

# Qualitative Evaluation of the Helper Service

Research for Marie Curie Cancer Care

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# Executive Summary

The Marie Curie Helper Service provides support to terminally ill people and their families, through the use of volunteer helpers. These helpers provide social, emotional and practical support to terminally ill people and carers, usually through regular visits to their home. It was initially established in Somerset in May 2009 and a second service was launched in Nottingham in October 2010. Both services have undergone further development and expansion, and further services are being developed in two new areas.

Ipsos MORI carried out qualitative research to feed into a wider evaluation of the helper service being conducted by Marie Curie. The qualitative research explored the following areas:

- the service aims
- benefits and factors for success
- understanding and expectations for the service
- service delivery
- challenges facing the service
- the future development of the service.

Depth interviews and focus groups with key audiences involved in the service in Somerset and Nottingham were held between November 2011 and February 2012. The audiences covered were the service managers, referrers, helpers, volunteer assessors, terminally ill people and carers.

## **The service aims**

All audiences described the aims of the service in broad terms of supporting terminally ill people and their families. A key function was considered to be combating the social isolation faced by some people with terminal illness. Referrers in particular saw the service as filling a gap in the community for their clients without other means of support. However, service managers thought that the service could equally benefit those with friends and family. Further, they were very clear that the service could benefit either the terminally ill person or the carer (or both). Other audiences tended to prioritise one over the other, often depending on their own experience or background.

All agreed that a primary aim was the provision of emotional support. Service managers also thought that providing information and signposting to other services could enable a terminally ill person to remain in their own home for longer. This seemed to be less of a focus for other audiences, who tended to think that helpers could support clients by helping out with small everyday tasks.

## **Benefits of the service**

The support provided was considered under four headings of emotional support, companionship, practical support and information provision.

The **emotional support** provided was clearly recognised by all participants and was seen as the key factor distinguishing the helper service from other services. Having a helper meant that terminally ill people had an outlet for their thoughts and feelings. They talked about what

was worrying them that day or their feelings about their situation – these were things they felt they could not (or should not) share with their health professionals. In many cases they also did not want to discuss these things with their family and friends who they thought were too involved or may become overburdened. A helper was able to provide them with an objective point of view and offer impartial advice or could just listen without judgement. Equally, the helper was someone for the carer to talk to, other than the person they were caring for.

This support was thought to have a positive effect on the emotional wellbeing of the terminally ill person. The helper could provide reassurance, offering advice on particular problems. Some interviewees thought that simply sharing their feelings helped them to cope better with their situation. There were similar benefits for the carer where they were able to talk to the helper, but there were also additional incidental benefits from knowing that the terminally ill person had someone else to talk to, easing the emotional burden on them.

Helpers frequently offered **companionship** to the terminally ill person, ranging from something akin to a 'sitting service', to something much closer to friendship. The parties would hold general conversations, or chat about common interests or take part in shared activities and hobbies (e.g. shopping, meals out, sports matches).

Again, the benefits were described by participants in terms of improved emotional wellbeing. Some terminally ill people thought that the helper could fill the gap left by family and friends and talked about the enjoyment and happiness they got out of the visits. They welcomed the visits as a dose of normality – and saw that time as an escape from the reality of their situation. They sometimes talked about regaining a sense of independence. This companionship was also thought to be positive for the carer's mental health and wellbeing – giving them peace of mind during the time of the visit and offering them some respite, allowing them to get on with their own lives.

**Practical support** provided by helpers included small tasks around the home, occasional assistance with personal care and sometimes taking the person shopping or to necessary appointments. However, there was some uncertainty about what a helper could and should assist with. Referrers and clients were not always sure what they were able to ask for help with.

Assistance with small tasks, such as unloading the washing machine, was seen as making the life of the terminally ill person or their carer that bit easier. Other support, such as taking them to appointments, meant that they were able to do things they would not have been able to do at all otherwise. Additionally, this gave them some comfort that they had someone to turn to, should they need it.

Where the support was primarily provided to the terminally ill person, the carer received **respite** from their caring duties. This was one of the most common benefits cited by carers, with the greatest impact on their lives. It allowed them to carry out basic tasks like shopping, and gave them a sense of normality by allowing them to focus on their own needs for a short time.

While helpers were less likely to **provide information about services**, this support was provided in some instances. Some helpers had signposted terminally ill people to other services, telling them what was available and how to access it. Where necessary, they looked into it themselves or asked the service manager for advice.

Where this was provided, it meant that terminally ill people were able to access services they wouldn't otherwise have known about. Few examples were provided though, as in most cases, neither the helper nor the clients saw this as a primary function of the helper service.

