

## Brief Report

# “Compassion Outside of the Box”: The Role of Allied Healthcare Professionals in Providing a Companion Service for Patients at the End of Life During the COVID-19 Pandemic



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## Abstract

**Context.** In response to the COVID-19 pandemic, NHS England prohibited people visiting acute hospital trusts. An end-of-life companion scheme was introduced to support the delivery of care for seriously unwell and dying patients during this time.

**Objectives.** This study aims to capture the companions' experience and activities, including qualitative feedback, as well as outline recommendations for this role in future services and training.

**Methods.** The companions' service comprised Allied Healthcare Professionals working for the trust who volunteered for the role following a reduction in their normal workload due to COVID-19. They worked in shifts covering a 12-hour period every day of the week with patients identified by the palliative care team. Companions completed questionnaires containing a 4 domains mixture of Likert scale and free text responses before and after their experience. Details of the visits were recorded in daily spreadsheets.

**Results.** The majority of companions were from the physiotherapy team with a range of experience working in the NHS. In total, 64 patients were seen over 382 visits. The companions often carried out more than one activity per visit including communication with the patient and next of kin, personal care, literature, and spirituality. Data showed a statistically significant association between experience as a companion and reduced anxiety around spending time with dying people.

**Conclusion.** This study highlights an interesting approach to changing job roles for health-care professionals during the COVID-19 pandemic as well as recognizing the importance of allied health professionals in the multidisciplinary approach to palliative and end-of-life care. *J Pain Symptom Manage* 2021;62:141–148. © 2020 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

## Key Words

COVID-19, companions, allied healthcare professionals, care of the dying, end-of-life care, holistic care

## Key Message

This article describes a mixed-method study reviewing a novel end-of-life Companion service comprised allied healthcare professionals in response to the COVID-19 pandemic. The results show a statistically significant association between experience as a companion and reduced anxiety around spending time with dying people.

## Introduction

Compassionate care at the end of life (EOL) is holistic and individual.<sup>1,2</sup> Family and friends often have a significant role in supporting this.<sup>3</sup> On 8th April 2020, in response to the worsening COVID-19 pandemic, NHS England prohibited people from visiting acute hospital trusts.<sup>4</sup> Limited exclusion criteria for most trusts included restricted time slots

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with the dying and no visitors on wards for suspected or confirmed COVID-19 patients or in intensive care.<sup>5</sup> The roles of allied health professionals (AHPs) changed rapidly during this time, some were deployed to different clinical areas and others had significantly reduced workload.<sup>6</sup>

Physiotherapists are key in the multidisciplinary approach to palliative and EOL care<sup>7</sup> aiming to improve quality of life, maintain independence, and reduce carer strain.<sup>8</sup> Physiotherapists are empathetic with patients in this setting and provide respectful and dignified care.<sup>9</sup>

Companion schemes exist in a number of hospitals to support patients, families, and staff in the delivery of care for patients at the EOL.<sup>10</sup> Companions are trained volunteers, supported by the local hospice or inpatient palliative care team (PCT).<sup>11</sup> An end-of-life companion service was introduced to the trust during the COVID-19 pandemic. This was contrived of AHPs, the majority from the physiotherapy department.

This study aims to capture the experience and activities of these companions, as well as outline recommendations for this role in future services and training.

## Methods

Following advice from the Health Research Authority, this mixed-method study gained approval from the Trust R&I lead and Caldicott Guardian. It is based on fully anonymized data with the companions as participants.

The companion service ran from the 23rd April 2020 to 27th May 2020. It was led by a palliative medicine consultant, junior doctor, clinical physiotherapist specialist with experience in providing bereavement counseling, and an EOL clinical nurse specialist.

The companions were all AHPs in the trust whose workload had reduced as a result of COVID-19. The service was advertised via email and word of mouth. Those wishing to volunteer initially met with the clinical physiotherapist specialist to discuss what the service entailed and ensure they knew where to seek emotional support. All persons who had this meeting went on to volunteer as a companion. Subsequently a focused training session was delivered by the lead Chaplain and the trust specialist palliative care team (SPCT). The service comprised 28 companions. Each day was divided into three, four-hour shifts, allocated on a voluntary basis. The SPCT identified appropriate patients and a member of the team led each handover. These consisted of updates to the daily spreadsheet recording patient details alongside the opportunity to debrief. Patients were allocated by ward and previous companion visits.

## Companion Activity

The companions undertook a variety of activities covering five main themes [Table 1].

