decisions such as having an anticipatory care plan in place, completing a DNACPR form or moving to a different care setting, such as a care home. It is often then left to care staff to attempt to correct and alleviate the concerns associated with this information minefield.

By utilising systems that 'speak' to each other, unnecessary delays to palliative and end of life care interventions can be avoided and the person in receipt of support can truly remain at the centre of decision-making and quality care, regardless of the sector or setting they are in. However, this does not take away from the need for professionals to speak to each other, not least to understand each other's roles in supporting a person's palliative and end of life journey. Many of the examples of communication breakdown and lack of clarity, particularly for homecare staff, seem to relate to an underappreciation of the distinct yet mutually beneficial contributions of care staff and other professionals. Therefore opportunities to better understand and utilise the wider network of support, alongside the adoption of better information sharing mechanisms, may go some way to promoting more routinely positive experiences of getting it right for the individual.

## What does 'good' look like?

*"Knowing what I did was right and that it was done to the best of my ability."*

> **"Text book experience is not sufficient."**
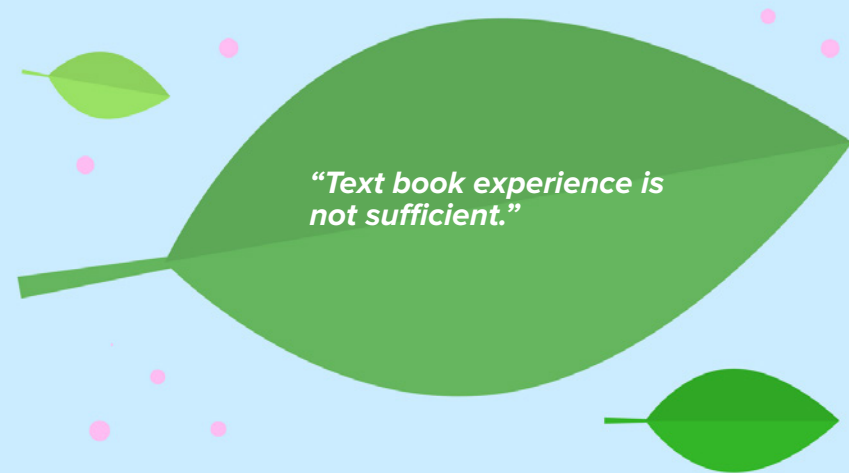
# 4. THE IMPORTANCE OF EXPERIENCE

**Given the diverse role of care staff in delivering palliative and end of life care and the array of skills required to do this well, the question of experience becomes an important one: is palliative experience a prerequisite to quality care delivery? Do personal experiences of death influence professional ones? Can you learn how to do this well? And how do the answers to these questions affect the recruitment and retention of good care staff? These are all questions that were answered in moving, illuminating and complex ways by care staff in the course of the research.**

## Experience and learning

Across the four focus groups, there was significant variation in experience levels within each location and within different care services ranging from very little experience of palliative and end of life care, to those who had been working in care services for their full working lives and had supported hundreds of people in their final days.

A frequently discussed topic amongst all participants, regardless of experience level, was how challenging the role of providing palliative and end of life care is for most inexperienced carers. Inexperience was taken to mean anyone new to care provision or with little exposure to death, including but not exclusively younger care workers. This view was common across those who identified themselves as relatively inexperienced as well as amongst more senior staff, who often supported newer colleagues through their experiences and had once been in their shoes.

*"I think it's very hard for the younger ones. They might not have seen a dead body or experienced death before. They find it really hard."*

*"I think junior staff need a lot of support to be brave enough to be there at the end."*

Participants expressed the need to prepare, again practically and emotionally, for palliative and end of life support rather than just being expected to learn through experience.

*"We need training for young staff, or anybody new actually."*

*"If there is a lack of training and they don't know what to expect, it's extremely emotional."*

More specifically, they identified how important it is for staff to be informed about the physiological changes to the body that occur when someone is dying to alleviate some of the shock people may experience when faced with this. Without understanding why changes such as mottled skin and poor circulation occur, anxiety is heightened by not knowing how to react and support people through changes.

Some participants shared examples of the distress they had faced when experiencing end of life for the first time and not knowing what to expect. One staff member gave a particularly vivid example of how a lack of detailed knowledge impacted on them in their early days as a care worker:

*"Training needs to cover everything – how someone dies, what you need to do… I had no idea that when someone dies they have air in them and make a noise. I was an 18 year old carer and that was traumatic."*

Furthermore, the emotional support provided by care staff can be a difficult burden to bear for those with less knowledge about the process and stages of dying. Participants emphasised the requirement for effective staff support systems, such as mentoring, to provide guidance and advice throughout this crucial initial learning phase. However this can lead to a heavy reliance on more experienced care staff, which creates both practical and emotional challenges for them also.

The initial support and learning required for new staff does not imply that this in itself is sufficient in equipping staff to manage the many complex elements of providing palliative and end of life care. In fact, not one of the 50 staff who took part in the research categorised themselves as being fully endowed with the knowledge, experience and confidence to do this, owing to the fact that every experience is unique.

*"You don't get used to it, you cope with it. I don't think you ever feel comfortable."*

Instead, participants described the dying journey as a continual learning process on which all members of staff travel:

*"You learn as you go along."*

*"Experience isn't everything. You learn something new every day."*

Despite this there does appear to be some clear benefits of more experience, even if this is gained over a series of years rather than weeks. Staff detailed the increased confidence, reduced fear and improved ability to cope with emotional experiences that regular exposure to palliative and end of life care support has afforded them. It also better enables staff to process and compartmentalise negative experiences in a way that doesn't overwhelm them as it may do initially.

*"It would be fine if it was a science and you could pinpoint why it's happening but you can't. It takes years of experience to be able to deal with it… to put everything into its department."*

This suggests that experience is perhaps most beneficial for supporting workers' mental wellbeing, coping mechanisms and ability to manage emotions, rather than as a means of learning the practices and interventions of actually delivering that care to individuals at the end of life. This theory is further substantiated by the words of less experienced care workers:

*"I'd worry I wasn't giving the right support, saying the right thing, making the wrong assumptions or not supporting the family enough."*

Many of the fears shared by those who hadn't been specifically responsible for supporting someone's palliative care journey related to how they thought they would cope emotionally. They also worried whether, in their own eyes and the eyes of the supported person and their family, they would be seen to have supported someone in the 'right' way to have a good death.

## Personal experiences

Experience was also considered from the perspective of dealing with death and dying outside of a work environment. It quickly became clear that staff's personal experiences of death and dying have a profound impact on how they view and support palliative and end of life care in a professional capacity. In almost all instances, participants reflected that having had personal experiences made managing emotion more difficult, but that it also significantly increased empathy; in fact, these two effects were inextricably linked.

*"Once you've been through a personal bereavement it makes it harder because you put yourself in their place."*

*"If you have been through a personal bereavement it makes you more caring and able to appreciate everyone's efforts."*

A number of participants commented on how difficult it can be to separate out the two experiences, as one evokes memories of the other or brings back recollections of dealing with particular conditions:

*"It's difficult if you've got personal family experience and then trying to be professional and detach yourself."*

Even participants who didn't describe themselves as emotional tended to share examples of being unable to prevent themselves from getting upset at work where they had identified similarities with their own experiences of grief. They tended to apportion this to their empathy with families:

*"I wasn't crying because we lost wee Josie, I was crying because I was watching her daughter break her heart. It reminded me of losing my own mum."*

*"I'm crying because I see the pain in their families. It breaks my heart."*

Care staff found this particularly difficult if they had had recent bereavements in their personal lives. In fact, some found supporting the palliative and end of life care of others in the weeks and months after their own experiences to be "too much." This could often come as a surprise to staff themselves, who may not have faced personal bereavement until later in life whilst having gone through it in a professional capacity for some time.

Without fail, participants who talked about their personal experiences of death identified these events as having changed their perspective and approach to supporting others through the dying journey, to the extent that some felt unable to continue to do their job where it had evoked a raw or negative experience.

**"Doing my own job made me realise all of the things I didn't do for my own dad. The guilt took over me and I actually left the job."**

It is well known that grief and coming to terms with death looks very different for different people. It can often be a long process that hits people in unexpected ways. For some care staff, being involved in other people's care journeys will echo elements of personal experiences and become difficult to manage. At least three participants said they had considered leaving the care sector after experiencing a personal bereavement. Fortunately they had either chosen to remain or returned soon after. It is therefore clear that managing similarities in personal and professional experiences is an important consideration for staff retention.

For others, personal experiences could be positively channelled into their approach to supporting others:

## Recruitment and retention

The degree to which experience enables or hinders someone to deliver high quality, compassionate care at the end of life has significant implications for the recruitment of new care staff and the retention of existing ones. This has particular importance given the well-documented staffing shortages being faced by the care sector, combined with the drive to continuously improving care through the employment and recognition of staff with the right skills and values.

**"It doesn't matter how much training is in place, if you don't have the people it makes no difference."**

Many of the participants shared how the challenges in recruiting and retaining staff are negatively affecting their ability to deliver the necessary support to people at the end of life. This places opportunities for people to experience a good death under significant threat.

**"Staffing levels are so frustrating... It's so, so stressful. I don't want anyone to die alone."**

**"I don't feel we support them as well as we should. We are so short staffed... doing 120 things at once."**

It is therefore crucial that staffing shortages are addressed effectively and as a matter of urgency. However given the increased frequency of providing palliative and end of life care support and the complexity and skill level involved in this, it potentially creates even more challenges in ensuring the right people are recruited to the sector.

**"My father had the most horrendous death in hospital. I don't want anyone else to go through what he did."**

A number of participants demonstrated their empathy through a tendency to project personal sentiments on to professional care situations. Many used phrases such as, "imagine it was your parent or grandparent." They reflected on how seeing a loved one go through the dying journey had changed the way they support others, either allowing them to uphold positive elements or guard against negative aspects of their own experience. Either way, they directed the feelings induced by their own circumstances into a motivation to get it right for others.

It is important that the relationship between these two experiences is recognised and understood by both employers and commissioners of services, given the emotional strain that it can place on staff. Undoubtedly, the impact will differ between individual members of staff. However, if we want them all to deliver the highest levels of compassionate care to people at the end of life, compassion must also be shown in our treatment of their lives and experiences, and sufficient time, space and appropriate support given to process these events.

**"Having the right staff is very important. You need compassionate attitudes."**

**"You can't train someone to be empathetic. You have it or you don't. You know right away if someone is right for it."**

Staff felt very strongly that it was crucial that their colleagues shared their values and ambition in delivering care to people "as if they were your own family", and expressed their frustrations to the point of anger where they felt individuals had been let down by deficient staff.

**"Some people just see it as any other job."**

However they also recognised that the pressures of the job mean it isn't right for everyone, particularly given that the job demands a lot from people on both a professional and a personal level:

**"It's not 9-5, it's a vocation. I've seen me there at 10pm (having started at 7.30am) if it's palliative care."**

This was echoed across care home and care at home services, with multiple staff giving examples of long working hours and shift patterns and of choosing to provide additional support to individuals in their own time. They didn't share these examples in a boastful way, nor even to complain, but because they saw it as 'part of their job' as well as it being important to them and their values on a personal level that someone is supported properly.

However, it is the communication of what comprises 'part of the job' that participants felt was contributing to a number of individuals either entering care for the wrong reasons or leaving within a short timescale. Many shared the fact that palliative and end of life care is either not mentioned or skimmed over as one element of the role in recruitment processes, leading to many having false impressions of what is required of care staff on a daily basis. Whilst some had had an introduction to this care in induction processes, many felt insufficiently informed, trained or supported when commencing the role.