## **Success factors**

Participants highlighted a number of factors as being key to the success of the helper-client relationship and ultimately the service. Terminally ill people, carers and helpers all emphasised how important it was that the helper and client had some common ground; sharing the same interests was thought to be a useful starting point for the relationship. They also highlighted personal attributes that made for a good helper, such as empathy and kindness. They also recognised the level of commitment that was required from the helper. Given these factors, service managers and helpers stressed that success was dependent on attracting suitable candidates and providing them with appropriate training and support. The assessment and matching process was also seen as a key factor and was widely judged to work well in the current services.

## **Understanding and expectations of the service**

Initial reactions to the service from terminally ill people and carers were described as positive. They could see the benefits of the service and many had no reservations. However, some were more hesitant at that early stage. They had concerns about dealing with strangers or sometimes were reluctant to admit they needed help. This could be the case for either the terminally ill person or the carer, who sometimes felt guilty that they could not cope with their caring responsibilities.

At the time of initial contact from Marie Curie, understanding and expectations varied considerably. The service managers, volunteer assessors and helpers said that some clients had very little understanding of what the service provided or even why they had been referred. Even further into the relationship there was still sometimes uncertainty on the part of clients about the boundaries of the helper role. Helpers themselves were broadly confident that they knew what was expected of them, but there were still some small questions around physical and practical tasks that may need further clarification.

## **Service delivery**

The recruitment and screening process was thought to take significant time and effort but it was agreed it was necessary to ensure that potential helpers were suitable, well equipped to deal with the role and able to act as an advocate of the service.

Helpers found the training programme to be useful and comprehensive, though they would prefer slightly less emphasis on risk and health and safety, with more time spent on practical exercises preparing them for dealing with different situations.

Referrers explained that they made a decision to refer based on the perceived need of their client. They assessed need in relation to the individual's social isolation and the stress demands of the particular situation. In some cases they would ignore the eligibility criteria of the helper service (e.g. that the person was within the last twelve months of life) if they thought that a need was acute.

There was positive feedback on the referral process. Referrers emphasised their relationship with the service manager as crucial to its effectiveness. They thought it was flexible and were pleased that they could simply pick up the phone to the service manager to check whether the service was suitable for their client. According to service managers and assessors, the number of inappropriate referrals (e.g. the person is not at the end of life, or too close to end of life) has fallen, but referrers would still like more information to help them decide whether the service is suitable for their client or to help with client concerns. Some also asked for more feedback from the helper service after a referral has been made and dealt with.

All audiences recognised the importance of assessments in ascertaining the need of the terminally ill person or carer and ensuring a suitable match. Volunteer assessors, helpers and clients thought these were being carried out skilfully and sensitively.

## **Challenges**

Challenges for the different audiences varied considerably, though some were interlinked.

For **service managers**, they focused on procedural aspects of the service. For example, they had faced difficulties in ensuring that referrals were made at the appropriate time of the person's life so that the service could best provide support, though this was improving. They also expressed frustration that they may be missing the truly socially isolated and not reaching those in greatest need. They felt they had made some progress in reducing the bureaucracy involved but felt this could improve further. Finally, they were concerned about meeting demand in the future, following further expansion; they were also worried about continued delivery of the service in the face of financial pressures.

**Helpers** were more likely to refer to the challenges they faced in dealing with the helper-client relationship. For example, they sometimes faced difficulties in negotiating existing family relationships where these could sometimes be strained or complex. They also sometimes struggled to define and maintain suitable boundaries for the relationship; they were acting as friends but had to impose some limits. They also found it difficult to deal with the death of a terminally ill person and end the relationship with the bereaved carer.

**Referrers** faced two particular challenges: some were unclear about the remit of the service and sometimes they faced challenges in persuading the clients to accept help from the service.

## **Future development and recommendations**

The research has highlighted a number of points for further consideration as the service moves forward. These are listed below:

- As the service expands, ensure its core voluntary ethos is maintained.
- Ensure expansion is not at the cost of speed, flexibility and quality.
- Maintain personal relationships with referrers.
- Clarify the boundaries of what the helper can do, if that is what helpers want.
- Think about whether some boundaries can be extended in certain cases.
- Improve the provision of practical information by helpers, if this is a key aim of the service.
- Revisit the content of the training.
- Support networking between helpers.





# 1. Introduction

## 1.1 Background

The Marie Curie Helper Service uses volunteers (helpers) to support terminally ill people and their families or carers, usually through visits at home. The service aims to improve people's ability to stay in their homes if they are terminally ill and for their carers to continue with their caring role. The volunteers spend a short period of time (usually a few hours each week) with the terminally ill person or their carer and may support them in a number of different ways. They can provide:

- a listening ear and emotional support
- a short break for families and carers from their caring role
- information on relevant local services
- support for a few months after bereavement.

