

Marie Curie Companions at Musgrove Park Hospital

A Six Month Review

1. Overview

The Marie Curie Companions service at Musgrove Park Hospital aims to improve the dying experience for people who die in hospital and to emotionally support their families.

Between July 2014 and February 2015, the service received 74 referrals for support from a Companion volunteer. This has resulted in 173 hours and 55 minutes of support provided across 119 visits. Visits mainly involved companionship. The majority of referrals came from the Dunkery (Stroke) and Wordsworth (Care of the Older People) wards and 70% were for dying people with a primary diagnosis of a condition other than cancer. This means that the Companions service is reaching different people than those who are supported by the MCNS.

The Marie Curie Companions service at Musgrove Park Hospital has had a positive impact on the families of dying people within the hospital. The service has provided them and their families with emotional support and someone they can talk to at this difficult time along with the reassurance for families that someone is with their loved one when they need to take a rest break or attend to a task.

The service has helped to reduce self-reported levels of stress in the nursing staff who wish to spend time with people who are dying but do not have the time whilst working on a busy ward. The nurses have increased the number of conversations they have about death and dying since the implementation of the service and now feel that there is more support available for them to refer dying patients and their families to receive.

The partnership between Marie Curie and Musgrove Park Hospital has helped to increase the profile of what Marie Curie do as an organisation. It has provided local people with more volunteering opportunities in the hospital to support members of their own community and may have increased local fundraising opportunities for both organisations.

In summary, the partnership between Marie Curie and Musgrove Park Hospital has resulted in the successful development of a new service delivering emotional support to dying people and their families who are within the hospital.

2. Introduction

The Marie Curie Companions at Musgrove Park Hospital service was developed in order to better support people who are dying, and their families, whilst they are in hospital. People who are dying in hospital may have few visitors or, if they do, they may be overwhelmed. Companion volunteers can provide emotional and practical support for these people at this difficult time.

The Marie Curie Companions are a group of 14 volunteers (this is set to increase once the new group have been fully inducted) who have been specifically recruited and trained by Marie Curie and Musgrove Park Hospital in supporting people who are dying and their families. These volunteers work together in shifts of three hours across the hospital to support patients and families who have been referred to the service by ward staff. Initially, the service covered the three medical wards across the hospital. Since December 2014 the service has been extended to cover all wards across the hospital where there is a dying person or their family member who would like access to support from a companion volunteer. Shifts are 6pm to 9pm Monday to Friday and 3pm to 9pm (two shifts) at the weekends. This service is the first of its kind for Marie Curie and therefore, we need to learn whether it is replicable across other locations.

The pilot aims to meet the following outcomes:

- Patients and families receive relevant information and practical support
- Patients and families feel that they have access to relevant information and practical support
- Patients and families are informed about death and dying
- Patients and families feel supported (in the hospital)
- Health care professionals have increased confidence in having more conversations about death and dying
- Decrease in perceived staff levels of anxiety/concern related to end of life care
- Staff are confident in the volunteers
- Volunteers are confident in speaking to patients, families and ward staff

Marie Curie also hope to understand who the service is supporting and if it is replicable.

2.1 Service aim

The overall aim of the Marie Curie Companions at Musgrove Park Hospital service is to improve the dying experience for people who die in hospital and to emotionally support their families.

2.2 Purpose of the review

The purpose of this review is to provide information about whether the Companions service has achieved or is on the way to achieving its planned outcomes. Given that there have only been six months of service delivery since the implementation of the service, the full impact of the service may not yet be known.

2.2.1 Evaluation questions

1. What is the profile of the patients being referred to the pilot and how does this differ to other Marie Curie services?
2. Does the pilot meet the support needs of patients dying in hospital?
 - a. What support do patients need?
 - b. What support do we provide?
3. What is the impact of the pilot on the staff on the wards where the project has been introduced?
4. What is the impact of the pilot on the patient and their families?
 - a. What are their experiences of the project?
 - b. What is the impact on the dying experience?
5. What is the experience of the volunteer?
 - a. Does the training meet the needs of the volunteer?
 - b. Do the volunteers feel supported in their role?

2.2.2 Data sources

This report refers to data from pre and post service implementation hospital ward staff surveys, completed referral forms, completed companion visit forms, companion feedback surveys, a focus group with volunteers and interviews with nursing staff and family members of patients who received the service. By using multiple sources in this way, we hope to establish what has happened during and what peoples experiences are of the first six months of service delivery.

This report examines *patient data* from the referral forms received by the service. Volunteers were asked to fill in a report of the support provided across each visit. These completed visit forms provide us with *individual visit data*. Companion volunteer *surveys* were completed in order to explore the experiences of the volunteers along with how supported they felt within their role. Hospital ward staff *surveys* were completed prior to the onset of the service in the original three wards in order to explore what support was currently available at that time for dying patients and their families and these were repeated in January 2015 to understand the impact the service has had on the perceptions of the staff regarding the support now available. Qualitative *interviews* were performed with family members of the person who had died.

All participants gave consent to take part in the interviews that lasted approximately 30 minutes in the participant's home. Companions were also invited to participate in a *focus group* in order to gain an in depth understanding of their role. Interviews and the focus group took place in February 2015. An independent evaluation consultancy (Bright Purpose Consulting) was commissioned to carry out these interviews and the focus group, analyse the feedback they received and report back on their findings. Findings throughout this report are taken directly from the consultancy's report.

Further interviews were conducted by the Marie Curie Evaluation team with the service manager, lead end of life care nurse and hospital ward staff members. These interviews were performed to further explore the experiences of those involved with developing and using the companions service.

3 Results

In this section, the results of the review are presented. This will begin with a description of the development of the service and how this runs on a day to day basis, from the service manager's perspective. This section will also cover the amount and type of support that has been provided by the companions and to whom (ie patients and/or their families), the impact of the service on the hospital nursing staff and on dying people and their families within the hospital. Finally, the impact of the partnership working on both organisations will be discussed along with the future development of the service moving forward.