This lack of support was mirrored in the reasons why participants felt experienced staff were leaving the sector:

**"Staff are leaving because they are ill equipped to cope with end of life care, and they aren't coping."**

**"We do long shifts and can be 8 days without a day off, which results in sickness."**

## Experience versus training

There is certainly a fine balance to strike between preparing people through experience and teaching them through training, particularly for palliative and end of life care which is so unique and person-specific. As one participant reflected:

**"If you're told how to do something, you'll do it that way and not necessarily in the best way for the person."**

Regardless of experience levels, there is certainly a need for a significant degree of initial and ongoing learning and support. It is the way in which this is provided, the quality of it and the value that it demonstrates is placed on this workforce that is of most importance. A lot of this relates to recognising the skilled and varied nature of the care worker's role in supporting people at end of life, and taking the necessary steps to ensure that individuals feel as prepared as possible to undertake this. For instance, one participant noted that the training that was available around palliative and end of life care tended to be in an online or classroom format, which was deemed unhelpful in relation to the reality of this support:

**"It's not adequate to just have online tick boxes. Online training is automatic, not empathetic."**

**"I worked in a hospice and it was the nicest place I've ever worked because of the staffing levels. It's not like us, just in and out."**

A combination of inadequate learning and support systems, difficult working practices and staff shortages is resulting in an intolerable physical and emotional toll on many care staff. In turn, this is driving quality staff towards feeling resigned to leaving care services because they cannot provide the desired levels of time, support and personal expenditure required to give people the best support at end of life.

Lack of training, learning and support around palliative and end of life care present significant problems for all experience levels, and are compounding the recruitment and retention difficulties in the sector. This is a vicious cycle; with less people entering and more people leaving, this puts even more strain on an already stretched workforce and in turn forces them to consider whether their working situation is sustainable.

Participants suggested that more hands-on, face-to-face, interactive approaches to learning would be more beneficial, with opportunities to:

- Ask questions
- Reflect on experiences
- Role play aspects of palliative and end of life care
- Work with people delivering support in different settings such as hospice workers and district nurses
- Take information away and refer back to it
- Refresh learning on an annual basis
- Gain mentoring experience
- Cover the full holistic spectrum of palliative and end of life support.

It is therefore about ensuring the support and learning is not only available but that it is reflective of what delivering this care actually entails, is meaningful and is high quality. This also involves ensuring the infrastructure and culture of the organisation is conducive to the development of skills, knowledge and support mechanisms. Otherwise, the current system prevails whereby the ability of care staff to deliver good palliative and end of life care is largely premised on hope and goodwill. That is, until something gives; usually the workers' own physical and mental health and wellbeing.

Whilst there is certainly a role for social care providers in ensuring that experience, support and learning are joined up and effective, this is actually a task for the integrated health and social care system. This partnership undertaking must be premised on the availability and prioritisation of good quality information about working in palliative care, mutual support mechanisms, informed discussions and shared learning opportunities.

By joining these up more effectively, training, professional experience and personal experience become much less oppositional and much more mutually beneficial. This would be of benefit to all staff, regardless of how long they have been working in palliative and end of life care, and to the social care sector in general through more successful recruitment and retention strategies.

## What does 'good' look like?

*"Training would give us confidence and competence in delivering care, so we don't shy away from it."*



*"Giving people confidence, self-esteem, dignity...and preserving that."*

# 5. BEING THERE - SUPPORTING PERSON-CENTRED DEATH

**It is important to understand what it is that makes palliative care unique and what the role of care workers in 'being there' to support person-centred death really consists of. By exploring what person-centred palliative and end of life care means for all parties involved, it allows us to better appreciate both why this type of care presents so many challenges, but also why it can be extremely rewarding.**

Essentially, participants identified three key components of person-centred palliative and end of life care:

• Comfort
• Relationships, and
• Choice.

That is not to say that the application of these components looks the same for all individuals. In fact, it is often the different meanings of these for different people that make the dying experience so truly unique in its levels of both difficulty and fulfilment. However, these three elements are intimately linked to one other and cannot exist in isolation; without all three, the possibility of a good death is unattainable.

## Making connections

Relationships are central to the dying experience for both individuals being supported and care workers.

*"If you don't care for people, you're not doing your job. It's about building relationships whilst staying professional and respecting boundaries."*

*"They become like your granny. It's difficult with professional boundaries sometimes. For example, giving cuddles... but it's important."*

It was interesting that 'professional boundaries' were mentioned so frequently and how easy it is for lines between the professional and personal to become blurred. Whilst participants emphasised how important it is to maintain professionalism at all times, particularly given the critical skilled interventions they perform, they also recognised just how essential human physical contact and connections are to individuals at this extremely uncertain and often frightening time in their lives.

It was clear that participants often struggled with a sense of 'permission' to show this softer, tactile and emotional side of care, either from their employers or from families. Whilst none had found this to be an overt problem or something they had been challenged on, their words reflected an uncertainty about whether they should get attached to people in this way:

*"I felt that I wasn't even a family member, so who was I to be upset?"*

*"I couldn't even speak to the family in case I broke down in front of them."*

However provided these bonds were sought by the individual being supported and they could provide a form of comfort, staff felt they were completely inseparable from other forms of care. Care workers are incredibly perceptive to the needs of the people they care for, and these attachments are a fundamental element of supporting solace. They are also unavoidable, given the intimate nature of the relationship between individuals and support workers near the end of life.

Where staff did struggle was in circumstances whereby individuals had made a choice to be alone or to detach themselves from others, or if they did not have any other close relationships (family or friends). This was particularly true for care at home staff, who expressed their angst at the realisation that they could be the only person an individual would see from one day to the next, and even that would only be for short periods of time.

*"If they have no one, I feel I need to be their person. I need to be there."*

The natural empathy of this workforce can lead to internal conflict between what an individual wants and what they themselves may want in a similar situation (such as having loved ones around). However, staff stressed the importance of always respecting an individual's wishes, even if these were contrary to their own.

Attachments are fundamental to palliative and end of life care delivery across both care home and care at home services. Care home staff described individuals they had supported for a long time as "friends rather than residents" and similarly, care at home staff spoke of building relationships through visiting people over a number of months or years. For both groups of staff, these long-standing bonds made the process of dying and eventual death even more difficult to come to terms with and again made the lines between professional and personal relationships indistinct.

*"I'm very emotional. That's just me, I get attached."*

*"I cried my eyes out when someone died. I just get so attached to them. That's life I suppose. I always try my best – that's all I can do."*

## Family attachments

An often overlooked element of palliative and end of life care provision is the enhanced relationship role that care staff have, which extends to providing extensive support to families at this often distressing time.

*"Families are really important. They know me, I know them... and I am there for them too."*

Given that families will often have an intensive presence and role in supporting a loved one at end of life, it is inevitable that relationships will also be formed between them and care staff. As already explored, families tend to rely on this workforce to act as an information point and liaison between different health and social care organisations and professionals. We also know that care workers' previous professional and personal experiences enable them to support someone's wider care network with sensitivity and compassion. Whilst this undoubtedly places an additional pressure on care staff, they very much see it as a crucial element of the service they provide. In fact, many spoke of how important this element is and how they wouldn't perceive themselves to be doing their job properly if an individual's care was not extended to providing comfort to their loved ones.

*"Families are always so grateful for the attention that they are given at this time."*

*"Families who put parents into care homes for palliative or end of life care can feel guilt and staff need to help them realise that it is ok."*

The prioritisation of choice and control is also noticeable in these relationships and supports, ranging from the desired degree of carer involvement at the end of life to the degree of family involvement:

*"I let the family decide if they want me to be there. Usually, they do. They need support."*

*"Not everyone can cope with loved ones passing. Some families don't want to be there and we have to support that choice too."*

Again, it is difficult for care staff not to apply their own feelings, perceptions and circumstances to others' end of life situations. For instance, some use the logic, "If it was my mum or dad, I'd want to be there". However individual and family choice is continuously reinforced as paramount, even where this deviates significantly from carers' own choices. This takes an admirable amount of emotional intelligence and adaptability to be able to respond to and manage these situations well.

Where this becomes especially challenging is when the interests of the individual receiving palliative or end of life care conflict with the views of family members or other professionals:

*"We want to keep everybody comfortable – clients and families – but it's not always easy. Sometimes it's the decisions of other people and not always the decision a client wants. It makes me feel sad."*

*"It can be difficult managing family's wishes versus what is best for the person. For instance, some families want their loved one to have clean sheets every day or frequent changes of clothes which can mean getting them in and out of bed. How do we make decisions about what support to give, when it can be a choice between being less clean but pain free or clean but screaming in pain?"*

Care staff can often feel caught in the middle and responsible for navigating through these difficult situations in order to continue delivering person-centred care. It also returns us to the question of the role of care staff, what professional authority they have to make decisions and how their expertise is valued. This becomes especially difficult when family dynamics are introduced, whereby conflict can unintentionally overtake the needs, dignity and comfort of the person. What's more, the heightened emotional atmosphere linked to palliative and end of life care can lead to misplaced apportioning of guilt and blame so workers feel even more uneasy about dealing with these situations. This leaves care staff in a very difficult position, where they are often unsure of their license to contribute to care planning or advocate on an individual's behalf:

*"In many cases we know the person better than their families. We have the conversations about music at funerals, etc. We know they want to talk about these things and we listen."*

This highlights how challenging it can be for care staff to prioritise and balance choice, comfort and relationship-based care on the palliative and end of life care journey. It also raises the question of whose choice, comfort and bonds take precedence. Whilst it's easy to say that the individual receiving support should be at the centre of all decisions and care approaches, the reality is that what makes that person an individual is a complex series of connections, choices and perspectives. What is effectively being asked of care staff is that they navigate these, often autonomously and with little support or training, in order to pin down exactly how person-centred care can best be delivered. Consideration therefore needs to be given to how we better support staff to manage this complexity – practically and emotionally.

## Anticipatory care planning

One of the ways in which staff felt person-centred palliative and end of life care could be prepared for, communicated and delivered more effectively is through the meaningful and consistent use of care planning, and particularly anticipatory care planning.

*"Everything needs to be documented at the start so we know what people want and everyone is aware."*

*"We need to talk about things before the person dies. That way you can involve the person and their family."*

Participants shared a range of detailed and emotional examples of where care planning had contributed positively to person-centred death:

*"He was desperate for a fish supper and I brought it to him... that was his last meal. It was really nice to know that I had given him the things he really wanted."*

*"A gentleman came into the home to spend the last few weeks of his life. He had cancer and died after two weeks but it was a positive death. He had his relatives around him, he was free from pain and we all took turns to sit with him. The family could have all their meals with him and had a bed next to him. Home wasn't an option, but a care home was what he wanted – he didn't want to die in hospital."*

However they were also able to highlight instances where a failure to effectively plan care in advance had led to very negative experiences:

*"I cared for someone with dementia and it wasn't done very well. The care plan hadn't outlined her plans for death. It seemed that her needs had never been properly discussed."*

*"One lady was brought to the care home from hospital at 10.30pm on a Friday night with unfamiliar nurses. She had dementia and was scared so kept trying to escape from the car. We weren't given any information about her condition or medication. She spent the night ill and scared, and had to be readmitted to hospital at 6am."*

The bad experiences tended to have a profound and often traumatic effect on care staff, whilst the positive ones reminded them of why they do their job and the difference they are making. Participants felt strongly that everyone should have choices when it comes to death and therefore have the opportunity to experience a positive and peaceful death and dying journey. It seems that inability to properly anticipate and plan for care needs is particularly problematic for individuals with dementia, whereby communication difficulties near the end of life can make knowing and respecting wishes extremely challenging for health and social care professionals, and for families. It is therefore critical that plans are not only in existence, but that they include end of life wishes specifically, are accurate, up to date and holistic in nature rather than solely clinical.

