



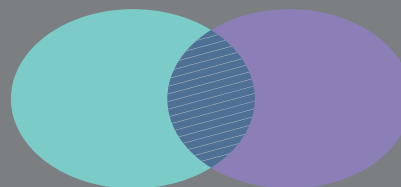
SUPPORTING SOLACE: PALLIATIVE & END OF LIFE CARE DATA REPORT 2017

PEOLC: The Survey



45 responding organisations
representing over 8,000 care
workers & over 5,000 supported
individuals

69% private sector services
31% voluntary sector
services



A range of residential care,
nursing home, specialist, care at
home and housing support
services represented, all
delivering PEOLC

The Findings

PEOLC involvement

66% of services increased their
PEOLC provision over the
previous 12 months

Average estimated number
of supported individuals with
co-morbidities

81%

85%



of support workers involved in PEOLC



28% of organisations believe that
the PEOLC needs of individuals
they support are not being met in
the way they would best want to
meet them

Training



70% of organisations provide specific
PEOLC training
with 40% of this delivered regularly

Nearly a third of training delivered
in partnership with the NHS, with
the same amount delivered with
hospices



But **55%** of organisations
believe current training is insufficient to
equip staff to deliver PEOLC

Support



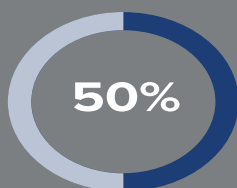
Over three quarters of
organisations provide
emotional & spiritual support
to staff

68% of organisations want to be
able to provide more emotional
& spiritual support



56% do not provide
bereavement training

Value



Receive NHS
support for
PEOLC



61% feel their
role in PEOLC
is valued



Only 12% are
commissioned
to deliver
PEOLC



1. INTRODUCTION

This short report has been produced as a result of survey research undertaken with members of Scottish Care.

The survey and resulting report has been produced as part of Scottish Care's *Supporting Solace* research project, which commenced in November 2016 and focuses on the provision of palliative and end of life care by independent sector social care services in Scotland.

The *Supporting Solace* project has a number of aims:

- 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
- To identify the current skills, plus the training needs, of the front line care workforce in the independent sector
- To explore the emotional, psychological and spiritual impact on front line staff of delivering palliative and end of life care
- To identify any recommendations which would better support palliative and end of life care delivery within an integrated workforce environment
- To identify innovative and best practice around palliative and end of life care provision within the independent sector.

To achieve these aims, Scottish Care carried out four elements of original research:

- Focus groups with front line workers in independent sector care home, care at home and housing support services across four geographical locations
- A survey for managers and owners of independent sector care organisations exploring their approaches to palliative and end of life care
- A collation of information around local projects, partnerships and initiatives
- An invitation for those working in palliative and end of life care to share creative examples of what 'speaks to them' about this type of provision.

This report relates to the successful completion of the second element of this research, in that it summarises the findings of a survey undertaken with Scottish Care member organisations on areas such as training, support, commissioning and partnership specifically in relation to the palliative and end of life care they deliver.

It follows on from the publication of *Trees that Bend in the Wind* in February 2017, which was a more detailed report capturing the experiences, thoughts and feelings of front line workers involved in the delivery of palliative and end of life care. The *Trees* report explored a range of important factors including the importance for care workers to feel skilled, knowledgeable, valued and supported in their work. It also highlighted the fact that delivering this sort of compassionate care goes well beyond 'work' and is bound up in the lives and personal values of those who deliver it, and sometimes to their own detriment.

Whilst broadly similar themes are explored in each report, this new report seeks to look at the more systemic context, environment and planning processes which underpin the experiences of front line workers engaged in caring for people at the end of their lives.

2. METHODOLOGY

This report was compiled from responses to an online survey, created and managed by Scottish Care and run over a two month period between November 2016 and February 2017. The survey was sent via email to all Scottish Care member organisations, with an emphasis that this should be completed at an organisation-wide level as opposed to completion by individual services.