Whilst both terminally ill people and carers are intended to benefit from the service, either can be the primary client.

The service was developed in 2009 in response to feedback from families and carers who had received support from the Marie Curie Nursing Service. The service was initially launched in May 2009 in Somerset. As of December 2011 the service had developed to support around 35 clients with around 45 volunteers registered at any one time in that area. In September 2011, the service was expanded to cover the Bristol area and volunteers were recruited and trained to start supporting clients from late 2011.

The service was launched in October 2010 in Nottingham and by January 2012, there were around 20 volunteers supporting roughly the same number of clients. Development of the service to cover Nottinghamshire is underway with the training of potentially up to 20 more volunteers.

In both Somerset and Nottingham, as the service developed, a new role of volunteer assessor was introduced. Existing helpers were recruited and trained to take on the function of assessing new clients to the service to establish their needs and match them to a suitable helper. This function had initially been carried out by the service managers, who continued to assess some clients once the volunteer assessors were in place.

Services are also being developed in Liverpool and East London. Given the early stages of development of these sites, the evaluation of the helper service is based on the Somerset and Nottingham sites only.

## 1.2 Research objectives

The aim of this research was to provide qualitative evidence of the success or otherwise of the helper service in Somerset and Nottingham in order to feed into a wider evaluation of the service being conducted by Marie Curie.

Specifically, the qualitative research explored the following issues:

- the service aims
- benefits and factors for success
- understanding and expectations for the service
- service delivery
- the role of the helper
- challenges facing the service
- the future development of the service.

The wider evaluation being conducted by Marie Curie is intended to inform decisions to be taken by Trustees in May 2012 about the future of the helper service.

### 1.3 Methodology

A logic model has been developed by Marie Curie to show how the service is understood to produce its intended outcomes. The model, shown on the following page, demonstrates how the qualitative research fits into the wider evaluation and has guided decisions on the data needed to inform the evaluation.

**Problem statement:**  
 The social, emotional and practical support available to terminally ill people and their carers from professionals involved in their care often does not fully meet their needs in these domains.

**Goal:**  
 To provide social, emotional and practical support to maximise the wellbeing of terminally ill people and their carers

**Data sources**  
 Green = database  
 Red = questionnaires  
 Blue = client survey  
 Purple = interviews

**Rationale:**

- There is a gap in the social, emotional and practical support available to terminally ill people and their carers that can be filled by trained volunteers.

**Key assumptions:**

- Terminally ill people and their carers have unmet social, practical and emotional support needs. They also have information needs.
- Short breaks (respite) from caring can help to relieve the emotional and physical burden on carers.
- Trained volunteers can meet these needs with the support of a volunteer manager.

**Resources:**

- Helper volunteers
- Volunteer assessors
- Service manager
- Admin support
- MCNS management
- CS project mgmt
- Volunteering team
- Marketing / comms
- Evaluation team

**Activities:**

- Promotion of the service
- Recruitment and training of volunteers
- Referrals made
- Client assessments
- Helper visits
- Helper telephone calls
- Manager supports volunteers

**Outputs:**

- Trained volunteers
- More individuals receive support from Marie Curie
- Individuals supported 'earlier in the journey' than the Nursing Service

**Volunteers provide:**

- emotional support (e.g. 'listening ear')
- companionship
- practical support
- information / signpost to other services
- post-bereavement support to carers

**Short term impacts:**

- Clients feel they are receiving emotional and practical support
- Clients feel the service is providing companionship
- Clients receive information about services
- Carers feel they get a break from caring
- Clients find MCH visits enjoyable

**Longer term impacts:**

- Improved client wellbeing
- Reduced carer burden
- Clients make changes to their care as a result of information from Helper / service manager
- Carers supported after the death of the person they have cared for

**External factors / local context:**

- Local MCNS profile (e.g. MCNS / DCP / hospice)
- Characteristics of local area (rurality, socio-demographic profile, availability of other palliative care services etc.)
- Partnership arrangements (e.g. with MC / independent hospice)

Marie Curie has collected quantitative service data, client satisfaction data and standardised measures on mental wellbeing and carer burden. The study carried out by Ipsos MORI consisted of qualitative research with a range of key groups involved in the helper service. These groups were:

- service managers
- referrers to the service
- helpers
- volunteer assessors
- terminally ill people
- carers.

The research was carried out through a combination of focus groups and depth interviews. The breakdown of methods used with each audience is shown in the following table.