It is important to recognise that care planning does not imply a need for rigidity around providing palliative and end of life care, nor does it mean a reliance on extensive paperwork. Instead, participants highlighted the ways in which it can contribute to the holistic support of an individual and a means of capturing their wishes before reaching a time whereby the deterioration of their health and wellbeing limits their ability to communicate these.

*"I was a nurse but decided to become a care worker because the paperwork was too much. Recently, a resident died in my arms. I went with my instinct. In the end, paperwork didn't make any difference to him."*

It is the relationships and closeness of care staff to individuals that enables them to use their knowledge of the person to seamlessly adapt the care delivered, even if this means departing from care plans at times, because they know that person's choices and how to provide comfort to them.

## Talking about death and dying

This intimacy often means care workers are best placed to have conversations around death and dying with the people they support in a safe and supportive way. Participants, particularly those from care homes, spoke about their role in encouraging discussions around end of life wishes at an early stage:

*"We discuss end of life and future planning with residents and families right from the start."*

*"It's about choice, dignity, respect and how they've lived their life. Collaborative working makes for a good death."*

Again however, we risk assuming that because these conversations do take place, staff feel confident and competent to have them. Instead the research found that workers often struggle to know how to prompt conversations around this difficult and emotive subject, or that they do not have the sufficient time and space to have these sensitive conversations.

*"We usually don't know what people want – who is having these conversations? Is this our place? We're scared to say the wrong thing."*

*"I want to help him talk about his future but don't know how to expand this discussion."*

We have an empathetic, compassionate, dedicated workforce with experience in palliative and end of life care who are a crucial resource in supporting people to achieve positive outcomes, in death as well as life. They can have these conversations with individuals and promote anticipatory care planning and open conversations around death. However, that resource has to be recognised, nurtured and valued.

We also need to acknowledge how difficult encouraging people to positively prepare for death can be. As a society, we still struggle to talk about our wishes and outlooks when it comes to dying and death.

*"It's difficult to deal with a person's fear of death."*

It therefore cannot be expected that care staff can, in isolation, glean this complex information from people and help them to accept death as a part of life. To then put this learning into practice to deliver positive experiences, particularly given that care staff may only begin supporting some people very close to end of life, presents additional challenges and can only be achieved in partnership with others. This is a task for the whole health and social care system to contribute to, as well as the wider population.

## Supporting the soul

People's views and choices around death are often closely aligned to their religious, cultural and spiritual beliefs. It is these beliefs that can help to alleviate an individual's apprehensions around death and provide comfort to them and their families. It is also important to recognise that care workers' beliefs can have a significant bearing on their approach to care delivery, and on how they are able to manage feelings associated with death and dying.

In relation to supporting someone to have a person-centred palliative and end of life care experience, staff detailed the ways in which they respect individual's religious views:

*"I talk a lot about planning someone's death with them. I ask what verse of the Bible they want, if they do. If they don't know, I go through it with them."*

*"Faith is so important... that interests me. When I was younger, you were either Church of Scotland or Catholic. It's wider now."*

Staff recognised the fact that the multi-cultural, multi-faith society we live in, coupled with the fact that people are living longer, means they are supporting a wider range of belief systems and spiritual outlooks than they had done in the past, and are increasingly likely to need to take account of this into the future. However, the very nature of this diversity means that it is impossible for staff to know the particulars of every culture, religion and spiritual belief or to learn this quickly, especially when communication with an individual may be limited. They therefore stressed how important it is that these elements of someone's life and care are recorded effectively in care plans in order to diminish carers' anxiety about saying or doing the wrong thing. This also helps to ensure the individual and their family are comforted by the knowledge that their beliefs are respected and upheld, including by those whose own beliefs are different.

*"Personal rituals, religions and beliefs are unique to each person, but it's important that we know and acknowledge them."*

Conversations also illuminated ways in which care staff apply their own belief systems to emotional situations as a means of processing and coping with them.

*"I tend to leave the window open after someone has died, for their soul to leave through."*

*"When it's an older person, it seems the natural order of things. I can cope with older people dying because it feels like it must be their 'time', but not with younger people."*

*"Staff put up pictures of the person that has died, like a shrine."*

However, some participants did describe difficult situations whereby colleagues had struggled or been unable to take the religious or cultural needs of individuals into account when supporting them and had instead concentrated on their own faith and belief systems.

*"It is important that staff don't overstep the line by imposing their beliefs or values on others at end of life."*

It is essential that staff get sufficient space and learning opportunities to explore the religious, cultural and spiritual component of the dying journey, not only to better enable them to support people at the end of life but so that they can explore their own attitudes and beliefs and how these impact on their care and support of others. Without explicitly recognising their own belief systems and how these are constructed, it can become difficult for staff to come to terms with frequent and traumatic experiences of death and can negatively impact – albeit unintentionally – on their ability to deliver true person-centred care in this regard.

## What does 'good' look like?

*"For the carers to know the person and to build a good relationship with family to enable them to be supported too."*
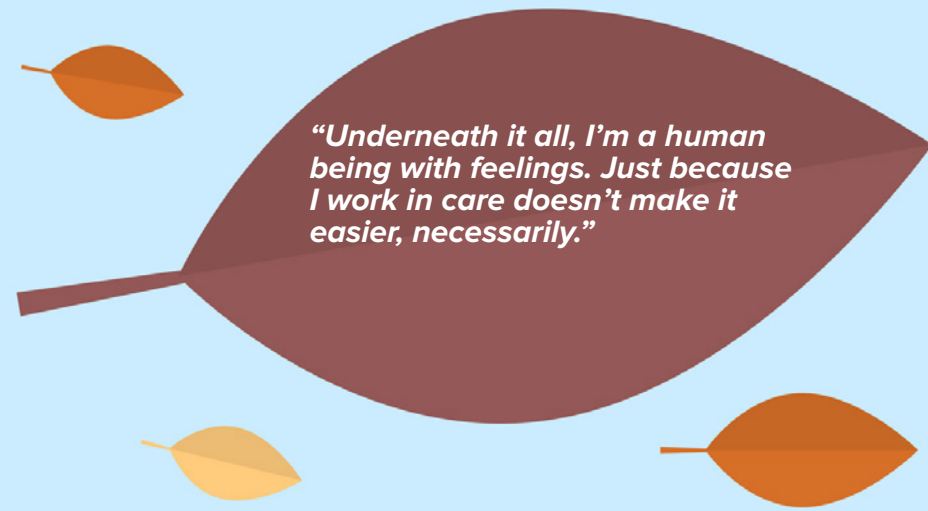
*"Underneath it all, I'm a human being with feelings. Just because I work in care doesn't make it easier, necessarily."*

# 6. PERSONAL IMPACT

**From delivering delicate personal care to comforting families, and from encouraging someone to record their final wishes to holding their hand as they die, what is asked and given of care staff is nothing short of immense. But in giving so much of themselves, what does this take away from care workers, physically and emotionally? And what steps do they take to protect themselves in this exposing and affecting form of care?**

## Dealing with the realities of death

Coping with dying and death itself is extremely draining for all involved, regardless of how many times it is experienced and irrespective of whether it is a part of someone's job. Not least the afore-mentioned uniqueness and unexpectedness of the dying journey, coupled with care workers often facing situations alone and without a lot of training, makes the fear of the unknown a difficult sensation to deal with on a daily basis:

**"Every time you go in, you don't know if she's going to be there. But you get used to that feeling. People who go suddenly are more difficult to cope with."**

**"I was told what to expect, but didn't have sufficient training. I felt emotional about what I could have done differently."**

This is particularly exacerbated for staff working in care at home services:

**"Lone working makes your fears grow. Ten visits to make after experiencing a death... you just have to make it work."**

**"How am I actually meant to react if they die right now? It hit me... I'm totally on my own. It frightened me".**

These overwhelming senses of anxiety, fear and stress were revealed at various stages of the discussions. If staff are not feeling prepared, calm and able to deal with death it becomes very difficult for them to apply these principles positively to supporting the care, wellbeing and environment of someone at the end of life. Eventually, the build-up of these negative states of mind will overcome the individual and most likely steer them towards a decision to cease delivering this type of care. This has serious implications for the future of care services, given that they are increasingly likely to need to specialise in palliative and end of life care.

## Pain management

It is also important to recognise that the stresses and strains of supporting people are not solely about end of life and death, but that many aspects of palliative care are emotional and distressing. Of these, participants emphasised pain management as the most challenging part of their role in supporting someone, and one that is very difficult to do effectively for a lot of people.

**"It was horrendous to hear someone screaming like that."**

**"Not managing pain, even when you try your best, is really distressing."**

This was highlighted as one of, if not the most, traumatic elements of palliative and end of life care both for the individual and the care worker. In relation to how a death could be positive for an individual, all four focus groups mentioned pain relief and being pain free multiple times. Whereas almost everyone's wish is for a peaceful, comfortable, pain free death and support workers strive to achieve this for people, they often feel an extreme sense of guilt if they are not able to. They strongly feel that they have let people down, even when rationally they know that the eradication of pain is not always possible.

**"We have this view of people being medicated to the hilt and pain free. It's not reality."**

This emphasises the conflictions and contradictions that exist between perceptions of what death is like and what care staff's role in this is, and the difficult realities of supporting comfort when the body is involuntarily closing down.

## Managing emotion

Palliative and end of life care cannot be considered without an examination of emotion. Given the often extreme and distressing nature of this care, the relationships and the losses that colour it, combined with the empathy and compassion we seek and value in care staff, it would be concerning if the expression of emotion didn't feature heavily. The reality is that it is present in some form, overtly or discreetly, in every interaction and intervention and in every quote from the research participants featured in this report.

However, what emerged were clear divergences in opinion as to whether staff felt able or willing to show signs of distress in the process of supporting someone through palliative and end of life care, extending to after their death.

**"Emotions are much harder to deal with than the physical care."**

**"I find it totally draining dealing with emotions at times."**

Some participants very closely aligned their expressing of emotion with their ability to deliver compassionate, person-centred care and recognised these displays as an inevitable outcome of that care:

**"The minute I stop crying is the minute I stop doing my job."**

Others relied on their emotional intelligence to establish when the display of emotion was appropriate, often gauging this by their relationships with families:

**"It's good to show emotion but some families are different. Some families don't want us to leave the room, others need time on their own."**

Interestingly the role of families played a large part in determining whether staff felt able to get upset about someone's death. This ranged from those who had experienced families being comforted by the shared grief of care staff due to its indication of affection and relationships, to those who believed they had no right to be part of the grieving process given that they had only known an individual in a caring capacity.

This covering up of strong emotion was a recurrent theme, with most participants revealing that they did not feel able or willing to show signs of distress or sadness whilst undertaking their role:

**"I'm a senior carer and I feel that I shouldn't cry. I should be professional. But then I go home and think about it."**

**"It still upsets me... when I come out I go and have a cry."**

**"I feel I shouldn't cry. I should stay strong for colleagues. I go home and feel a bit heartless."**

This was particularly noticeable in participants with more experience, including those in senior caring positions or with responsibility for mentoring and supporting other staff. This particular group felt a personal obligation to support other staff, who are perhaps less experienced around death and the management of emotions attached to that process. However, their habit of concealing emotions was often accompanied by a more negative self-reflection on how that portrays them as a person. They also admitted that it could delay the onset of the natural emotional healing process associated with coming to terms with a death. This suggests potentially unhealthy coping methods are being adopted publicly by staff in response to their perception that becoming emotional would indicate weakness or unprofessionalism. Yet the same people are, in private, concerned that this stifling method indicates a lack of caring. This is a conflict that needs to be recognised and worked through with staff in order that they can express their emotions in a safe and supported way that isn't to the detriment of their emotional health and mental wellbeing in the longer term.