## Data Collection

A bespoke questionnaire was designed for the companions containing four domains mixture of Likert scale and free-text responses. Questionnaire content was based on clinical judgment by the team implementing the service, considering service provision, staff well-being, and benefits to patients. These were sent out as online links via email; one prior to starting and one at the end of the service [Appendix 1].

Demographics such as job role, length of time working for the NHS, and gender were collected in both questionnaires. They were asked about anxiety spending time with dying people; conducting virtual visits; their emotional response; where to seek support and the difference the service would make.

Companion activity was logged on daily spreadsheets, recording the patients seen, number of visits they had, and length of visit. They also included columns for the activities undertaken at each visit which companions would tick as appropriate.

## Results

Sixteen (57%) of 28 companions completed the initial questionnaire and 20 of 28 (67%) completed the final questionnaire.

The majority of AHPs, 15/20 (75%), were from the physiotherapy team (Figure 1). Additional job roles included outpatient nurse specialists and occupational

Table 1  
Companion Activity

Activity Theme	Activities Included
Personal care	Mouthcare, positioning, or washing the patient.
Communication	Talking about memories and interests, facilitating virtual visits, updating next of kin, or reading out letters from loved ones.
Symptom control	Asking nursing staff to assess for symptom-relieving medications. Nonpharmacological methods such as repositioning, massage, and relaxation.
Spirituality and literature	Reading a book or newspaper, playing music, or facilitating a visit from the Chaplain.
Providing company	Talking, holding their hand, or being with them in companionable silence.

therapists. One companion in each of the surveys identified as male with the rest identifying as female. The companions had a range of experience working in the NHS, from under a year to 33 years, 11/20 (55%) had worked for less than 10 years, 5/20 (25%) for 10–19 years and 4/20 (20%) for 10–19 years (Figure 2).

### Companion Activity

Over five weeks, the companions saw 64 patients and completed 382 visits. During this time, 108 patients died in the hospital and the SPCT saw 141 patients of whom 63 died. The mean number of patients seen each day was 8.6 (range 3–16, median 9) with a mean total of 11.9 daily visits (range 3–23, median 11). Overall mean minutes spent at each visit was 62.4 (range 5–150, median 61.5).

The companions often carried out more than one activity per visit (Figure 3). The calculated means across all visits show 85% (325/382) included communication with the patient, 17.2% (66/382) involved symptom control, and 2.6% (10/382) being with the patient as they died; 36.3% (139/382) involved literature and spirituality and the same number included personal care. A mean 29.6% (71/240) contained communication with the next of kin; this was only measured from week 2 onwards following ethical approval.

### Companion Experience

Initially, 7 (44%) of 16 respondents reported feeling anxious about sitting with dying patients. In the final questionnaire, none of the respondents reported this anxiety; a 100% decrease. Using the Fisher's exact

test, the  $P$ -value is 0.0014, showing a statistically significant association between experience as a companion and reduced anxiety around spending time with dying people (Figure 4).

Before participation, 9 (56%) of 16 respondents were worried about the emotional cost with 10 (62%) of 16 knowing where to seek support. At the end of the service, 12 (66%) of 20 responding companions reported finding it emotionally challenging but all knew where to seek help; a 61% increase. SW

In both questionnaires, all companions who responded felt the service would make a difference. In the initial survey, 11 (68%) of 16 respondents strongly agreed with the statement compared to 19 (95%) of 20 in the final survey; a 40% increase.

Anxiety levels among companions before starting the service did not correlate to length of time worked in the NHS (Figure 5).

The free-text element of the questionnaires enabled qualitative feedback (Table 2). Seventeen of the companions left additional feedback with 100% reporting a positive experience. A number of themes emerged: it was rewarding personally and professionally ( $n = 11$ , 64%), they valued the comfort they were able provide to the families of patients ( $n = 10$ , 59%) and pleasure showing care and compassion to patients ( $n = 9$ , 53%). Other themes were enjoyment working within a multidisciplinary team, benefit gained from attending training sessions and becoming more comfortable talking about death and dying. All companions would recommend it to others as a rewarding and enjoyable role.