In total, 45 organisations responded to the survey. Whilst this is a relatively small sample, in actual fact the number of workers represented through the responding organisations totals over 8% of the total independent sector social care workforce in Scotland. This reflects the fact that respondents ranged from very small organisations operating only one service to corporate organisations with a large number of services across Scotland and therefore a considerable workforce attached to these services.

Based on data collected, we can estimate that these organisations were supporting over 5,000 individuals at the time of the survey. This is a conservative estimate, given that some respondents did not complete this question clearly and were therefore discounted in this calculation.

Respondents varied considerably in terms of geographical location, with representation from services in 29 of the 32 Scottish Local Authorities. Included in this were a range of Local Authority geographical and population sizes, coterminous and non-coterminous Health Board and Local Authority areas and a wide spread of urban and rural locations.

Responses were collected across independent sector care home, care at home and housing support services. They also included organisations who operate multiple types of care services. This is reflected in the figures below:

- 42% residential care homes
- 44% nursing care homes
- 9% specialist care homes
- 18% care at home services
- 4% housing support services
- 9% combined care at home and housing support services,
- 7% other, including a community hospice team and specialist services for deaf adults

Of the responses, 69% were completed on behalf of private organisations and the remaining 31% represented voluntary providers of care services, including registered charities.

3. THE FINDINGS

Involvement

Whilst the average number of people who receive palliative and end of life care as part of independent sector support services was 42%, the actual numbers varied greatly across providers - ranging from 2-100%. Given that one provider described the people who use care home and care at home services as all being in need of some form of palliative care, the range of figures could be indicative of the uncertainty and lack of clarity around the terminology and approaches associated with palliative and end of life care.

Overall, 66% of providers reported an increase in the provision of palliative and end of life care and support over the last three years, and only 6% reported a decrease. Three reasons were given to explain these statistics:

- Firstly, there is an aging population - we are living for longer and often with complex and chronic illnesses, so more people are requiring palliative and end of life care and support services.
- People are accessing services later in life, so are often in need of palliative and/or end of life care from the point of accessing services.
- Care that would traditionally have been delivered in hospital is now being delivered in a person's home or in a care home. Some respondents also reported having to care for people for whom there were no beds in hospital.

All independent sector organisations who responded employ staff who provide palliative and end of life care. This breaks down as 85%

of support workers, and 73% of nurses reported as providing palliative and end of life care. The 10% difference implies that qualifications are not an indicator of whether or not you provide palliative and end of life care, but raises questions around access to specialist training depending on whether you are a nurse or social care provider. Training will be discussed in more detail later in this report.

Respondents described providing palliative and end of life care and support to people with a full range of conditions, but not HIV/Aids. It is actually difficult to map the type of conditions people may have because an average of 81% of people who use palliative and end of life care and support have multi-morbidities. This means that organisations and their staff are providing care and support for a wide range of symptoms and experiences. What's more, this range is likely to widen further and include conditions such as HIV/Aids in the future as people live longer despite having life-limiting conditions.

Is it good enough?

Significantly, 28% of respondents believe that the palliative and end of life care needs of the people they support are not being met in the best way. When asked 'what do you need to provide high quality palliative and end of life care?' the response was funding for training, and more staff. In addition, the themes of support (internal and external) and commissioning were also raised, and will be discussed further in this report.



Training

The *Trees that Bend in the Wind* report identified lack of training as a key issue raised by front line workers in relation to palliative and end of life care. This survey was designed to provide some context and supporting evidence however, and perhaps contrarily, the quantitative results show that 70% of organisations provide specific training in palliative and end of life care.

On digging deeper, over half (55%) of them do not believe the training their organisation provides to be sufficient to fully equip staff to deliver high quality palliative and end of life care, which perhaps shows that it is not simply the delivery of training that is important, but that the context, content and regularity of training is significant.

Many described barriers such as time and cost, with others requesting more detailed, specific and multi-disciplinary training. Another issue raised was having no review of training or training pathway – for 30% of providers, palliative and end of life care training was delivered as part of an induction or as a one-off, but was not built upon or revisited. Training was identified as one of the two most important things in delivery of high quality palliative and end of life care, the other being the number of available workers.