A few individuals adopted a more pragmatic approach to showing signs of grief:

**"I don't cry, it's my job to get on with it. If I didn't, I'd spend my whole life greeting."**

**"We have to toughen up and not allow emotions to take over. We need to do the job. That is what we are there for... the families can't do it."**

**"I've experienced 33 deaths in the last year, 32 of which have been in the care home. If I went to bits every time, I'd always be crying."**

Interestingly, these observations were almost always accompanied by a secondary statement:

**"It doesn't make you a hard person."**

It seems that those who don't express emotion outwardly whilst supporting palliative care, end of life care and death feel that they need, on some level, to justify this and re-establish their caring qualities. Instead it should be celebrated that as much as those receiving support are unique, so are care staff and the ways in which they process difficult situations. There is no correct way to respond to death, loss and bereavement. We need to be supporting care staff to identify with their own grieving processes and to understand that difference is both acceptable and indeed desirable.

## Coping mechanisms

The outward expression of grief is just one of the ways in which care staff adopt mechanisms and strategies to cope with palliative and end of life care, and to replenish that which is taken from them emotionally and physically by this challenging journey.

In relation to palliative care, some workers prioritise the maintenance of a sense of normality both for them and the individuals they are supporting. By using emotional intelligence and knowledge of individuals built through relationships to establish boundaries, care staff use communication tools such as humour to cope with the emotional reality of caring:

**"I like to still be able to have a laugh with them. It makes it easier for me and them to have a bit of normality. That last thing they need is some dour bugger! The person that's dying knows it. They don't need me telling them every day."**

This also illustrates ways in which the caring relationship between individuals and staff is not only complex but mutually supportive. Attention is often, and understandably, paid to the ways in which care workers assist those requiring palliative and end of life care but in reality, those individuals are also central to care staff's lives and can act as an anchor and a focus in otherwise turbulent circumstances.

Some also cope by applying their own outlook on life and death as a means of comforting themselves when experiencing loss:

**"It's not that I don't care anymore, I see it as part of their life."**

**"At least you were in their lives before they passed away. I'm part of their life. I'm happy with that."**

**"Sometimes it is important to realise that death is maybe better than being ill."**

By focusing on and rationalising quality of life, care staff are able to reflect more positively on an individual's death. The setting of an individual's death and the achievement of their wishes are also central to whether carers can take comfort from someone's end of life experience:

**"People seem happier to die in their own home. I'm comforted by that."**

**"I feel cheated if a resident dies in hospital. I feel that I should have been there to see that they had their wishes."**

Others use the transference of their caring tendencies as a coping mechanism:

**"At the end, I can blank it out, put another hat on and support my staff."**

By focusing on colleagues or families, some carers attempt to detach themselves emotionally from death and prioritise the needs of others. However, it is important to note that those who did not express emotion outwardly were a real minority. Whilst it is admirable that they are able to support other people at this difficult time, it is important that 'blanking it out' is genuinely what helps these individuals to come to terms with death rather than using this as a means of avoiding or supressing emotions or worse still, because they feel their own emotions are inferior to those of others. Again, individual coping strategies need to be appreciated and respected but regardless of what these are, there needs to be sufficient time, space and understanding for staff to put these into place.

## Achieving closure

One very important element of palliative and end of life care is the achievement of closure after a bereavement. This is certainly something that came across as crucial for a number of participants, and was often captured through the depiction of 'rituals' that care staff carry out:

**"We wash the person... we feel it's the last thing we can do."**

**"After someone dies, all staff on duty including kitchen staff and others stand outside the bedroom and follow the person out, creating a guard of honour. It's just what we do."**

The importance placed on respect, dignity and tenderness in palliative and end of life is evident in care staff's public and private responses to the death of someone they have supported. The moving ways in which support workers shared their examples of being there for a deceased person for the last time highlight just how much these bonds impact on care staff. What's more, the ways in which they internalise these rituals and marks of respect and underplay their wider importance through phrases such as "It's just what we do" highlight why these remarkable individuals need to be valued and retained in social care.

Respect, dignity and tenderness are also sustained in staff's communication in the minutes and hours after someone's death, as much as they are when supporting someone in life. Many spoke of the fact that hearing is the last sense to shut down. Care workers therefore ensure they always speak to the individual they are caring for rather than about or over them. Despite the knowledge that someone has died, staff appear to uphold this principle and value it in the process of achieving closure:

**"Having some time with the person after they've died – to just chat to them, clean them, say things to them. Even though I know they've died, to just have that space and time with them before they are taken away."**

**"When I'm laying out the body, it's my chance to say goodbye."**

**"I kiss them and say goodbye. It's important that I get to say my goodbyes."**

Likewise, an inability to be able to achieve this closure as a result of a sudden death, a carer not being available, time pressures or limited capacity can have a very negative impact on staff. This is particularly challenging for care at home staff who are much less likely to have any time or flexibility around being there for someone at the very end of life or for post-death rituals. Furthermore, individuals who are supported at home are at present more likely to be moved to a care home or a hospital setting when their palliative and end of life care needs become considerable.

Many staff spoke of the importance they placed on being able to attend the funerals of those they had supported. In fact some had been involved in selecting hymns and others had even acted as pallbearers, which reinforces the strength of attachments between care staff, individuals they support and their families. This form of closure becomes particularly challenging to achieve when staff shortages such as those which currently exist in the sector limit the possibility of freeing up staff to attend funerals.

## Enduring memories

What came through very strongly in the course of the research was how the experience of supporting someone through palliative and end of life care does not stop at the point of an individual's death, or even at their funeral.

**"Everyone I've looked after... they're in here. They're in my heart."**

Instead, these attachments and experiences remain with care staff long after an individual has died. What's more their bonds to families, forged through shared emotional experiences, lead to carers delivering ongoing support to them in their own time and often maintaining contact for many years.

**"We cared for someone in their own home. After they died, we went in to strip the bed and return the room to normal because we knew his wife couldn't handle doing that. We did it in our own time."**

**"Families and spouses build up relationships with the carers too and have that companionship. When their loved one dies, they're losing twice."**

**"It's about remembering those left behind... sending birthday cards etc."**

**"When I'm out and about, I still see families of people I've supported and have a chat."**

These are clear examples of care staff going above and beyond their duty to deliver exceptionally person centred informal support. They are not expected, nor are they paid, to do this but the relationships they have developed and the values they hold, motivate them to do this. These are the sorts of good news stories that should be being shared and celebrated across the country, and are an example of how caring is so much more than a job. It is a vocation and should be valued as such.

However, not all of the after-effects of providing palliative and end of life care are positive for care staff. For many, the reality is one coloured by self-doubt, traumatic recollections and guilt.

**"I cared for one lady who was 104 and straight as a die. When she knew she was palliative, she said to me, 'I'm pleased because I know I'm going to die, but I'll come back and haunt you if I have to go to hospital.' She ended up falling and breaking her hip and died in hospital. I'll never forgive myself."**

**"I'll go home at night and reflect... what I could have done better."**

Another participant candidly shared the fact that she was experiencing recurring nightmares after discovering a sudden death in someone's home, and was finding work a very anxious experience as a result. Additionally participants spoke of their fear that they hadn't 'given' enough of themselves during the end of life experience, with this being a particular issue for newer care staff.

For staff to be dealing with these difficult outcomes of a death is challenging enough, but combining this with the fact that they will simultaneously support others through this journey with all the associated strains this incurs, is concerning for their mental health and wellbeing. It is essential that staff have opportunities to reflect on their experiences and process them properly, with the appropriate support where required.

Participants identified a number of things that would be useful to them in order to better manage the risk of harmful emotional fallout. These included:

- Spending time with people who knew the individual, to talk about them
- Sharing stories and being able to celebrate someone's life
- Feelings and emotions being recognised by other colleagues
- Debriefing opportunities to consider what was done well and what could be improved
- Feedback from families and other support professionals about the positive impact they had on someone's end of life
- A point of contact, either within or outside a person's organisation, to discuss feelings
- Opportunities to reflect on positive and negative experiences and learn from them
- Recognition that everyone grieves in different ways, and needs time to do this

A number of staff positively recognised some of these elements as already being in place within their organisations. However, all participants felt that more could be done to support them to deal with the personal impact of palliative and end of life care.

At its most simple, staff wanted better recognition of the fact that this type of care does require them to give a lot of themselves for what will always be an upsetting outcome – a death – and that it is not always easy to replenish what is lost:

*"Just somebody asking, 'Are you OK?... That would be enough to acknowledge a death and the impact of it."*

## What does 'good' look like?

*"Knowing you've got someone to talk to... that they'll support you & that you can get it off your shoulders."*



*"We take for granted the importance of our role at the end, often with little instruction."*

# 7. VALUING PALLIATIVE AND END OF LIFE CARE

**Do we value the dying journey? Do we value the role of care staff in this journey? Is there more we could do to support solace? These are big questions, but were illuminated by discussions with these 50 care workers.**

## Valuing social care staff

*"Frustrated, sad, angry, guilty, unrealistic expectations... we are responsible & accountable for providing palliative care. This is often undervalued."*

Most participants in this research felt that the complexity of their role was neither understood nor appreciated by those without direct experience of delivering palliative and end of life care in social care settings. This included society in general but also other health and social care professionals. They spoke about their feelings of not being listened to, and of their work being dismissed as unimportant or unprofessional.

These sentiments were further exacerbated by the shortage of care staff. With so many participants emphasising the importance of having time and 'being there' for people at the end of life, they perceived the lack of opportunity to do this because of a lack of resource as an indication of death and dying not being respected as a crucial element of social care support.

This feeling of being unappreciated also has a significant impact on staff confidence. One staff member gave an example where someone she was supporting with dementia was transferred to hospital. Whilst there, her view was that the interventions the lady experienced were inappropriate and distressing given her particular needs.

However, the care worker had felt that the setting was too "medical" for her to be able to impart her views on what the individual really needed and wanted at this time. Having explored just how many enhanced skills are required to deliver palliative and end of life care in independent sector services, it should not be the case that care staff feel inadequate or unable to share their knowledge, views and experiences with colleagues in other sectors or services. To the contrary, they should be regarded as experts in this field and key contributors to an individuals' palliative or end of life care journey.

## Valuing staff support

This sense of value also needs to be meaningful and experienced as standard in carers' workplaces. This does not only relate to recognition of the role they do, given that most employers will be the strongest advocates of their staff and the varied, complex and skilled roles they undertake. Instead, it relates to valuing staff's own wellbeing through recognition of the impact that the dying journey has on them as individuals. This form of value manifests in practical terms, at least in part, as the availability and quality of staff support.

*"Some people want to talk about it, others don't. I support myself, but I could have more support."*

*"There's no emotional support for us as carers. Sometimes you can get depressed."*

Most participants recognised the existence of some form of support mechanism within their organisations, including confidential staff helplines, breaks in between the allocation of individuals requiring palliative care, and opportunities for one-to-one conversations with employers. However, many either hadn't utilised these supports or felt they fell short in their ability to adequately address the needs of care staff experiencing the effects of trauma and loss.

*"Support is somebody in an office. They don't often know who I am talking about...they know who I am looking after on paper."*

Instead, staff recognised that their main form of support was through other colleagues.