The companions highlighted some challenges and service improvement suggestions. Recommendations

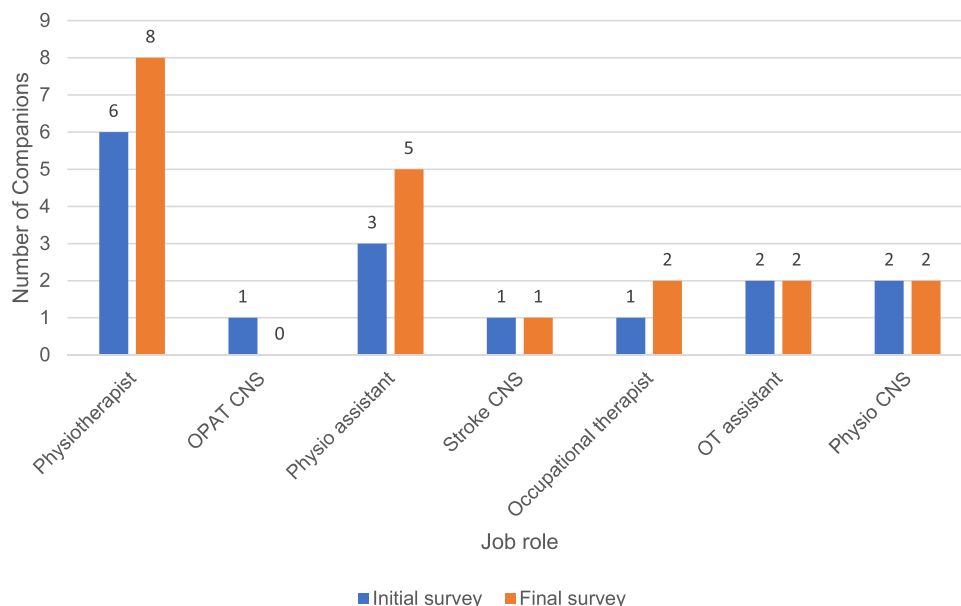


Figure 1. Job roles of companions.

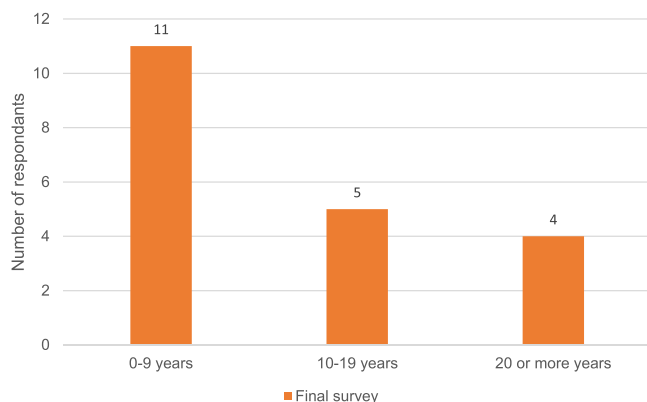


Figure 2. Number of years the companions had worked for the NHS.

focused predominately on process such as improving the handover documentation and having a coordinator. Five companions (29%) commented on the high emotional cost of being a companion, all felt they had been well supported but wanted the burden acknowledged.

## Discussion

The companions undertook several important roles in the care of the dying. The majority of visits (85%) included communication with the person and over a third (36%) involved literature and spirituality. This gave patients the opportunity to discuss memories and interests, take part in hobbies and connect to loved ones who were unable to visit. This ensured they received holistic and compassionate care despite the restrictions resulting from the pandemic.

The majority of AHPs forming the end-of-life companion service were physiotherapy personnel, reflecting the change in the workforce due to the pandemic and the recruitment process. The inpatient therapy team comprises 86 physiotherapists, 23 occupational therapists, and 31 therapy assistants. The companions were recruited via email to all therapies in the trust followed by word of mouth encouragement. A senior clinical specialist physiotherapist was central in the implementation of the service which may explain the significant proportion of physiotherapists.

Several reasons as to why their professional experience meant they felt able to take on the role of a companion can be suggested.

First, a central part of the job of a physiotherapist is to identify the specific needs of a patient and work with them to improve quality of life. This requires an individualized approach and excellent communication skills; both of which are transferable to the role of a companion. Additionally, the training and work of a physiotherapist allows them to offer a range of

practical skills as a companion. Thirty-six percent of companion visits included personal care and 17% included symptom control. Physiotherapists are confident in handling people as well as experienced in working within a multidisciplinary ward team which may enable these companions to seek out help from nursing or medical staff if they notice a person becoming unsettled or distressed. Finally, communicating with families is a significant component of physiotherapist workload, giving them an understanding of patient confidentiality and appropriate terminology. This skill is transferable and this study highlights the value of companions in communicating with both the person and their next of kin.