Given the sensitivities around death and dying, it was not surprising to find that most (83%) training is delivered face to face. Reading material was provided to 40% of staff, and 23% had access to e-learning. A significant number of respondents also described providing on-the-job support to staff, especially new staff, including regular 1:1 supervision and coaching.

For 58% of the workforce, training was delivered in-house. It would be interesting to investigate the impact this has on the ability of staff to contribute because of the potential for in-house expectations on staff, or because they are not able to focus solely on their training because they are still 'on-shift' and may need to be called away at any time.

29% of services have accessed training through the NHS, and the same number again through hospice services. In terms of partnership working, it is positive to see that collaborative training opportunities exist and it would be worthwhile to further examine the impact the undertaking of this type of training has on how well trained independent sector workers feel, as well as whether the availability of this is subject to geographical variation.

Support

Staff delivering palliative and end of life care and support reported that it can impact significantly on their emotional and spiritual needs. This survey wanted to investigate whether organisations provide support in this area, and to find out more about the type of support delivered. Interestingly, strong themes around the delivery and experience of palliative and end of life care have also been raised in focus groups with front line staff as part of Scottish Care's 2017 mental health research.

Whilst as many as 77% of organisations reported that they provide support for emotional and spiritual needs, they do this in a variety of ways to include support between staff, 1:1 supervision, and access to a specialist helpline. Significantly, 68% of providers reported that they want to offer more emotional/spiritual support. In particular, many mentioned a desire to employ a trained counsellor to support staff. More work needs to be done to investigate the appropriateness and effectiveness of current and future support,

taking in to account the style of delivery and the nature of the provision including how this differs between care home and care at home services.

A significant gap was highlighted around bereavement, with over half (56%) not covering bereavement as part of any palliative and end of life care training. Of those who do provide training in bereavement, a significant number reported the use of e-learning. It would be useful to investigate the appropriateness of using an electronic package to cover such an emotive topic, especially given that for many young staff, this is the first time in their life that they experience death.

Supervision and support from other staff seems to be the most widely delivered form of support, but many also sign post to specialist agencies such as Cruse and CRISIS. Providers linked to a religious faith described support from ministers and priests and including prayers in provision.

Value

Many respondents described the importance of joined-up care in creating a care plan. They specifically defined joined up as including the GP, Community Psychiatric Nurse, other specialists and the provider, as well as the person and their family. One provider also described the links they have with the local hospice who provide training and support.

As well as good practice in terms of delivery, it was recognised that a joined-up approach with health services also offered positive support to independent sector organisations. This support was a reality for around 50% of organisations, with the remaining 50% receiving little or no support from the NHS. The formal support reported in response to the survey was mostly targeted at registered nurses.

In addition, G.P. surgeries, national charities and local hospices were also described as being supportive in some areas. More work would need to be undertaken to deduce whether this is geographical or related to any other factor, such as the type of service, or timeliness of access, particularly given that many services indicated that they receive no support from other services.

These results raise the question of where the responsibility and expertise should lie, and whether more investigation is required into finding a strategy towards providing mutual support and more consistent collaborative working. Given that most support is targeted at nurses, this potentially identifies a gap for support workers; the vast majority of whom provide care

and support to people with palliative and end of life care needs.

A sense of value and worth is important in the workplace, and Scottish Care's previous research (namely *Voices from the Nursing Front Line* and *Trees that Bend in the Wind*) highlighted that many people working in the care sector describe feeling undervalued in society and by the media. These results suggest that the experience may be a little different at an organisational level for those delivering palliative and end of life care as 61% reported that their role in providing this support is valued. However, given that 36% said that they were unsure, it would seem that further investigation needs to be done around the impact that higher perceived value could have on joined-up working, workers' experience and ultimately, the provision of care of and support. It was suggested that multi-disciplinary training could provide part of the solution, perhaps because it would better enable professionals in different parts of the sector to understand the role of independent sector services in relation to palliative and end of life care and vice versa.

In addition, given the aforementioned finding that nurses have a greater access to specialist training than support workers despite them both delivering palliative and end of life care, it could be that a greater value is being placed on nurses than on paid carers and support workers or that their contribution in this type of care is better recognised than the equally crucial role of non-clinical staff.