*"We comfort each other as staff."*

This could be equivalent colleagues, senior carers, managers or other staff but where there was huge divergence was in the relative effectiveness of these informal supports between care home and care at home services.

Care home staff tended to note the availability of other staff members for advice, guidance and mutual support. Some said they "felt lucky" to have this built in support system in comparison to their colleagues in the more isolating environment of care at home services.

Care at home workers raised issues of feeling separate from other services, having less face to face contact with colleagues and undertaking rural working as factors contributing to their sense of being unsupported in their palliative and end of life care roles.

*"At least in the care home there is a team. Here, we are very remote and so all of us just end up parking in a layby and having a good cry."*

*"You need to know someone is at the end of the phone 24/7, especially with lone working. But that's all we have to support us."*

The very nature of this work environment makes the establishment of strong, interpersonal support networks more challenging. Nevertheless, this does not take away from the need for care workers to feel accompanied and assisted on their palliative and end of life journeys, or for that support to be tailored to the individual and reflective of their uniqueness in the same way that the care they deliver to others is. It therefore calls for us to discover more innovative solutions, created in partnership with a workforce who knows what support it needs.

Where these two forms of care service did not differ in relation to staff support was on the issue of time. More specifically, individuals from both types of service identified the lack of sufficient time for staff to be supported through a death or other traumatic experience before they are expected to resume their roles.

*"We had a 19 year old carer, who had cared for a man for a year and a half. She sat with him as he died. After it she walked out, I gave her a hug, she cried and then we had to set up lunch. I thought, 'this is terrible, she needs someone'."*

*"I go and have a cup of tea, then it's back to work."*

*"Someone I knew took a week off because their dog died. If I deal with a death, I'll probably need to do the rest of my shift and the gap in my visits will immediately get filled."*

Whilst it is true that some staff want to retain a sense of normality and keep busy as a means of dealing with their experiences, the fact that time and space does not seem to be available for those who do require it is problematic. It could even be that some of those who choose to 'get on with it' do so because they don't feel they have support options at present.

## Valuing resources

The issue of time points to a wider concern within the care sector of stretched and under resourced services, staff shortages and inflexible 'task and time' care at home contracts. The current commissioning, regulation and delivery environment is not compatible with a person-centred outcomes-based approach to palliative and end of life care and certainly not with one that values the wellbeing of the carer as well as of the supported individual.

*"We are at the bottom of the pile. Only critical care needs are paid for... It's all down to money."*

The issue of commissioning constraints on time was echoed in participants' reflections on individuals' needs, as well as their own. As with most elements of the dying journey, the experience of the worker is intimately and inextricably linked to that of the person they are supporting:

*"You don't have enough time to give this dying person what they want... not even what they want, what they need."*

*"Who is there the rest of the day? We would love to stay with her. By the time we've changed her pads, we have 7 minutes with her."*

In these discussions, staff highlighted the ways in which time restrictions negatively impacted on their ability to deliver the holistic care required by an individual at the end of life. For care at home staff in particular this is a real challenge, because they are often constrained in their provision by contracted care hours. Whilst participants spoke of the frequent need for 24 hour practical care interventions for individuals at the end of life, they also felt strongly that they just needed to "be there" at the end of someone's life:

*"I will spend as much time as I need when it is needed... I forget about the schedule. I use my own time if I have to."*

This commitment to ensuring people feel comforted, supported and loved could clearly be all-encompassing for care staff. Numerous examples were given of staff who had spent significant proportions of time "being there" for people on the end of life journey, but that the limits on their working time meant a pressure on them to fit their lives around providing this support. This is testament to the dedication of this workforce, but can result in burnout from poor work/life balance or facing criticism from employers or regulators in relation to the fulfilment of their many other obligations.

## Valuing solace

Having considered the many ways in which delivering palliative and end of life care demands exorbitant amounts from the people who deliver it, and having explored the complex stresses and strains the social care workforce contend with on a daily basis in doing so, one might quite reasonably ask why anyone would want or indeed choose to deliver this care.

The answer, as articulated so eloquently by the research participants, is that whilst this journey takes a lot from you, it also gives a lot back. Not least, it provides care workers with a unique sense of self-worth and purpose.

*"I really like working within palliative care. You can make the end of their life special. It's more intimate."*

*"It's really rewarding... to be there to hold somebody's hand."*

*"I feel proud because I have helped someone in their last days."*

*"It's a privilege to do this... an honour."*

Whilst paperwork, systems and clinical interventions form essential parts of this unpredictable journey, the one constant is the value and reward of the relationships it generates. These attachments mould care staff in different ways with each experience.

*"If the family thank you at the end, that gets me through my job. If the family is happy, I feel great."*

*"I want the family to know I did a good job."*

It is these small gestures of appreciation which keep our care staff supporting the solace of so many individuals in the extraordinary ways they do.

However, it is imperative that as a matter of priority, we show our appreciation of this workforce and value their role in palliative and end of life care on a much larger scale.

## What does 'good' look like?

*"Somebody saying, "I'm glad it was you who was with him.... The part I played in a good death being recognised."*

# 8.   CONCLUSIONS

**Palliative care and end of life can be traumatic. It is premised on impending loss. It can be painful, frightening and lonely. It stretches and strains everybody involved in supporting someone at end of life, often more than they have ever been before and sometimes to their absolute limits.**

But it can also be beautiful. It is centred on life, both ongoing and already lived. It can be peaceful, comforting and full of love. It can repair people, not physically but emotionally and spiritually, and can be the catalyst for attachments that long outlive any person.

Either way the experience etches itself onto the memories and lives of those associated with it, never to be the same again, like the rings of a tree trunk. It will always be sad, but not always at the expense of some happiness.

What we ask of our social care workforce is that they occupy and direct the space between traumatic and beautiful, navigating through sadness and happiness along the journey.

Complex? Daunting? It is both, yet this report has highlighted the vast number of ways in which it is also so much more. There is perhaps no other career that asks people to bend to unpredictability, emotion and constant change in the way that social care, and palliative and end of life care in particular, does.

This reality was depicted so eloquently by a care worker in Dumfries in the first of the four research focus groups. Unprompted, they said, "We are the trees that bend in the wind" to describe the ways in which they adapt, change and are changed by the circumstances of a palliative or end of life care journey. It implies pressure, strain and the risk of breaking, or at least of losing part of oneself in the process. But it also suggests the opportunity to return to calm if those forces are relieved, to continue to act as a pillar of strength and to flourish in the right conditions.

Whether the tree grows, loses branches or breaks entirely is dependent on the elements of nature. Whether a care worker develops, gives too much of themselves or faces intolerable strain is dependent on the conditions surrounding the support of palliative and end of life care. And whether an individual going through the palliative and end of life journey has a traumatic or beautiful experience in the social care sector is, we would argue, largely premised on the strength, ability and skills of the front line workforce.

The tree, care worker and individual might always be bent and changed by their experiences, but there are always damage limitation opportunities and indeed ways in which strength can be nurtured.

In summarising what front line care staff have told us about their experiences of delivering palliative and end of life care, this tree metaphor remains particularly illustrative.

## Root and branch: the thorough or radical nature of a process or operation

Many people would identify 'being made comfortable' as important in end of life care. What may not have previously been understood are the complexities and nuances that comprise the achievement of comfort – on both a physical and psychological level. This report highlights the vast range of technical and practical competencies that care workers have to utilise in palliative and end of life care delivery. This time of life is the most fragile, precarious, precious and completely dependent on appropriate care and timely clinical interventions. Care staff require extensive knowledge about conditions, signs, symptoms and the dying journey in its entirety in order to best target support and also to know when to ask for additional expertise and input. We would argue that end of life is often the most care-intensive period of someone's life and requires much more from care staff than just a hand to hold. We hope the content of this report has provided a better understanding of the range of interventions the front line are engaged in.

Yet presence, tactility, affection and reassurance are equally fundamental elements of providing emotional and spiritual comfort through palliative and end of life care, and require an additional yet completely different set of skills from care staff.

This workforce prioritise and epitomise truly holistic care provision, including the recognition of spirituality, wishes and mental health needs, and are the foundation around which a 'good death' is built. Front line support workers have extremely high levels of emotional intelligence and are incredibly perceptive to the needs of the people they care for. These skills are such an important part of their role in supporting solace, but are completely undervalued and often not even acknowledged by people making significant decisions about the organising and financing of this crucial area of care. Additionally the support worker is often the voice of the person they care for and the linchpin around which their support is coordinated. They advocate on an individual's behalf, support decision making, update other health and social care professionals and inform family members. They defend a person's rights and wishes, in life and after death, and more often than not out-with contracted and paid arrangements.

This root and branch approach to palliative and end of life care asks, nay demands, an inordinate amount of personal and professional outlay from staff but it is what characterises this social care workforce. It highlights the unique contribution that social care can make to someone's life, and emphasises the importance of preserving the 'human' element of care delivery in every setting. A dying person is so much more than their prognosis, and a care worker is so much more than someone who delivers specific inputs to them.

## Out on a limb: in a position where one is not joined or supported by anyone else or is otherwise isolated

Yet we expect care staff to undertake this huge ask as just another part of their job. We assume they'll not only get on with it but do it well, often without professional input or societal recognition. As a result, the independent care sector and its invaluable workforce are often excluded from workforce planning processes, professional decision making forums and public consciousness of esteemed professions or essential care services.

This report highlights how excluded many care workers feel from support within their organisations and from wider health and social care integrated working arrangements. We would argue that this is no longer acceptable.

It is essential that the workforce feel empowered to make informed decisions and to adapt care when required, and that they experience an organisational infrastructure which is supportive to their own solace. We know that this is especially difficult for care at home services whereby the current nature of care delivery dictates the reality of highly structured working practices and less location-based staff teams and therefore workers can feel more alone and isolated. Yet regardless of setting it is imperative, and time critical, that innovative solutions are developed to support this workforce in emotional and challenging situations. Support and its intensity will look different for different people, but its availability should not.

What's more, an integrated health and social care landscape needs to not only be inclusive of the independent sector but must clearly recognise the skills, experiences and observations of its workforce as equally valid and professional. At present, many care staff feel subordinate to their health colleagues and that their role is not valued by others. They recognise and would welcome opportunities to learn from and with other professionals involved in the delivery of palliative and end of life care. However, they don't believe that external colleagues appreciate what care staff can bring to the table, or that they necessarily understand the role of care workers in palliative and end of life care. This is not helped by the current use of language to describe different roles in health and social care; whilst we refer to 'health professionals', we do not attribute care workers with a similarly esteemed title and we certainly do not explicitly recognise their often specialist palliative and end of life care abilities. In fact, as evidenced in this report, there isn't even a consistency of terminology across care staff themselves.

For palliative and end of life care provision, it is not only useful but vital that everyone works together to implement whole system change. If we can't get it right for this type of care, which epitomises the need for care and resource to follow the person, we will face huge difficulty in realising the ambition for health and social care integration and in shifting the balance of care from acute to community settings.

We would argue that placing care staff out on a limb in the health and social care landscape will not achieve the person-centred care that the Strategic Framework for Action demands.

## Up a tree: in a difficult situation without escape

The research has also highlighted the personal impact on care workers of supporting someone at the end of life. Whilst this can be positively life-affirming in terms of relationships, fulfilment and a sense of purpose, more often than not this impact is felt in terms of post-traumatic stress, suppressed feelings and detrimental emotional and physical wellbeing. We cannot underestimate the impact of sadness – a word that was often used by participants in the focus group discussions. If someone continually feels sad, this can potentially manifest itself as depression and unhealthy behaviours and lifestyles. If we expect care staff to routinely and relentlessly provide intensive palliative and end of life care, sadness will become a dominant emotion.