3.1 Launching the Companions service

As part of the interview with the service manager, the initial set up of the Companions service was discussed. The service was initially planned to be 12 months long, however due to the length of time required to ensure everything was in place there have been six months of actual delivery during this time.

The initial setting up of the service involved a lot of internal communication between the service manager and the staff within the hospital in order to ensure that everyone at the hospital was on board with the new service. One of the first issues to address was to identify the wards where the service would initially run to enable the service manager to introduce herself.

'I was able to approach the wards and just say hello, this is what the project is about.'
(Service manager)

A crucial factor in moving forward with the project, was to set up a project steering group. This group included the lead end of life care nurse, the bereavement officer, the volunteer manager, the chaplain and the service manager. The purpose of this group was to set up and deliver the service and as part of this they were required to plan the recruitment and the training of the future Companion volunteers.

Recruiting the right people for the companion role was a crucial part of setting up the service. Volunteers were recruited from within the local community using a range of methods. These were led by the service manager and included advertisements on local radio stations as well as hosting an open event for potential volunteers to gain further information about the role.

'We started a recruitment campaign and we did this by advertising in the press and through the website – lots of contacts from people in different organisations that we knew...I think the main thing we were looking for is compassion.' (Service manager)

The companion volunteers were provided with training across five weeks to prepare them for their role in supporting dying people and their families. This was led by the service manager and supported by the hospital team, including the lead end of life care nurse. Training was provided to inform the volunteers of their role boundaries, developing their communication skills and what they should expect to see when someone is at the end of life and what signs to look for when they are in the dying phase. Volunteers were also informed of the bereavement process and supported in

developing their confidence of working with dying people and their families. The volunteers were nervous about the role which they were about to embark on and this training help to support them with this.

'...they felt quite nervous and were concerned about what is the right thing to say because the patients that the companions were seeing...were going to die soon and the families were aware of that and so they were sitting with people who knew that they were going to lose someone... very soon and the companions felt that... there are no magic words and that's part of the learning process...' (Service manager)

When reflecting on the training as part of the focus group, the companions said they were initially concerned that they may not be up to the role. However, they felt the training had prepared them well and the service manager had ensured they had the training necessary to perform the role. The Companion volunteers were also asked to complete a feedback survey to report on their experiences of the training they received as part of their induction. All eight Companions who completed the survey felt the training was either good (1/8) or very good (7/8). After receiving the training, volunteers felt their role as a Companion was clear to them and agreed that they had a good understanding of the hospital environment. However, one volunteer said it would be useful to gain some experience of the hospital ward environment as part of the training.

Communication was an important part of the Companion training provided. All Companions felt that, after the training, they could communicate with dying patients and their visitors and had no problems doing this as part of their role. They also felt that they had a good understanding of the dying process.

All except one Companion felt that after their training they understood the bereavement service. However, only half of the volunteers surveyed felt they had a good understanding of spirituality. This suggests that spirituality is a concept that may not be fully understood by the Companions and is something that could be clarified and improved in future training activities.

Once the Companions had received their training and been through the necessary security checks they could begin volunteering. During the first few months of the running of the service and whilst the companions were inexperienced, the service manager was on hand during their shifts in order to provide support to the volunteers. This meant that the project manager had to be available for extended hours and follow up with volunteers to ensure they were ok.

'I met them...in the evening and first of all I took them round the wards and introduced them... The next time...if I had a referral I took them along to meet the family and the patient... I introduced them and after a little while I left them.... I would stay in the evening until they'd completed their visit so that we could have a talk through about how it went, what their feelings were about it...' (Service manager)

As part of the Companion volunteer feedback survey, the companions said that they felt supported in their role and agreed that the service manager had played a crucial role in this. This was echoed in the feedback they provided in the volunteer focus-group with the external evaluator. The

companion volunteers discussed as a group how they felt able to contact the service manager after a visit to discuss any worries or concerns they may have.

3.2 Day to day running of the service

The daily running of the service involves a large amount of face to face contact between the service manager and the ward staff in order to identify whether there are any new referrals to the companions service. Whilst the options of telephone and email referrals were provided to hospital staff, these have not been utilised. The service manager felt that nurses asking for emotional support for their patients was initially a difficult process and involved a slow moving culture change within the hospital. The culture change within the hospital is a process that is still on-going and as a result a more personal and face to face method of gathering referrals is still required.

In order to receive referrals, the service manager attends wards every day in order to identify if there is anyone who is dying, or whether there are family members or visitors who may benefit from receiving emotional support from a Companion volunteer.

Once a referral has been received, the service manager will speak to each person or their family members, where appropriate, in order to understand their individual circumstances and tailor the Companion support to them. This process can take some time and the service manager often finds that she also provides support and a listening ear to the dying person or their families at this time. This illustrates the person centred service that is being provided at Musgrove Park Hospital, as the dying person and their families are at the centre of the planning and the delivery of the support they receive.

Volunteer companions will then be selected based on their availability along with their individual characteristics and how well they match with the individual or family who require support. The matching between the patient or family and the volunteer will depend on the characteristics discussed with the service manager. These characteristics can include gender, age and likes and dislikes depending on the individual request. The service manager will then contact the companion via text message to let them know they have someone to support on the same day.

When a volunteer arrives to provide support, they will first go to the clinical site office. This is where they sign in and out and where they can access the details of the individual they will be supporting. The volunteer companion will then provide support to the dying patient and/or their family. This support can range from providing company, emotional support, doing practical things and advocating for the patient or their family. After the support has been delivered, the companion completes an activity form detailing the type of support they provided and any concerns they might have. During the focus group, the companion volunteers spoke of how this activity log is sometimes used as an opportunity to reflect and provide closure so that they don't take it all home with them. As one volunteer said:

"If you commit it to paper it helps you close the book" (Companion volunteer)

This activity form is then left at the clinical site office where the companion will also sign out. The service manager will then collect the activity forms and follow up any queries the companions may have. This data is also entered by the service manager into a spread sheet that is held locally at Musgrove Park Hospital.

3.3 Activity

This section includes details of how many people have been referred to the Companions service in the time frame under review along with how many visits have been received. What this data does not capture is how many family members may have been supported, but not referred, by the service whilst a Companion is providing support. Therefore, it is likely that this service has supported many more individuals than the number of referrals suggests.