<b>Audience:</b>	<b>Somerset</b>	<b>Nottingham*</b>
Service manager	1 x depth interview	1 x depth interview
Referrer	3 x depth interviews	2 x depth interviews
Helper	1 x focus group (4 attended)	1 x focus group (8 attended) 4 x depth interviews
Volunteer assessor	1 x focus group (3 attended)**	1 x depth interview***
Terminally ill person	5 x depth interviews	4 x depth interviews
Carer	4 x depth interviews	4 x depth interviews

\*This includes seven interviews carried out by Marie Curie – four with helpers, two with terminally ill people and one with a carer

\*\*One participant also attended helper group in the capacity of a helper

\*\*\*Also attended focus group in capacity as a helper

All research was conducted using topic guides designed by the research team in partnership with Marie Curie. Fieldwork took place between November 2011 and February 2012. Copies of the topic guides can be found in the appendix.

### **Interviews with service managers**

The interviews with service managers explored their understanding of the aims of the service; how the aims should be achieved; their role in achieving them; what they thought worked well, and less well, within the service; the barriers they faced in delivering the service; their perceptions of service delivery; and ways in which the service could be improved or developed.

Marie Curie provided Ipsos MORI with contact details for the service managers. Interviews were carried out either face-to-face or by telephone, according to their availability. The interviews lasted around one hour.

## **Interviews with referrers**

The interviews with referrers explored their awareness of the service and the services it provides; their overall perceptions of the service; their understanding of the referral process; the 'type' of people they had referred; reasons why they would or would not refer people to the service; reactions and feedback from terminally ill people and carers; and thoughts on how the service could be improved.

A list of healthcare professionals who had referred people to the service was provided by Marie Curie. The list contained district nurses, community palliative care nurse specialists, PCT end of life team members, and social workers. The referrers were contacted by telephone and invited to participate in an in-depth telephone interview. Two were unable to participate. Interviews were generally between 45 minutes and one hour long.

In each area the following numbers of referrers were approached and interviewed:

- Nottingham: five referrers approached, two interviewed.
- Somerset: four referrers approached, three interviewed.

## **Focus group with helpers and volunteer assessors**

The focus groups with helpers explored their reasons for volunteering and how they became involved in the service; what the role of a helper involved; their experiences as a helper; their perceptions of the service; what they saw as the main benefits of the service; what they thought worked well, and less well, within the service; their perceptions of support provided by helpers and the service; the barriers they faced in providing the service; and ways in which the service could be improved. In addition, the group with volunteer assessors in Somerset explored the motivations for taking on the additional role and the impact this had on volunteers; their experiences of assessments; the training and support received to carry out the role and ways in which their role could be improved.

The focus groups took place during existing training days organised by Marie Curie and were facilitated by a member of the Ipsos MORI research team. Participants were assured that the research was designed to explore the service as a whole, as opposed to their performance as a helper or volunteer assessor. The focus groups each lasted around one and a half hours.

In each area the following numbers of helpers and volunteer assessors were approached by Ipsos MORI and interviewed or participated in focus groups (please note other helpers were approached and interviewed by Marie Curie, as the table above shows):

- Nottingham:
  - 12 helpers approached, eight participated in a focus group
  - two volunteer assessors approached, one interviewed.

- Somerset:
  - four helpers approached, four participated in a focus group
  - four volunteer assessors approached, three participated in a focus group.

### **Interviews with terminally ill people and carers currently using the service**

The interviews with terminally ill people and carers explored how they initially became aware of the service; the information they were given about it; any reservations or concerns they had about using the service; what happened during visits; what they liked best, and least, about the service; ways in which the service benefited them; what would help to improve the service; and how the service compared to other services used.

Given the sensitivity of the research, it was felt that the research would be best introduced to carers and terminally ill people via helpers or the service managers, with whom they were likely to have built up trust.

An information sheet and consent form were provided to terminally ill people and carers. Interviews were conducted in-home or by telephone depending on the health and availability of the participant. It was made clear to terminally ill people that their carer (or any other friend/relative) could be present if this is what they wished, and that interviews could be paused, terminated, or rearranged at any point. In the event, several of the interviews were paired depths, in which the terminally ill person and their carer were interviewed together. Some questions were directed at both participants, for either or both to answer, while others were directed specifically at the terminally ill person or carer.

It was made clear to participants that the research was designed to explore the service as a whole, as opposed to the performance of individual helpers. Interviews lasted around 30 minutes each.