We therefore know that staff require opportunities and mechanisms to channel their emotions constructively. They need sufficient space and time to achieve some relief and closure from end of life experiences - whether they are positive or negative. They also value opportunities for reflection and demonstrated a willingness to continuously learn, improve and develop. This is extremely positive and indicative of the quality of staff working in palliative and end of life care provision, but quickly becomes a concern if the only escape staff can identify is through exiting the social care sector due to intolerable practical and emotional burdens.

We must recognise, plan for and respond to the impact of death, dying and bereavement on care staff in the same way we anticipate and support the needs of individuals receiving palliative and end of life care.

## Can't see the wood for the trees: fail to grasp the main issue because of over-attention to details

If we can't talk about dying, how can we write about it?

The research has identified that proactive and positive preparation for death is still a huge societal and sectoral challenge.

This includes individuals, families and care workers being able to openly discuss preferences and wishes around death and dying. It also relates to communication with families and health and social care staff, and between colleagues, in terms of breaking bad news around death. Finally, it incorporates the effective and timely capturing and sharing of information through anticipatory care plans.

Whilst each of the many complex elements of palliative and end of life care are essential to explore and are successful in helping to inform the wider picture, we also need to grapple directly with the wider issue of our response to death and dying in Scotland.

Throughout the report, examples are given of both the benefits of talking openly about death and the dying experience, and the negative consequences where these fundamental discussions have not taken place. Often, families cannot bear to talk about death with their loved ones, and care professionals cannot interrogate their own feelings about death in order to place them in context to the delivery of end of life support to others. The intention of this report is not to be critical towards particular sectors, professional groups, organisations or individuals. Not being good about talking about dying is endemic throughout society. Nevertheless, the report highlights the need for everyone to become more comfortable with the concept that death is an inevitable outcome of life.

We need to ensure that anticipatory care planning in its widest sense is not only compatible with the changing landscape of care delivery in which more people are supported at home and in homely settings but that it both fits with, and drives, more open and honest discussions about death.

## Money doesn't grow on trees

It does not need this report to remind people that we are facing significant resource issues in the social care sector. These relate to staffing levels, capacity, time, skills mix and learning, as well as the obvious funding challenge.

What this report does highlight is the risk we face if the resourcing issue for palliative and end of life care is not addressed as a matter of urgency. Clearly the current commissioning, regulation and delivery infrastructure pertaining to older people's care is not serving to support a good death, or even access to a clear palliative care pathway. Staff are increasingly being stretched to breaking point and are leaving the sector, more older people are dying alone and without essential supports, and attention is disproportionately directed towards safety and practical care rather than holistic, ambitious support that is often recognised in other care pathways such as the terminal diagnosis of cancer. This report celebrates that people are living longer lives, but people do not die of 'old age' as a condition, and older people's journeys and often multi-morbidities need to be equally recognised and their experience valued.

We recognise that much of this is changing, but it is not changing quickly enough nor is this change sufficiently attuned to the particular challenges of palliative and end of life care provision for older people. Current initiatives are also unlikely to address the fundamental issues of constrained budgets coupled with higher expectations, leading to the ongoing and damaging expectation that care staff can continue to do more with less. We can't afford to paper over the cracks; the implications of doing so could result in a slow – or perhaps rapid – demise of a critically important sector.

Positively however, much of what is required can be addressed through using resources more effectively and having open, honest and sometimes challenging discussions about what it is that we want our care services to deliver in relation to palliative and end of life care. The health and social care sector has an invaluable resource in the independent sector workforce, but it is being put under so much pressure with so little access to learning, support and sufficient time that it is not being used to its potential.

Something will give, and the people we support through the dying journey deserve us all to both recognise this, and do things differently. Money may not grow on trees, but neither do dedicated, skilled staff with the motivation to deliver the best possible end of life care. Neither can be realised nor sustained by a hope and a prayer.

## A tree is known by its fruit

It cannot be emphasised enough that the fruit of the social care tree are the workforce.

The remarkable individuals interviewed as part of this research personified the principles and values that any of us would want to be upheld in our own dying journeys. "You can't train empathy" is what they told us, and their relative lack of training but extremely high levels of empathy demonstrated this. They were brimming with innovative ideas and personal ambition for improving the end of life experience for all individuals. This filled us with hope about what the future of the dying journey could look like if we listen more to our front line care workforce and include them in more conversations – at a local and national level.

However, even these committed individuals and their colleagues will be insufficient in meeting the palliative and end of life care needs of our population. They themselves emphasised how strained they are as a result of current staff shortages, and recognised how critical it is that more people enter the workforce and are able to deliver high quality end of life care.

This has implications for recruitment procedures, and the report has highlighted how important it is that interviews and subsequent selection decisions are values-based. We need to better inform prospective care workers about the reality of the role and support them through the opportunities and challenges it presents. Initiatives such as the Scottish Social Services Council's 'Careers in Care'[9] can contribute to this if palliative and end of life care delivery is given prominence. It is counter-productive to recruit people into the sector without emphasising their critical role in caring for people at the end of their life and all that that entails. Without honesty about the role, we are not supporting people to remain in the sector, develop a rewarding career or to cope with the complexities of palliative and end of life care.

Prioritising emotional skills as much as practical competency also has implications for regulatory practice. The new human rights-based National Care Standards recognise holistic care, including spirituality, as fundamental to the care experience. In fact, they are premised on the individual's experience of care rather than on interventions which is exactly what care staff have told us should be the case for palliative and end of life care delivery. It is therefore imperative that the health and social care system orients itself to be conducive to this approach, and that inspection – and regulatory expectations - against these standards follow suit. There is no better way to test how this works in practice than against palliative and end of life care provision. This may require us, in collaboration with partner organisations, to review current qualification requirements and expectations and their relevance for the front line workforce, in order that we are equally valuing emotional and academic intelligence.

## Top of the tree: holding the highest level of a profession or career

Finally, we hope this report enables people to see that the work of the social care front line workforce is professional, intensive and complex. It requires a very wide yet very specific set of skills in order to deliver high quality palliative and end of life care which, it could be argued, sets them apart from other professions and even other colleagues within health and social care.

We therefore need to recognise and value care staff appropriately for these skills and their profound impact on people's lives, and deaths. They are experts in this field, and their voice needs to be heard in all professional forums in order to enhance knowledge transfer, partnership working and mutual respect.

We also need to better articulate their stories in a wider sphere, to celebrate and promote how important they are to individuals, families and the future of an integrated health and social care landscape. They deserve the highest level of professional and public esteem. It is incumbent on us all to ensure this happens.

[9] http://www.sssc.uk.com/your-career-in-care

# 9.   RECOMMENDATIONS

**As we progress further into the implementation of the Strategic Framework for Action on Palliative and End of Life Care 2016-2021[10], we believe that the voices of the front line social care workforce contained in this report and the messages they have about their experiences are not only valuable but essential to the future direction of palliative and end of life care in Scotland.  They need to be heard in the commissioning, strategic planning, regulation and delivery realms of health and social care and must be used to inform change in all of these areas.**

A good death in social care requires integrated services to prioritise person-centredness and to nurture the workforce who support death and dying.  This principle sits behind the following recommendations, which Scottish Care consider to be essential elements of an ongoing, collaborative journey to achieve and sustain high quality palliative and end of life care for all who require it.

## Maximise the timely & effective use of palliative and end of life care resources at a local level

Scottish Care recognises that there are already a considerable number of resources to support staff in their work in palliative and end of life settings.  However there seems to be little co-ordination of these resources, and varied access to them.  This includes individuals and local services with palliative and end of life care expertise.  As health and social care professionals increasingly work together to ensure the best outcomes for those who use our services, we would like to see:

- Mapping of existing resources so that any individual organisation is able to identify local resource, its nature and availability.  Scottish Care is currently undertaking an exercise to map good practice, innovation and partnership working in the independent sector around palliative and end of life care, which can contribute to this wider, collaborative piece of work.

- More joint working and learning with other palliative and end of life care partners including hospices, district nurses, GPs and others.  There are already some positive examples of shared learning and co-operation but we believe this collaboration needs to be enhanced and happening much more routinely.

- Particular attention should be given to the development of diverse resources to appeal to different contexts and workforce groups, especially those currently under-represented such as front line support workers in care at home services.

## Develop equal pathways through palliative and end of life care

Scottish Care believes that it is imperative that every individual has the right to access appropriate palliative and end of life care and supports, regardless of circumstances, status or geographical location.  Critical to this is the development of work which embeds a human rights based approach to the exercising of choice and control at the end of life, especially relating to the rights of older people.  We are calling for the development of specific work, which focuses on the distinctive needs of older people.  Our research has highlighted the negative attitudes to old age and frailty which sometimes prevail, even in a palliative context.  Dying of frailty or dementia, for example, should have a specific pathway in the same manner as those which have been developed for cancer and other conditions.

## Promote the use of anticipatory care plans (ACPs) for palliative and end of life care

This research has highlighted the critical and invaluable role of anticipatory care planning.  Scottish Care believes it is fundamental for the enabling of a quality end of life experience based on individual choice and autonomy that plans are developed as a matter of course.

These plans need to be consistent, integrated and accessible.  They must be developed at an early enough stage in someone's palliative care journey that they are able to contribute to it most effectively, for example if they have a diagnosis of dementia and communication may become more challenging at a later stage.

In particular it is essential that information is communicated and transferable across the different health and social care sectors, and that an ACP developed in one sector is given equal value and validity in another.  Work needs to be undertaken as a matter of priority to address barriers which practitioners in the social care sector experience in relation to information being withheld on the grounds of confidentiality.

Scottish Care is calling for the review of technology and the compatibility of existing systems.  We believe that there is significant opportunity to harness the innovation already evident in the independent sector and to ensure that smart technology is maximised in its potential to ensure positive, personal outcomes for individuals.

One research participant said, "End of life plan should be like a birthing plan."  In that sense the control is with the person not the professional.  It travels with the person and is a passport to quality provision.

## Get better at talking about dying

We are all dying.  We all need to become much more confident about talking about dying and the end of life.  Scottish Care would like to see the promotion of a National Conversation about Dying.  Such a conversation can learn much from the experiences of the women and men who are employed as care workers.  As part of this, Scottish Care is calling for support to be given to staff to enable them to develop both the leadership skills and confidence to talk about dying with the people they support.

## Make dying a positive career choice

The staff interviewed in this research consistently highlighted the extent to which they saw it as a 'privilege' to be involved in someone's death.  The development of 'values-based recruitment' strategies need to include the recruitment of staff who are empathetic, comfortable with and open to issues around the end of life, or have the potential to be.  Strategies must also be mindful of the different ages of entrants into the social care workforce, and adapt support accordingly.

We need to be honest about what role palliative and end of life care plays in the overall work of care staff, but as part of this emphasise that positive end of life care is a significant component of what makes it such a rewarding career.

The success of this is dependent on the prioritisation of support, learning and development opportunities throughout a care worker's career, from induction to retirement.

We would like positive stories about caring for older people at the end of their lives, including from families who have experienced social care support to their loved ones, become much more prominent in communicating social care as a career of choice.

## Put care homes and care at home services at the heart of palliative and end of life care education

Scottish Care welcomes Commitment 3 of the Strategic Framework for Action, which relates to the development of an integrated palliative and end of life care educational framework.  We believe that it will be critically important that such work sharply prioritises and focuses on the distinctive contribution of social care staff in palliative and end of life care contexts.