However, this study showed length of time working as an AHP did not correlate with initial levels of anxiety about sitting with dying patients. Therefore, experience cannot be the only explanation for why they were able to successfully fulfill the role of a companion with minimal training. It could be suggested that people who choose to become a physiotherapist do so because of an intrinsic desire to help and relieve suffering. Therefore, when put in a situation such as that of a companion in a pandemic, it is this same desire that enables them to show such compassion and kindness.

As well as looking at the qualities and skills physiotherapists were able to bring to the companion service, it is also important to analyze aspects of the role they took away.

Becoming a companion provided a role in the pandemic. Although more found it emotionally challenging than were initially expecting to, the feedback was overwhelmingly positive and all responders would recommend it to others. A number of comments included words such as “pride”, “inspiring,” and “rewarding,” showing the positive personal difference it made to the companions.

This study suggests a statistically significant likelihood of an AHP not being anxious around dying people if they have had experience as a companion, compared to those who have not. This finding assumes the study group acts as a proxy for all physiotherapists; however, they are a self-selecting group and thus could be assumed those who may be more comfortable around dying people than the general physiotherapy population.

It is noted only 2.6% of companion visits included the moment of death which may raise questions about how this led to a significant change of confidence in the companions. However, 100% of visits involved spending time with a person in the last days and hours of life. Comfort around a dying person is a skill many AHPs require beyond their role as a companion as they play an important role in the multidisciplinary SPCT.<sup>12,13</sup>

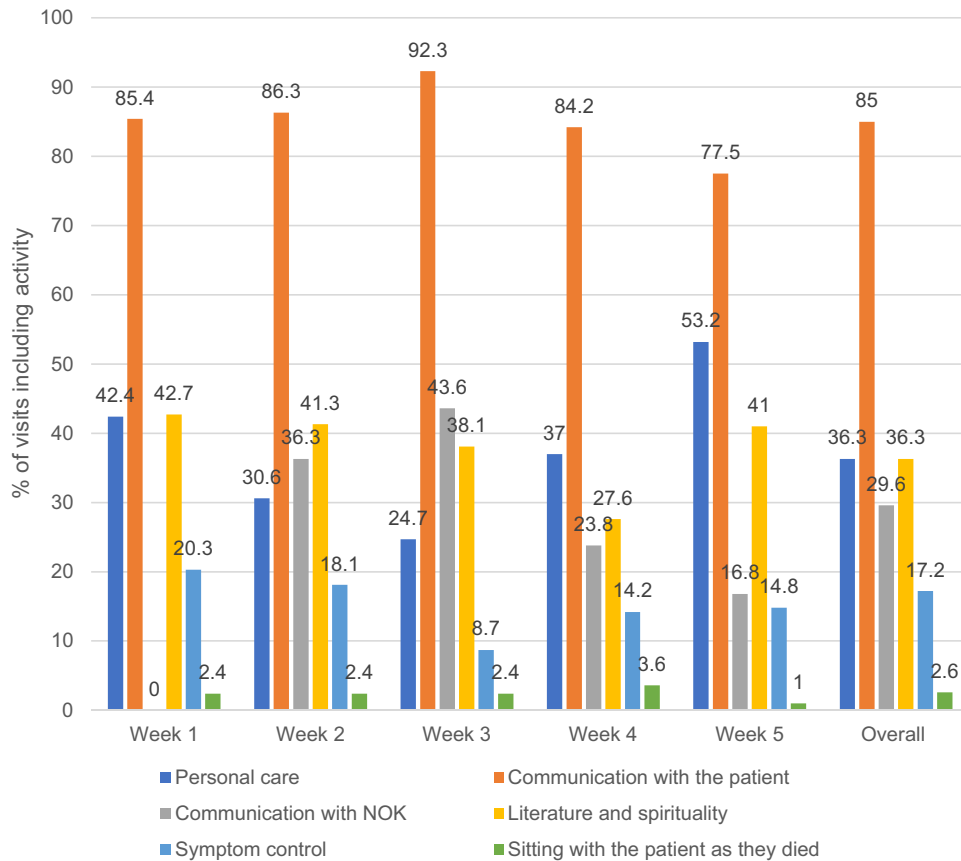


Figure 3. Companion activity.