Between 14th July 2014 and 14th February 2015, a total of 74 referrals for dying people and their families (66 patients and eight family members) were made to the Marie Curie Companions service. It is important to note that the initial target of referrals to the service was 75 referrals over a 12 month period. The service has seen almost the annual target of referrals in the first six months.

3.3.1 Patient and carer profile

Table 1 | Breakdown of referrals | referral log | July 2014 to February 2015

	Patient referred	Proportion of dying patients supported	Carer referred
Ward			
Barrington (Vascular, Bariatric, Upper Gastrointestinal)	2 (2%)	1/5 (20%)	0
Coleridge (Acute Medicine)	11 (15%)	9/65 (14%)	2 (3%)
Conservators (Acute Medicine, Endocrine)	1 (1%)	1/13 (8%)	0
Dunkery (Stroke)	12 (16%)	10/43 (23%)	3 (4%)
Eliot (Emergency, Care of Older People)	6 (8%)	5/48 (10%)	0
Fielding (Acute Medicine, Cardiology)	6 (8%)	6/26 (23%)	2 (3%)
Gould (Trauma and Orthopaedics)	1 (1%)	1/2 (50%)	0
Medical Assessment Unit (MAU) (Emergency Admissions, Acute Medicine)	4 (5%)	1/31 (3%)	0
Mendip (Acute Medicine)	3 (4%)	3/10 (30%)	0
Montacute (Colorectal, Urology)	5 (7%)	4/11 (36%)	0
Sedgemoor (Acute Medicine)	1 (1%)	1/47 (2%)	0
Shepard (Gastroenterology)	1 (1%)	1/24 (4%)	0
Triscombe (Stroke, Neurology, Rheumatology)	1 (1%)	0/5 (0%)	0
Wordsworth (Care of the Older People)	12 (16%)	10/43 (23%)	1 (1%)
Primary diagnosis (patient)			
Cancer	19 (26%)		0
Non cancer	44 (59%)		8 (11%)
Unknown	3 (4%)		0

Table one shows the majority of referrals were for the person who was dying and that these were mainly made by the Dunkery (Stroke) and Wordsworth (Care of the Older People) wards. The table also shows the proportion of patients who died per ward that were supported by the Companions service (where figures do not match referral figures, this is because the service ran across two part months and data for number of deaths were not available for an incomplete month). This shows that the greatest proportion of dying people were supported in Gould, Montacute and Mendip wards. For 70% of patients and carers referred the patient had a primary diagnosis for a condition other than cancer and for 26% of patients had a cancer diagnosis (diagnosis was not recorded for 4% of patients). This is an interesting finding given that the proportion of cancer patients in other Marie

Curie services is usually much higher (MCNS 74% of patients have cancer, MC hospices 77% have cancer and for Helper 72% of patients have cancer) and suggests that the Companions service may be reaching people that would not otherwise receive support from Marie Curie.

3.3.2 Support provided

The Companion volunteers provided support for a total of 173 hours and 55 minutes across 119 visits which is an average of one hour and 45 minutes of support per visit. There were an additional four attempted visits that resulted in zero hours of support due to a patient death, norovirus on the ward and the family deciding the support was no longer required.

Volunteers categorised the support they provided as one of the following (the volunteers could select more than one option):

- Companionship (patient conscious/not conscious or carer),
- emotional support (discussed worries with patient/carers or listened to patient/carers),
- information giving (sign posted carers or discussed support options),
- practical support (supported with hospital services or made a drink) and
- other activities.

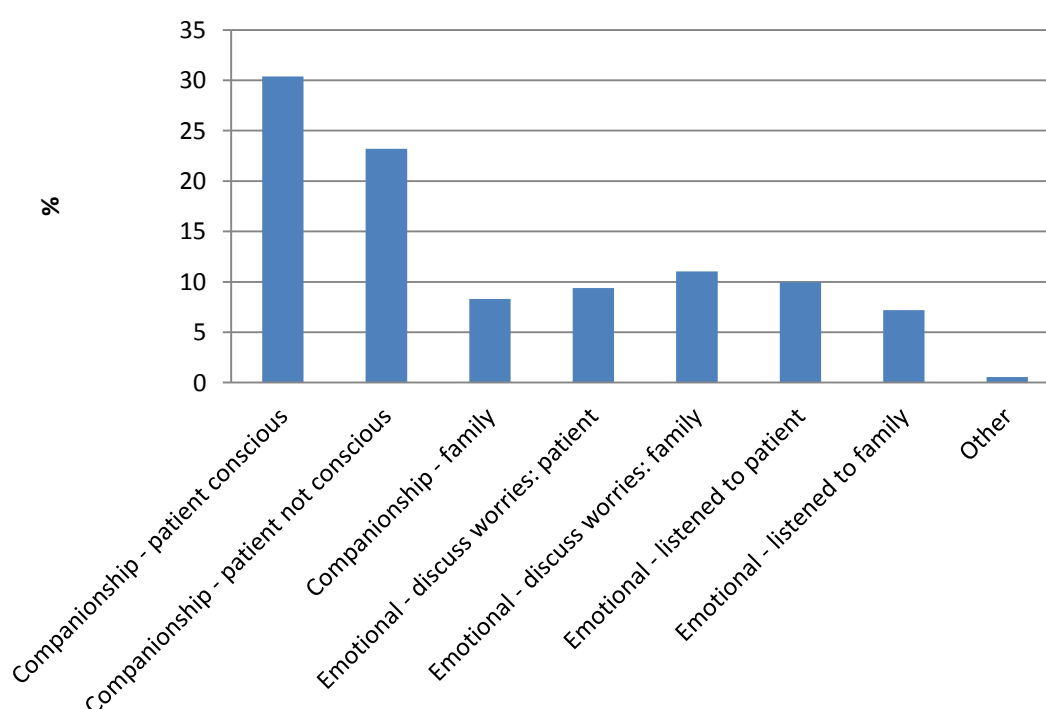


Chart 1 | Support provided to dying patients and their families | MC Companions March 2015

Chart one shows that volunteers reported that during their visits, they mostly provided companionship either listening to the patient or their family member. The majority of this time the

patient was reported as conscious (30%). Companionship was provided to the dying person's family in 8% of visits and emotional support was provided in 38% of visits.