As we have stated in our recently published report, Voices from the Nursing Front Line , Scottish Care is calling for the focused development of nursing specialisms within social care which target the distinctive contribution of the care home sector and, in this regard, especially around palliative care.  Nurses should be part of integrated development teams so that their enhanced palliative clinical skills can be accessed in a timely and appropriate way, and care workers can support, be supported by and learn from these interventions.

Scottish Care is calling upon our colleagues in further and higher educational environments to more strategically focus not only on developing but on highlighting the expertise social care staff bring to palliative and end of life care.

## Ensure staff - and families - have access to bereavement and counselling services

This research has highlighted something which is palpably obvious and that is that the death of the individual receiving focused care is not an end point on the palliative and end of life care journey for either care workers or family members.  We would like to see the development of a co-ordinated mechanism by which existing high quality post-death support services could be identified and signposted for individuals.

For care staff in particular Scottish Care is calling upon those who commission and provide services to be aware of the impact of working in a palliative and end of life context upon care staff.  We recognise that a great deal of support to such staff will be delivered in informal ways and in-house.

However, we are calling for the development of flexible approaches which would give staff space and time to access a range of options appropriate to them as individuals, especially addressing the challenges of professionally and geographically isolated workers.

Scottish Care would like to see consideration given to the development of structured support groups for care staff – both formal and informal. This would enable them to work through the issues which working within a palliative and end of life care context may give rise to, in whichever way is both practical and most comfortable for them.

## Ensure palliative and end of life care support and training is specifically targeted at the needs of the front line workforce

Effective and appropriate staff learning and development for front line support workers is central to the delivery of person centred palliative and end of life care. Scottish Care is calling on all partners to work together to develop programmes of support for this workforce to meet the growing and developing needs of end of life and palliative support in care homes and in care at home services. Such support needs to take account of the totality of an individual's career from induction through to retirement, utilise a wide range of approaches (especially blended learning) and be aware of diverse geographical contexts particularly the challenges of solo, remote and isolated working. Further learning support and development also has to recognise the growing complexities offered by multi-morbidities, neurological conditions, advanced dementia, HIV, etc.

## Commission solace

Without doubt a consistent message which participants in this research have highlighted is the urgent need for Integrated Joint Boards and Health and Social Care Partnerships to have honest conversations about what can be expected around palliative and end of life care under current commissioning arrangements, and whether time and task commissioning is compatible with this. Included in the necessity of such honest discussions is the degree to which contract monitoring systems, a common feature of current care at home tendering processes, can be suitably adapted to enable appropriate flexibility in palliative and end of life situations. It is imperative that ongoing discussions around the care home reform programme take this into consideration also.

Scottish Care would like to offer the use of our active forums, in which support workers participate, to work alongside commissioners and others to develop person-centred approaches to palliative and end of life care.

Scottish Care is also calling for a range of partners and stakeholders to work with us in identifying what 'good' could look like in a palliative and end of life care experience, and what resources and capacity would be required at the front line of social care. In particular we would wish to explore the potential for Self-Directed Support in enabling a person centred, choice oriented and rights based approach to palliative and end of life commissioned care for older people.

We believe it is possible within an integrated environment that the front line worker travels with the person they are supporting, thus ensuring critical, trustful and effective relationships are maintained. We also believe that this requires an exploration of the development of an integrated care worker role. If we cannot achieve meaningful cross-sector working in an end of life and palliative context then we are unlikely to achieve such co-operation elsewhere.

## Rearticulate the role of a front line social care worker

This research has highlighted the degree to which the social care sector needs to undertake work to better ensure that both health partners and the wider public gain a better understanding of what constitutes the role of a care worker today. This is a highly demanding, multi-skilled, autonomous and professional role. It needs to not only be recognised as such but appropriate value needs to be bestowed on those who do this fundamental work.

Consideration also needs to be given to whether existing job titles and their variable use are adequate for explaining the breadth and extent of this work, and for encouraging cross-sector professional recognition of the skills and knowledge of front line care workers.

## Provide better support to employers to enable them to support solace

The only way we can effectively support the key contribution of the front line workforce is if employers feel valued, equal and have sufficient investment in their services to implement training, learning and innovation, all of which enhance the 'wellness' of their employees.

There are various practical steps which contribute to this, including building in reflective palliative and end of life care 'space' and ensuring that all staff, regardless of their role in an organisation, are informed about the dying journey and its impact on the workforce. Understanding the importance of achieving closure and appreciating the grieving process – such as enabling staff to attend funerals and to spend time with bereaved family members - is part and parcel of a holistic approach to promoting staff wellbeing. We therefore need to better understand what organisations and employers need in order to achieve this in a consistent way.

Scottish Care has already begun this process by surveying our members on their organisational needs in relation to palliative and end of life care and staff support in particular.

Fundamentally this research has articulated the intrinsic value and contribution of front line social care staff and independent sector care services to achieving positive palliative and end of life care. Scottish Care believes it is therefore essential that these lessons are recognised in the on-going current debate about the sustainability of care home and care at home services and the critical role they play in both their local communities and the wider health and social care system.

## Protect the physical and mental health and wellbeing of the workforce

Our workforce is our greatest asset in social care. It is equally true to state that this workforce gives way above and beyond what they are contracted to do in order to deliver astonishing levels of care and support to people at the end of their lives. Commissioning and resourcing of effective services has to incorporate support to organisations to better enable them to look after the physical, emotional and spiritual wellbeing of the workforce. This is already a key priority of Scottish Care as an organisation. We recognise in this research and in our other work that the social care workforce is enduring unacceptable and unsustainable levels of emotional fatigue, stress and distress, which is having a negative impact on their mental wellbeing.

In order to deliver high quality palliative and end of life care, Scotland needs its front line social care workforce to be physically and emotionally healthy. In order that this can be achieved, Scottish Care is calling upon our partners to work with us to ensure an infrastructure that promotes wellness in its entirety is established.

*This report illustrates the immeasurable contribution of the independent sector front line workforce in offering a sense of solace in palliative and of life care; a workforce which bends according to the needs of the individual and moulds itself to the seasons of the dying person. This tree that bends is at risk of breaking unless all of us work together to ensure we resource, collaborate, develop, and create strength in the grounds of that solace.*