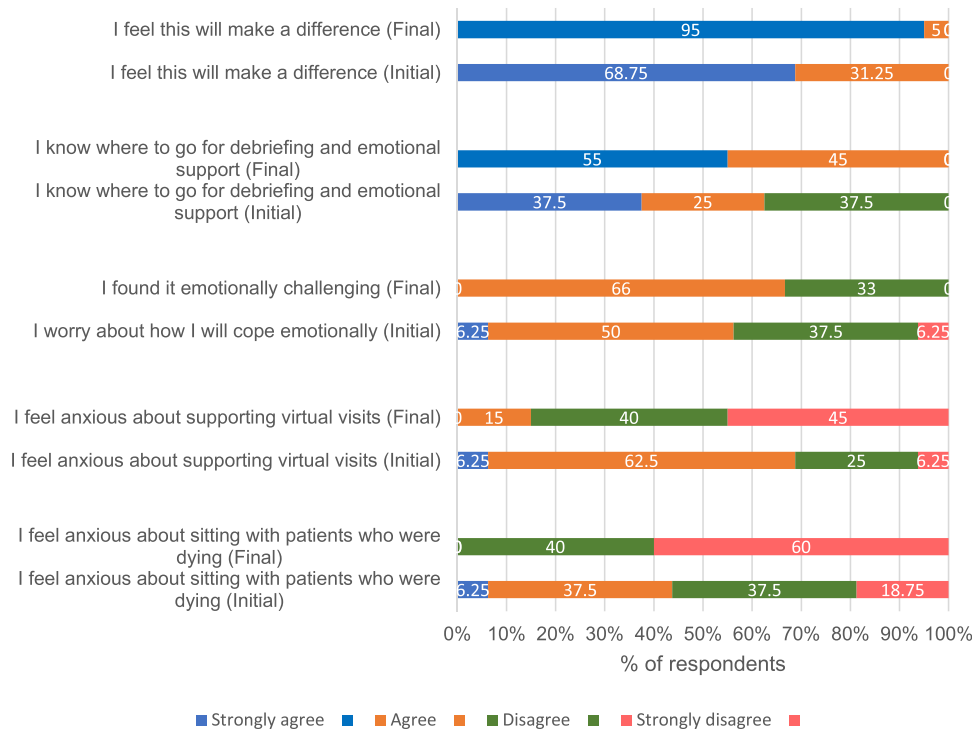


Figure 4. Companion feelings before and after the service.

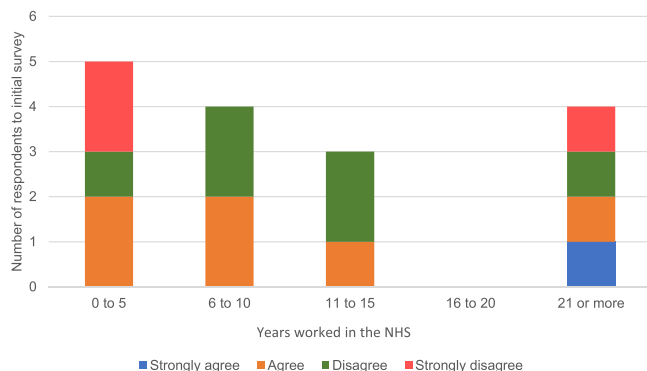


Figure 5. Anxiety regarding sitting with dying people before becoming a companion.

Data from 2019 showed 230,428 people died in a UK hospital in 2017.<sup>14</sup> However, many of these patients will not be seen by the SPCT.<sup>15</sup> Consequently, it becomes necessary to give all hospital AHPs skills and confidence working with dying patients. Despite this, there is a lack of structured and consistent training in EOL care among physiotherapy undergraduate courses and postgraduate rotations across the UK.<sup>16,17</sup> It could be suggested that time spent in roles such as that of a companion could be incorporated into future training to develop communication skills and reduce anxieties related to such patients. This could be achieved via placements with the SPCT or as a companion.

This study has several strengths: its mixed-methods nature allows in-depth and varied analysis. It was timely and took the opportunity provided by the change of working created by COVID-19 to respond to patient need. This rapid introduction and assessment of a new service enables learning in preparation for potential future spikes of infection. The straightforward nature ensured it could be conducted despite these pressures and still show tangible benefits.

There are also limitations to the study. Regarding data, the rapid introduction of the service left little time for piloting or validation of the questionnaire. It is not clear how many of the respondents answered both anonymous questionnaires; although because of consistency in companion presence the authors feel, there is sufficient overlap for reliable comparison.