3.4 Impact of the Companions service on hospital ward staff

Ward staff at Musgrove Park Hospital were asked to complete a survey prior to the onset of the Companions service and again once it had been running for several months. The aim of the survey was to understand what was happening with dying patients and the level of support they were receiving before the initiation of the Companions service. These findings are compared with the second survey which was completed in January/February 2015 to establish whether there has been any change in staff perceptions of support and their confidence to speak to patients about death and dying since the onset of the companion service.

3.4.1 Using the Companions service:

Nursing staff who completed the post service implementation survey were asked whether they had received adequate information about the service and their experiences of using it. From the 11 staff who completed the post implementation survey, eight (73%) had referred to the companions service. Those that had not used the service were either new staff or had found that the service had already been put in place by staff on a previous shift. Of those who had experienced the companions service, all rated this experience as very good (6/9) or good (3/9).

Nursing staff who had interacted with Companion volunteers found this a positive experience.

'They are nice, calm and helpful people.' (Nurse)

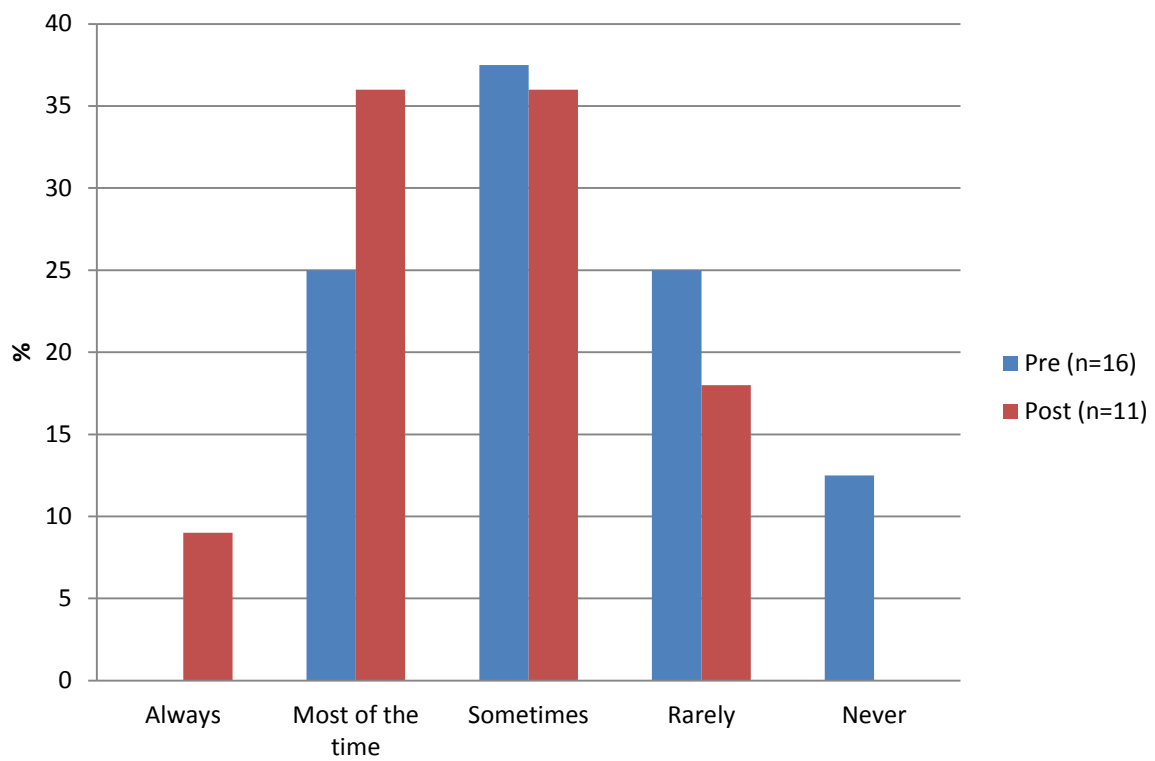


Chart 2 | Frequency of death and dying conversations | MC Companions March 2015

Chart two above displays the staff perceptions of the frequency of conversations they have about death and dying with dying patients and their families. This shows that there has been an increase in staff who have these conversations always and most of the time and a reduction in those that have these conversations rarely or never (none of the staff surveyed felt that they do not have these conversations at all). This suggests that there are more discussions about death and dying being held since the implementation of the Companions service at Musgrove Park Hospital.