Commissioning

Commissioning is an incredibly important element of care delivery, not least in relation to palliative and end of life care, in that it influences what can be delivered to an individual and how that is undertaken. Time-task commissioning and getting more for less has led to many care staff and individuals who access services describing how this focus on time and task has taken the person out of a person-centred approach to care and support. Given the emotive nuances around the delivery of palliative and end of life care, this seems to be a significant oversight, and in complete contrast with a human rights and outcomes based approach to care.

In keeping with this trend, only 12% of

respondents reported having been commissioned to deliver palliative and end of life care, yet 72% of respondents say that it either is or would be useful.

Interestingly, a range of views were captured on why specific palliative and end of life care commissioning would or would not be helpful. The reasons given as to why it would be a positive step related to improving understanding of what the independent sector delivers in this area amongst a wide range of stakeholders and would also enable services to direct resources and training to this thus further improving service quality. However, some did indicate that the nature of care provided and the needs of older

people that are supported by these organisations mean that palliative and end of life care is an intrinsic part of the service and therefore cannot be extracted in a commissioning sense. Either way, the findings highlight the need for

a more person-centred and flexible approach to commissioning which takes full account of the needs of an individual and of the service in delivering high quality palliative and end of life support to them.

Innovation

When asked specifically about innovation, very few responses came back. This may of course be evidence of the difficulty that social care has traditionally shown in recognising innovative practice within a person-centred field, given that every package of care is individual and hence in some way unique and innovative.

However, the following examples of innovation relating to palliative and end of life care were specifically highlighted:

- Local multi-disciplinary working with care home providers having free access to NHS training programme
- Local multi-disciplinary working with external specialist providers to develop a training and support programme to be rolled out across care homes via video conferencing and face to face training and support.

- A consultation event in Inverness regarding a proposed framework for palliative and end of life care
- An NHS End of Life Project in Lanarkshire
- Provision of care and support using a combination of care home and care at home services
- Membership of the Scottish Partnership for Palliative Care.

This positively indicates that some progressive work is taking place in this field within the independent sector, from which it will be important to capture outcomes and learning. To this end, Scottish Care is in the process of collating more information about local projects, initiatives and practice in palliative and end of life care with the intention of sharing this as another outcome of its Supporting Solace arm of work.



4. CONCLUSION

The findings of this report show that palliative and end of life care is a key aspect of the service provided by the independent care sector, and that demand is increasing as we are living longer. The vast majority of front line staff, be it support workers or nurses, provide palliative and end of life care as an intrinsic part of their job.

It is concerning that so many respondents believe that palliative and end of life care and support needs are not being met in the best way, and it is feasible to surmise that this number will increase as the demand for services also increases. The key reasons for this were the difficulties in recruitment and retention of staff, unmet training needs (in particular around bereavement), access to support and the impact of the way that services are commissioned.

In addition to solving the difficulties mentioned above, multi-disciplinary working and valuing the sector were given as key to delivering a high quality service.

Whilst providing an overview, this, like many surveys, has raised further issues and questions, such as the need for:

- **Increased awareness around the terminology and definition of palliative and end of life care to help identify when a person may require additional support, and subsequently, when the people working with them may also need additional support.**
- **Addressing the existence of a postcode lottery in relation to the availability of support, training and partnership opportunities based on location and the nature of the service.**
- **Consideration of the impact of a multi-disciplinary approach to supporting and training colleagues as a route to better joint working, and recognising the value of each sector's contribution to palliative and end of life care.**
- **A clear training pathway to span the palliative and end of life care journey, to include bereavement support.**
- **Established support mechanisms with clear lines of responsibility developed, applicable and accessible across health and social care, and using resources and expertise from both.**
- **Regular training that suits both the individual and the context.**
- **A human rights-based approach to commissioning which is fully inclusive of palliative care centred on flexible time allocation and relationship based care.**

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Thanks to all the organisations that took part in this research and shared their information around palliative and end of life care with Scottish Care.





If you would like to discuss this report
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