## THANK YOU

**Scottish Care would like to sincerely thank everybody who contributed to this report. To each person who participated in the focus groups a special thanks is due. It is your willingness to share so many personal, moving and insightful accounts of caring for people at the end of their life that has enriched the pages of this report.**
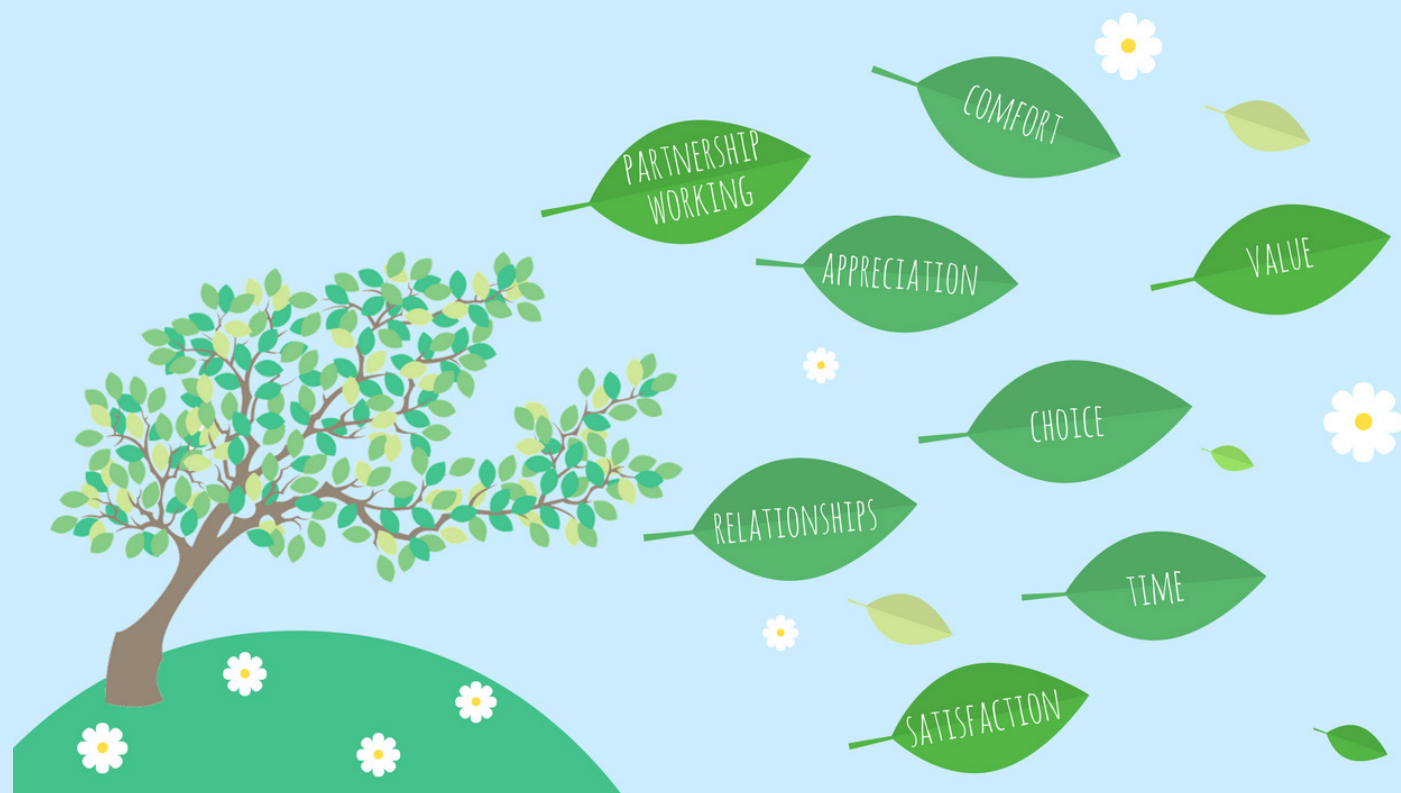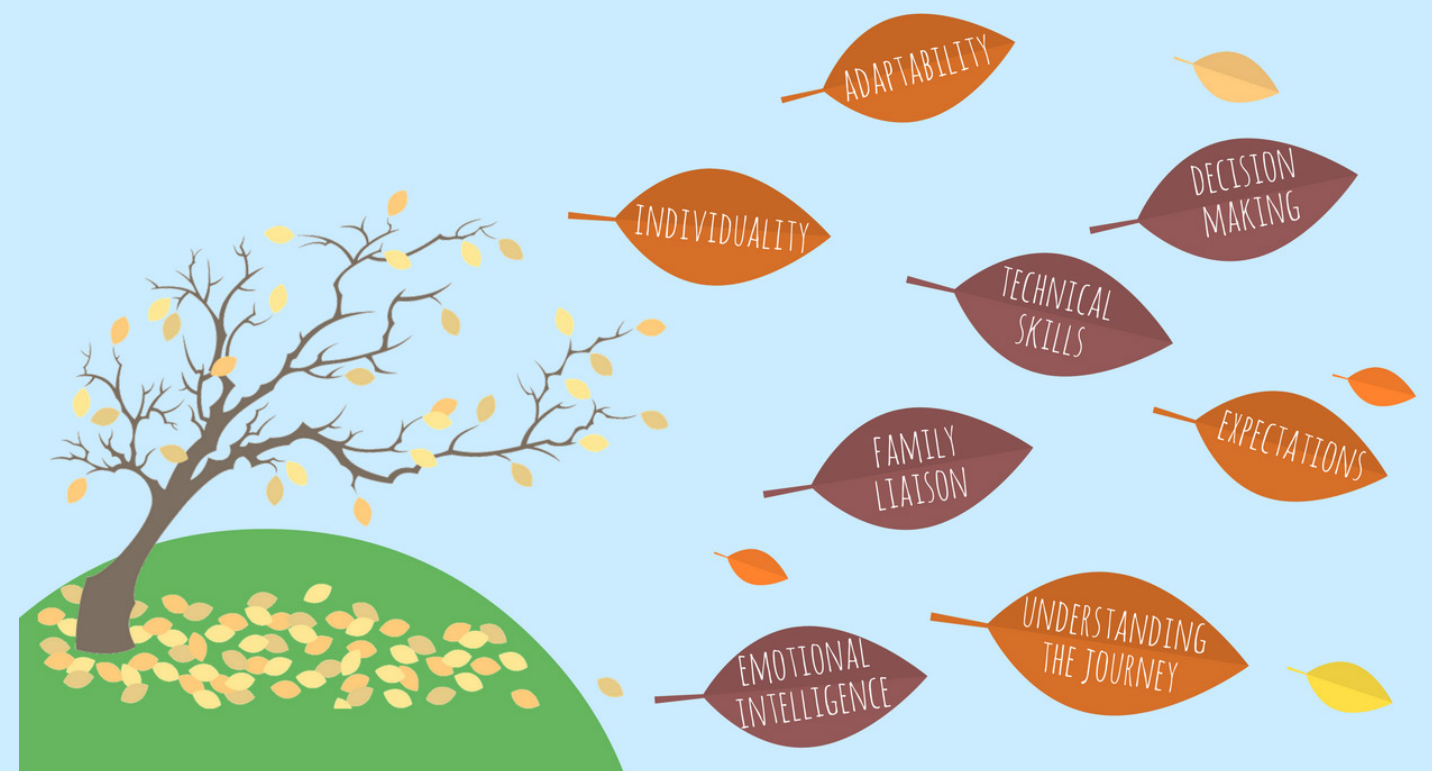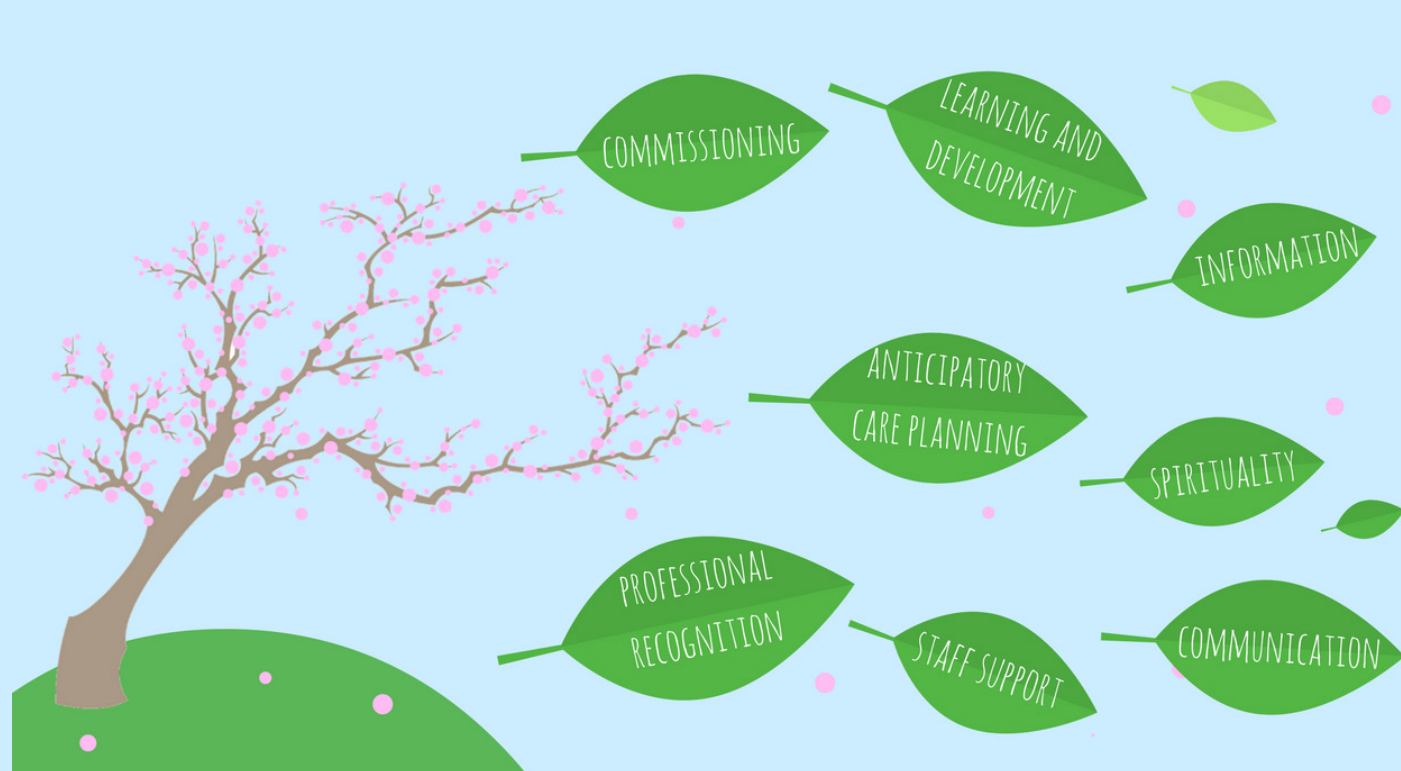
We also want to thank the organisations who supported this piece of research by enabling staff to attend and offering to host the focus groups. Allowing us to speak to such inspiring and dedicated social care workers has helped Scottish Care share the compassionate and complex end of life care being delivered to a wider audience. Your commitment continues to be a vital element of ensuring the voices of the front line workforce are heard.

We would also like to thank the Scottish Care Local Integration Leads who helped organise the focus groups in their localities, and participated in the discussions. Your support and help, as always, was invaluable.

The focus groups were conducted by Dr Donald Macaskill, Katharine Ross and Becca Gatherum.

This report was written by Becca Gatherum, with support from Katharine Ross and Dr Donald Macaskill.

COMMISSIONING

LEARNING AND DEVELOPMENT

INFORMATION

ANTICIPATORY CARE PLANNING

SPIRITUALITY

PROFESSIONAL RECOGNITION

STAFF SUPPORT

COMMUNICATION

ADAPTABILITY

INDIVIDUALITY

DECISION MAKING

TECHNICAL SKILLS

FAMILY LIAISON

EXPECTATIONS

EMOTIONAL INTELLIGENCE

UNDERSTANDING THE JOURNEY

PARTNERSHIP WORKING

COMFORT

VALUE

APPRECIATION

CHOICE

RELATIONSHIPS

TIME

SATISFACTION

ANXIETY

BREAKING BAD NEWS

PAIN

ISOLATION

GUILT

CONFLICT

BEREAVEMENT

STAFF SHORTAGES

# ABOUT SCOTTISH CARE

**Scottish Care is a membership organisation and the representative body for independent social care services in Scotland.**

A good death in social care requires integrated services to prioritise person-centredness and to nurture the workforce who support death and dying.  This principle sits behind the following recommendations, which Scottish Care consider to be essential elements of an ongoing, collaborative journey to achieve and sustain high quality palliative and end of life care for all who require it.

Scottish Care represents over 400 organisations, which totals almost 1000 individual services, delivering residential care, nursing care, day care, care at home and housing support services.

Our membership covers both private and voluntary sector provider organisations.  It includes organisations of varying types and sizes, amongst them single providers, small and medium sized groups, national providers and not-for-profit voluntary organisations and associations.

Our members deliver a wide range of registered services for older people as well as those with long term conditions, learning disabilities, physical disabilities, dementia or mental health problems.

The Scottish independent social care sector contributes to:

- The employment of over 100,000 people
- The employment of over 5,000 nurses

- The provision of 85% of care home places in Scotland
- The delivery of over 50% of home care hours for older people.

# ABOUT WORKFORCE MATTERS

**This report has been produced as part of the Workforce Matters project.**

Workforce Matters is the workforce planning & development arm of Scottish Care. Funded by the Scottish Government, this project:

- Supports independent sector providers to build their capacity for workforce development
- Engages with the workforce at a local and national level to ensure the independent sector can contribute to policy and practice development

- Supports providers to meet regulatory and registration requirements
- Ensures providers are updated with the latest employment and workforce news.

# APPENDIX 1: PARTICIPATING ORGANISATIONS

- Abbey Gardens
- ABBS – Dumfries and Galloway
- Anderson's Care Home
- Ashgill Care
- Baillieston Community Care
- Barchester – Highview House
- Black Isle Cares - Highland Home Carers
- Bluebird Care - Edinburgh
- Braeburn Care Home
- Bright Care - Edinburgh
- BUPA – Golfhill Care Home
- Call-In Homecare
- Cartvale Care Home
- Castle Care
- Constance Care
- Contrast Care

- Crossreach
- Crossreach - Eastwoodhill
- Fraser Home Care
- Glenurquhart Care Project
- Mears Care - Dumfries and Galloway
- Mears Care - Lothians
- Northcare
- Notwen House
- Oakview Manor
- Parklands Group - Urray House
- Primecare Health
- Rainbow Care
- Stewartry Care
- Stranraer Skills Station
- The Meadows Nursing Home

# APPENDIX 2: RESEARCH QUESTIONS

| Session Details | Possible Follow Ups |
|---|---|
| **Icebreaker: Participants asked to select and discuss one of the following statements in pairs.** | Selection of statements to choose from:<br>• I feel comfortable about seeing someone die<br>• When someone is dying I'm not sure if I am much use being there<br>• I think it is important to let families be on their own<br>• When somebody is dying I feel scared<br>• When someone is dying I try to be as busy as possible<br>• I am comfortable with thoughts of my own dying<br>• Some deaths really make me upset and weepy<br>• No two people die in the same way<br>• I find it hard to cry when someone dies<br>• The more people I see dying the more I get used to it<br>• People should be allowed to die the way they want to. |
| **General working experiences of palliative and end of life care: small group discussions of up to 5 participants.** | What has been your involvement, if any, been in caring for people at the end of life?<br>What has your role been?<br>What are you being asked to do? |
| **Personal explorations: small group discussions of up to 5 participants.** | Participants were asked to share, if comfortable to do so, their experiences of caring for somebody at the end of their life, ideally from their working lives.<br>How did you feel about this?<br>What did it feel like when you found that the care you would be delivering was palliative/end of life care?<br>Did this experience change as you cared for and supported the person?<br>Do you feel equipped to care for people at the end of life?<br>Do you think your organisation could have done more to support you – emotionally as well as practically?<br>Could other people or organisations perhaps have supported you? |
| **Training, learning and development: full group facilitated discussion** | Can you describe the training you have received in palliative and end of life care?<br>When did this training take place? During induction, on the job, on-line, combination or none at all?<br>Who was involved in the delivery of training?<br>Do you feel sufficiently skilled and comfortable caring for people who are dying or have received a terminal diagnosis?<br>What sort of training/learning would help you?<br>How should this be delivered? |
| **Looking to the future: group discussions of up to 7, with opportunities to write responses as well as discuss them** | A good end of life experience for people I care for would look like…<br>A good end of life experience for me as a front line support worker would look like…<br>After a death, I would feel supported if…<br>What needs to change to allow this to happen? |

# READER NOTES

**If you would like to discuss this report
or its findings, please contact:**

**Scottish Care**
54A Holmston Road,
Ayr, KA7 3BE
01292 270240
Co. SC243076