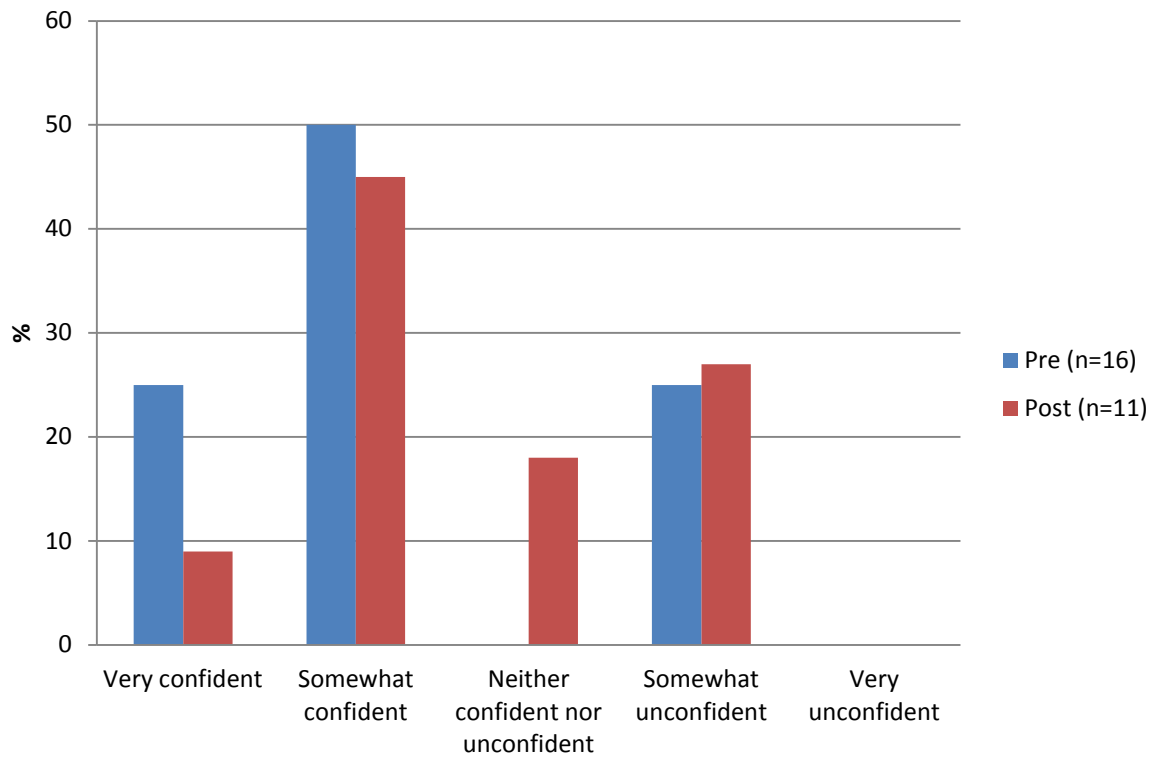


Chart 3 | Staff confidence in conversations about death and dying| MC Companions March 2015

Chart three shows the perceived confidence of the nursing staff surveyed in having conversations about death and dying with end of life patients and their families. This data suggests that although the number of conversations have increased that confidence has decreased for some of the staff surveyed. This is not too surprising, given that more conversations are occurring, and ward staff may be finding themselves in unfamiliar territory. Although it is not in the scope of the Companions service to increase the confidence of nursing staff to have conversations about death and dying, it is an important finding to feed back to Musgrove Park and to potentially shape future work with dying patients.

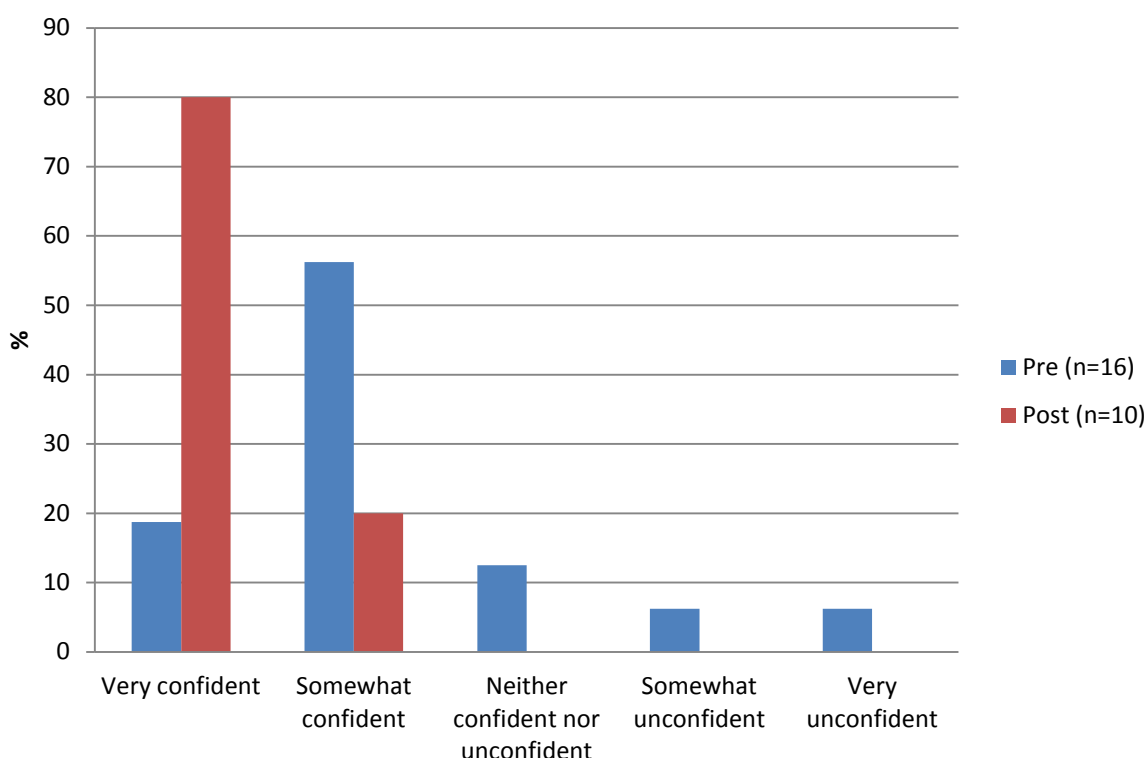


Chart 4 | Staff confidence in volunteers | MC Companions March 2015

Chart four shows that although staff initially had some reservations about the Marie Curie volunteers being able to deliver support to end of life patients and their families that their confidence has substantially increased since the implementation of the service. This is a very encouraging finding which suggests that ward staff have had positive experiences of the volunteers.

As part of the nursing staff survey, nurses were asked whether they felt there was emotional support available at the hospital for dying patients and their families. Since the introduction of the Companions service, nurses said that there is now more support available. Nurses are also now more likely to refer more dying patients and their families for emotional support. This suggests that nurses are using the service to provide emotional support for dying patients and their families.

Musgrove Park Hospital ward nursing staff who use the Companions service were asked about what the availability of this service means to them. They said this service meant they could spend more time with other patients as they know the dying patient is with a Companion. They spoke of how this helped to reduce their stress levels.