Companions self-reporting the service as beneficial does not necessarily correlate to a valuable service for the users; however, it is important in view of future incorporation into physiotherapy training. It was also clear to the authors that staff well-being in this setting was vital to ensure sustainable caregiving, thus key the companions' opinions were valued and facilitated the direction of the service.

Patient and relative voice was considered paramount by the authors during service development;

however, formal feedback was hindered by limited patient contact and visitor restrictions.

Feedback forms were sent to all bereaved relatives but only 7 responded which was felt to be due to the distressing nature of these bereavements at the first peak of the pandemic. As such no conclusions can be drawn from this. Comments included finding the service as “comforting,” “truly wonderful,” and “really appreciated”. Additional feedback was collected from comments given to the companions, ward teams, or palliative care team by families including positive statements such as “offered great relief”, “could not be more thankful” and “care that went above and beyond”.

The patient voice was difficult to capture; a known challenge in palliative care research exacerbated by increased workload of the clinical team, absence of loved ones to facilitate response, and the often rapid deterioration of those with COVID-19. However, there is evidence that having family members present improves the holistic care given to dying people<sup>3,18</sup> and it may be suggested that in their absence companions can provide this.

Given these limitations, this study is unable to conclude on the benefit of the service to the end user; however, it is important both to evaluate the impact on the provider in the time of a pandemic and assess how this can play a role in future training of physiotherapists. The informal feedback in this study will guide a business case to deliver this service in a structured way.

## Conclusion

This study highlights an interesting approach to the changing job roles of AHPs during the COVID-19 pandemic. Those who participated were able to adapt to the role of a companion and gained professional skills, transferable to their usual job role.

Importantly, it demonstrates a statistically significant likelihood of reduction in anxiety around dying people for an AHP following experience as a companion. The importance of AHPs in the multidisciplinary approach to palliative and end-of-life care has been recognized and the need for more interaction with dying patients in the curriculum for physiotherapy highlighted. Incorporating a period spent as a companion or with the SPCT during undergraduate training is suggested. Finally, this study has provided an important initial step in implementation of a permanent companion service in the trust.

## Disclosures and Acknowledgments

The authors are very grateful to Diane Turner (Clinical Specialist Physiotherapist) who was central to the

Table 2  
Qualitative Feedback From the Companions

Theme of Companion Feedback	Quotes From Companions
Positive impact on family members	<p>“To also be able to give reassurances to family with regular updates on the relative was again invaluable”</p> <p>“The feedback I had from family members showed what a significant difference we made to them”</p> <p>“We were able to reconnect them with their families and life beyond the hospital.”</p>
Rewarding experience	<p>“The shared experience both with other Companions, ward staff and most importantly the patients and relatives is one of the most positive things that I’ve come across during this very strange and difficult time working in healthcare.”</p> <p>“It was incredibly rewarding and a privilege to be able to support patients and their families during a very emotional time. I really feel it made a huge difference.”</p> <p>“It was incredibly rewarding and a privilege to be able to support patients and their families during a very emotional time. I really feel it made a huge difference.”</p>
Able to show care and compassion	<p>“Being a Companion allowed me to give a more personal and caring side of me at the hospital”</p>
Emotional impact	<p>“Although there are cases that draw from your emotional resources, I have found these are outweighed by the positive. It has helped me when I’ve communicated with the families as they help to restore that balance with their feedback on how much the service has meant to them.”</p> <p>“There is a lot of support both practically but also emotionally.”</p>

conception of this companion service and provided a great support to all AHPs who participated.

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## *Appendix 1*

### *Questionnaire sent to Companions Prior to Starting the Service*

1. What is your usual job role?
2. How many years have you worked for the NHS?
3. How would you identify yourself?
  - Female
  - Male
  - Prefer not to say
4. I feel anxious about the idea of sitting with very unwell or dying people.
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
5. I feel anxious about supporting virtual visits.
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
6. I worry about how I will cope emotionally.
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
7. I know where to go for debrief/emotional support.
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
8. I feel this will make a difference.
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree

### *Questionnaire sent to Companions After Finishing*

1. What is your usual job role?
2. How many years have you worked for the NHS?
3. How would you identify yourself?
  - Female
  - Male
  - Prefer not to say
4. I feel anxious about the idea of sitting with very unwell or dying people.
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree

5. I feel anxious about supporting virtual visits.
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
6. I found it emotionally challenging.
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
7. I knew where to go for debrief/emotional support.
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree
8. I feel this made a difference.
  - Strongly agree
  - Agree
  - Disagree
  - Strongly disagree