'Helps us to provide the best care and support to families, great for supporting us as do not often look after dying patients and their families.' (Nurse)

'I can look after patients who may need help knowing that someone is with the dying patient.' (Nurse)

Data from the qualitative interviews with the lead end of life care nurse and the service manager also supported the perceived reduction in nursing staff stress relating to end of life care since the service has been in place. They felt that the nursing staff within the hospital wanted to give the best possible care to their patients but are often too busy to spend time sitting with them whilst they are dying.

'...They're just so pleased that you can do that for that patient. I think they feel, I think maybe it does take away a little bit of the stress for them because someone's there and they're getting that support.' (Service manager)

3.5 Impact of the Companions service on dying people and their families

Interviews were carried out with 3 family members of patients who received support from the Companions Service in order to examine the impact of the service on the family member and the patient and their experience of using the service. These interviews were carried out by an independent evaluation organisation and the findings discussed below are taken from the formal report received from this organisation. Data were also collected on the perceived impact of the service on the dying person and their families using the staff feedback and companion feedback surveys and focus groups along with qualitative interviews with the service manager and the lead end of life care nurse.

Ward staff and volunteers believed that primarily the patients families saw the benefits of the service. This is because the majority of people who were visited by the companions were reported to be unconscious or of varying levels of consciousness during the times they were supported. However, nursing staff at the hospital did also feel that dying people who received support from a companion were calmer as a result.

'Patient appears calmer when companion present.' (Nurse)

A small number of the dying people supported were able to communicate with the volunteer Companions. One volunteer spoke of this communication as part of the volunteer focus group. The dying person supported had a fear of the dark and so the Companion brought along a candle (battery operated) when she visited. The dying person told the volunteer how she would never forget her support:

"Every time I see that candle I'll think of you, that person who cared for me in the dark"
(Companion volunteer)

The above quotation shows how the Companions endeavour to provide individualised support to dying people, where possible.

The benefits experienced by the family members of the dying person included being able to discuss their emotions and potentially their anticipatory grief as well as comfort from knowing that their loved one is not alone when they are required to attend to other commitments.

3.5.1 Anticipatory grief

Aldrich (1974) defined anticipatory grief as the process of grief that occurs prior to a loss versus grief that occurs after a loss. The experience of anticipatory grief can include a range of emotions such as: separation anxiety, existential aloneness (being aware of one's own aloneness), denial, sadness, anger and guilt amongst others (Fenstermaker, 2014). The interview data suggested that families are likely to be experiencing anticipatory grief whilst in the hospital setting and their loved one is dying. The service is perceived to have benefitted these people during this time by providing them with an opportunity to discuss their feelings, the history they share with the patient and also their plans for the future and dealing with their loss. Providing a companion gives them a safe space to discuss these feelings and may alleviate any burden associated with these discussions when had with other members of the family.

'...what happens is that people are able to talk they don't feel they are burdening their family members or they better not say that again. Or they can't keep going over it and over it because they might have been talking about it for months...what we offer is a safe place for people to go over their experiences and be able to think about their future without their loved one.' (Service manager)

Allowing family members and carers to discuss their emotions in this way may help them with the overall grieving process. Bereavement is a focus in Marie Curie's new strategic plan and the Marie Curie companions service supports this through helping families to come to terms with their future loss through discussing their emotions.

'So if you're thinking about bereavement and grieving perhaps Marie Curie are helping that process even before the loss of someone.' (Service manager)

3.5.2 Fear of a loved one dying alone

For the families and friends of dying people it was perceived by staff that there were concerns about leaving their loved one alone in hospital. This suggests they may potentially spend large amounts of time by their bedside without taking breaks themselves. Furthermore, they may have commitments to attend to at home which may cause them some distress when making the decision to leave their loved one. The service manager and the lead end of life care nurse said the companion service helped to alleviate some of the distress experienced by family members by providing them with someone who could be with their loved one whilst they took this time to rest and meet their other commitments.

'I'll check in and a relative might be there and they'll say thanks so much it was such a relief to know someone was going to be there when I couldn't get here.' (Service manager)

‘Some families live a long way away and they can’t get here... it’s reassuring for them to know mum didn’t die alone.’ (Lead end of life care nurse)

The findings from the interviews with family members support the service manager’s perceptions that the companions provided respite and reassurance in knowing someone was with their loved one.

“It gives so much comfort knowing she’s not on her own.” (Family member)

Family members also felt the service was of benefit to their loved one as well as themselves.

“It reassured us and I think it reassured her as well” (Family member)

In these interviews, it was suggested that by supporting families in this way and providing that reassurance and relief may have helped to prevent adverse health consequences for the dying person’s carers.

“I don’t know where I would have been without the support, probably in a very depressed state if I hadn’t had anyone there” (Family member)

3.5.3 Advocating for dying people and their families

As part of the Companion role, the volunteers are able to advocate for the dying person and their family members whilst they are in hospital. This can mean asking for a nurse to come and see the person, or to ask things that they may find difficult.

Nursing staff felt that the Companions advocated for the dying person by informing them of anything the dying person may need in between their routine checks. This may mean they can deliver some aspects of care, such as pain relief, quicker than if a Companion was not present.

‘...they can quickly feedback to the nursing team if there is anything that the patient needs for example: medications for pain.’ (Nurse)

The Companions themselves felt that this is an important part of their role. They feel that because they have developed good relationships with the staff, that they can raise their concerns without it being perceived as interference. One volunteer described this part of the role as:

“We’re there in place of a relative, a sort of surrogate” (Companion volunteer)

3.6 Partnership working between Marie Curie and Musgrove Park Hospital

Through the qualitative interviews and focus group, it became clear that the partnership delivery of the service has had an impact on how Marie Curie is perceived by those outside of the organisation.

It is a new way for people to volunteer for both organisations and to provide support for dying people and their families.

3.6.1 Opportunity for volunteering

The Companion volunteers all had a story about why they wanted to volunteer for the Marie Curie Companions service at Musgrove Park Hospital. Many of them had experienced the death of a loved one and they recognised that there is not much support for people at this time. When a person is dying, the volunteers felt they should 'see someone out' in the same way you come into the world: supported and cared for.

The Companions were attracted to volunteering for this role at Musgrove Park Hospital, in part, because of the link with Marie Curie. Many of the volunteers had worked with, or experienced the services of, Marie Curie and all respected the organisation. Some of the volunteers felt very strongly about this and would not have become a Companion if it were not for the partnership with Marie Curie.

3.6.2 Raises awareness

Marie Curie has been traditionally viewed as a cancer charity and people still view the organisation as one that predominantly supports people with cancer. This service is unlike other Marie Curie services as people are being supported in hospital rather than in their homes. Further to this, the majority of its recipients had a primary diagnosis other than cancer. Having this service situated within an acute trust, may not only raise the profile of Marie Curie overall but also raise awareness of the fact that the organisation supports everyone who has a terminal diagnosis, not only those with cancer.

'Well certainly people are more aware that Marie Curie as a charity is not just supporting cancer services so that's one thing. And quite often people will say to me oh but they don't have cancer, and I'll say 'that's ok' it's fine ...'you support people who don't have cancer?' yes we do.' (Service manager)

The hospital staff were not alone in thinking that Marie Curie only provides support to people with a cancer diagnosis. A family member who's loved one received support from the service held a similar opinion and felt the service may not have been meant for them:

"Considering she didn't have cancer I felt a bit of a fraud" (Family member)

By continuing to provide Companion support to all dying people and their families, Marie Curie may become better known as a charity that supports everyone with a terminal diagnosis, regardless of their condition.

3.6.3 Increased difficult conversations

Death and dying are traditionally difficult topics of conversation and can be somewhat difficult for those who are terminally ill and their families who are facing death. It may make accessing support from significant others difficult if they cannot easily have these conversations. It was felt that by bringing in members of the local community to support the dying and their families in the hospital would help to encourage these discussions in both Musgrove Park Hospital and within the local community.

In the community

It is felt that being a community driven service that this will help to encourage discussions about death and dying outside of the health care setting when companions talk about their volunteering experiences with others in the community.

'I see it very much as people in the community taking care of their own community if you like. And it's talking about the fact that ,we're helping you prepare for this death, which is a normal process for all of us. So it's normalising it by talking about it, raising awareness.'
(Service manager)

In the hospital

In the staff survey (section 3.4.1) it was found that nurses are beginning to have more conversations about death and dying with their dying patients and their families. This suggests nurses may now feel more supported in having these conversations with the knowledge that a Companion will be able to continue it. In the qualitative interviews, hospital nursing staff were described by the service manager and lead end of life care nurse as being very good at meeting the clinical needs of people who are dying. However, they are typically very busy in their role and may not have the time to spend talking to patients and their families about their emotional needs. It was felt that, as a consequence, nurses were not accustomed to taking into account the emotional needs at the end of life and found these conversations difficult. Having these conversations can also take large amounts of time and it was felt nurses may struggle to start discussing emotional needs knowing that their time would be required by other patients. Having the option of referring to the Companions service meant that nurses could begin discussing the emotional needs of the patients who are dying and their loved ones with the knowledge they could refer them for support to the companions service.

'...people are being well taken care of but it was quite clear that sometimes people don't ask about how else can we support you? So, talking to wards and saying well this is an emotional support service they found that sometimes quite difficult. ..what they say to me is that it's quite difficult to change that culture of absolutely people are physically cared for but the emotional side is really difficult and there are reasons around that. People don't have the time. It's too difficult. If they start the conversation, they can't stay to finish it.' (Service manager)

The project manager and lead end of life care nurse felt that this was progressing and that the emotional needs of patients and their families are now being considered more often for dying patients.

'They feel very strongly about it and say it's become part of their training around end of life, (asking families if they would like to use the service) have you thought about a Marie Curie companion?' (Service manager)

3.6.4 Fundraising

The Marie Curie Companions service at Musgrove Park Hospital provides local volunteers to provide emotional support to members of the local community. This may provide both organisations with an increased amount of fundraising opportunities, particularly at the local level. One family member discussed how they went on to raise money at their loved one's funeral after experiencing the support of the service:

"Something to think about when grieving - something to give back" (Family member)

4. Future development of the Companions service

The Companion service is still in its infancy and therefore there is scope to develop and to learn from any initial challenges. When asked to feedback on any changes they would make to the service, ward staff suggested that the service be available for longer hours and be easier to access at weekends.

'I would like it to be available for longer hours.' (Nurse)

'Just to have a weekend phone number available to make the service more accessible on Saturdays and Sundays.' (Nurse)

Volunteers agreed with the ward staff. During the qualitative interviews and the volunteer focus group, participants suggested that the service should be available to people in Accident and Emergency so that support could be provided to dying people who come into the hospital in an emergency situation.

Some of these changes are already underway. In the first instance, the service has been extended to cover all wards across the hospital. This means that anyone who is dying at Musgrove Park Hospital can have access to Companion support, if that is their wish. Secondly, the service is also working towards covering day shifts and as part of this more volunteers have been recruited and are currently undergoing security checks and training.

In addition to the availability and accessibility of the service, results from the surveys of volunteers and ward staff suggest that there are a few small areas of improvement that could be made. Ward staff reported a reduction in confidence in having conversations about death and dying and some Volunteers reported a lack of clarity around spiritual support. Both of these issues could be tackled fairly quickly with training or support around particular issues.

5. Summary of findings and conclusion

This section of the report summarises the findings from the activity forms, surveys, interviews and focus group in order to demonstrate the extent to which the Companions service has achieved or is on the way to achieving its planned outcomes.

5.1 Reach of service

During the first 6 months of service delivery, the Companions service supported 76 patients and their families in Musgrove Park Hospital. The majority of patients had a primary diagnosis of a condition other than cancer. This suggests that Marie Curie are potentially reaching people with the companions service that they would otherwise not support through community based services.

5.2 Benefits of service

The service delivers a number of benefits to ward staff, volunteers from the local community and most importantly, to dying patients and their families. The benefits of the service are discussed below.

5.2.1 More conversations about death and dying

Feedback from the ward staff in the hospital suggests that they are having conversations about death and dying with patients and their families more frequently since the implementation of the Companions service. This suggests that more patients and families are being informed about this situation and what to expect.

5.2.2 Patients and families receive or have access to relevant information and practical support

The vast majority of the support offered to patients and their families was considered to be companionship and emotional support. It is likely that this is a data recording issue and the companions are not recognising the practical support they are offering. There were however, instances where the companion would act as an advocate for the patient and raise issues with nursing staff or family members. Going forward, if providing access to information and practical support remain a key outcome for the service, companions will need to be supported to recognise where this support is being provided. There is also potential for future work to generate ideas for how to improve the level of practical support and information given to patients and their families.

5.2.3 Patients and families feel supported

Findings from the independent evaluation consultancy's interviews with family members and volunteers suggest that the companion service makes a large impact over the short time it is available.

For people who are dying, the service:

- ★ provides company when family can't be there, reducing feelings of loneliness and fear
- ★ provides someone to act as an advocate for themselves (and their family), to help raise issues or just bring things to the attention of the staff
- ★ provides someone to confide in

For family members and friends, the service:

- ★ enables people to get on with life without feeling they are compromising on the care and support for their loved one
- ★ gives respite for loved ones spending time at the bedside - everyone needs a break for the practical things like showering and getting fresh clothes or just having some time to themselves.
- ★ shares the burden when other family members can't help because of distance or other reasons
- ★ relieves the pressure of being in a room with someone who isn't communicating - someone to help 'keep up the conversation'
- ★ provides emotional support to relatives - a non-judgemental ear that can allow family members to offload
- ★ reduces the amount of time their loved one is alone, which provides comfort and reassurance

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5.2.4 Decrease in perceived staff levels of anxiety/concern related to end of life care

When asked about the benefits of the service on the ward staff, volunteers, the end of life lead and the ward staff themselves felt that having the service available to support dying patients enabled the nursing staff to focus on providing clinical support for patients. One nurse made note of the fact that having the service helped to remove the guilt of being too busy to provide emotional support to dying patients and that this has 'reduced the stress' they were experiencing as a result of this. One family member also commented that she felt the nurses appreciated having a Companion to support patients as well as they are so busy.

The increase in the number of conversations about death and dying occurring has however led to a decrease in staff confidence to have these conversations. Future support in this area is required to avoid this becoming a source of stress for the ward staff.

5.2.5 Confidence in volunteers

Surveys and interviews with ward staff suggest that the Companions service has been well received by hospital nursing staff, some of whom are now regularly referring dying people for emotional support from the Companion service. Once the service had been introduced, the ward staff confidence in the volunteers increased and many staff reported benefits to the patients, families and to themselves.

5.2.6 Confidence of volunteers

After receiving the training, volunteers felt their role as a Companion was clear to them and agreed that they had a good understanding of the hospital environment. All Companions felt that, after the training, they could communicate with dying patients and their visitors and had no problems doing this as part of their role. They also felt that they had a good understanding of the dying process.

5.2.7 Other Benefits

Marie Curie as an organisation has become better known (at least locally) for its work with all terminal conditions and not just cancer, a key strategic priority for the organisation nationally.

The service has also provided more volunteering opportunities with Marie Curie and may provide further opportunities for local fundraising for Marie Curie and Musgrove Park Hospital.

5.3 Is the service replicable?

As part of the 6 month review, Marie Curie hoped to understand the extent to which the service is replicable in other hospital settings. A number of issues have come to light that are important to consider if Marie Curie plan to roll out the service elsewhere.

5.3.1 Service manager

Volunteers, ward staff and family members of patients who were supported all commented on the supportive nature of the service manager for the companions service. The findings suggest that a large part of the success of the service can be attributed to the dedication of the service manager in building successful working relationships across the hospital and supporting the volunteers. In particular, for the initial few months the service manager made themselves available after the volunteers finished their shifts (at around 9pm, well after office hours) to ensure that they were supported to cope with what happened on their visit. Although other mechanism were then put in place to support companions after a visit (the diary), this initial support was welcomed by the volunteers and may have contributed to the consistency in companions across the time of the service.

Family members commented on the soft and 'peaceful' way they were approached by the project manager who would ask if they could help. Families felt supported, not only by the volunteers but by the project manager as well.

Volunteers spoke very highly of the project manager and felt that she played a crucial role in the success of the service. Her knowledge of the NHS and her ability to influence in an apolitical way was deemed important for the acceptance of the service within the hospital. Her ability to coordinate the referrals and her 'hands on' approach with families was recognised as contributing to the success. Her support for the volunteers to get them the right training and ensure they were fully supported has earned her the trust and respect of all the volunteers we spoke to.

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This suggests that Marie Curie would need to take particular care in the recruitment process for any new service manager. As well as having extensive experience of project management, the role holder would need to have a broad understanding of the NHS and be able to build effective relationships quickly in order to ensure the roll out of the service and appropriate referrals are made. They would also need to be flexible with their working hours and be able to support volunteers, patients and families to better cope with death and dying.

5.3.2 Training

In order to keep the costs down, training for volunteers was delivered by local leads for end of life care and bereavement in house at Musgrove Park. If the service were to be rolled out elsewhere with a similar cost model, negotiations around training within the hospital site should be considered.

5.3.3 Data capture

Throughout the early stages of the service, there have been a number of issues with data capture that make reporting against some outcomes difficult. For example, it is important to fully explain to the companions how to fill out the data collection forms (to ensure all of their work is being recorded), systems for data collection should be designed by the Marie Curie Analytics team to avoid having to manually analyse activity data, and routine collection of outcome measures from family members needs to be considered early. Future sites should learn from these issues to ensure the best possible results when reporting back to interested parties.

5.4 Conclusion

Family members could not speak highly enough of the service and expressed the view that it should continue as it had a lot to offer families and patients going through the same experiences. Though appreciative of the capacity of the service they would wholeheartedly support its continuation and would recommend the service to families and friends.

Volunteers too were committed to the continuation of the service and wanted to see it grow. They felt that having been up and running for a year they had ironed out the issues and were delivering a good service. It was recognised that they have developed at the right pace and felt that had the service expanded too quickly too soon it may not have been able to deliver the service it has.

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