In each area the following numbers of carers and terminally ill people were approached and interviewed by Ipsos MORI (please note, as the previous table shows, others were approached and interviewed by Marie Curie):

- Nottingham:
  - Five carers approached, three interviewed
  - Seven terminally ill people approached, two interviewed
- Somerset:
  - Seven carers approached, four interviewed
  - Eleven terminally ill people approached, five interviewed

## Analysis of the interviews and focus groups

With the permission of participants, all interviews and focus groups were recorded and transcribed verbatim for analysis. This includes the interviews conducted by Marie Curie; these have been analysed by Ipsos MORI and are included in this report.

The Ipsos MORI research team held an interim debrief analysis session halfway through the fieldwork and a final session at the end of fieldwork. At these sessions the team (including those who had conducted the interviews and facilitated the focus groups) shared findings from the research, taking each audience in turn, working systematically through the areas covered in the discussion guides. Themes were identified across the audiences and content from the transcripts was then grouped together within each theme.

Prior to the writing of the final report, the project team met once all the fieldwork had been completed for a full analysis discussion. This lasted around three hours and aimed to synthesise the key messages of the research in relation to Marie Curie's objectives, and develop in detail the structure of the report.

The research team approached the analysis based on a well-established four stage questioning framework. The discussions in the debrief sessions were underpinned by and aimed to address the following questions:

- **What have we got?** - what did people tell us during the research?
- **What does it mean?** - what are the messages to emerge from the discussions?
- **What does it all mean?** - how do these messages fit together into a "bigger picture"?
- **What does it mean for Marie Curie and the helper service?** - i.e. what implications and recommendations arise from the research?

*Verbatim* quotes illustrating each of the points were taken from the transcripts and these are used to illustrate findings throughout the report. Where this is the case, it is important to remember that the views expressed do not always represent the views of the group as a whole.

## Limitations of the research

This research was designed to explore perceptions of the helper service and the difference this has made to terminally ill people and their carers. It was not intended to provide any objective measures of change to their health and wellbeing. In addition, it did not attempt to measure the impact of the service in terms of the number of people who were able to be cared for at home for longer as a result of using the service. Indeed, without a control group it would be very difficult to assess what would have happened had these people not used the service. However, through the qualitative research with clients, helpers, referrers, and service managers, the qualitative evaluation looked at the ways in which the service benefits its recipients.

The scope of the research with service users was limited to terminally ill people, carers and referrers who have made use of the service. Therefore, comments on awareness and

perceptions of the service reflect only the views and experiences of those who have used the service; people who have either not heard of the service, or who have heard of it but chosen not to use it, are not represented.

Participants to this research were recruited via Marie Curie, the service managers or helpers. Ipsos MORI was not able to contact users of the service directly. This recruitment process may have led to more satisfied users taking part in the research.

#### **1.4 Publication of the data**

Our standard Terms and Conditions apply to this, as to all studies we carry out. Compliance with the MRS Code of Conduct and our clearing is necessary of any copy or data for publication, web-siting or press releases which contain any data derived from Ipsos MORI research. This is to protect the reputation of Ipsos MORI and its clients.



## 2. Aims of the Marie Curie Helper Service

This chapter examines the aims of the helper service, and explores the extent to which these are shared by the participants in the research.

As noted in the previous chapter, the Marie Curie Helper Service was established in Somerset in May 2009, and the pilot was extended to Nottingham in October 2010. In both areas, the service was set up in response to an identified need for non-medical support. With the multitude of services that a terminally ill person may be accessing towards the ends of their lives, the helper service would provide a consistent source of emotional support for both terminally ill people and their carers. The service aims to improve people's ability to stay in their homes if they are terminally ill and for their carers to continue with their caring role.

For all audiences involved in the research, the aims of the service related to the benefits that accrue to terminally ill people and their carers as a result of having a helper.

One of the primary aims identified was combating the social isolation of people with terminal illness through providing a volunteer with the time to talk and listen to them. This was very much seen as a core part of the service among all audiences. However, service managers said that the service also goes beyond this, by providing even those with family and friends with someone to support them. This allows them to discuss their situation in confidence with someone who is outside their family and friends, allowing them to talk honestly without having to consider the sensitivities that their family and friends may have.

Whilst the aims discussed above are targeted at terminally ill people, service managers saw the service as being aimed equally at carers. It provides respite for those caring for a terminally ill person, allowing them to have some relief from their caring duties, and to do basic tasks that they might not otherwise be able to do. In this way, service managers saw one of the aims of the service as being to support the mental health and wellbeing of carers.

These aims were identified by all audiences, not just service managers. However, while service managers saw these two aims as being of equal importance, other audiences tended to prioritise one over the other, depending on their own role and background. For example, referrers with a background in supporting carers tended to emphasise the carer respite aspect of the service, while those who were focused on patients tended to emphasise the needs of the terminally ill person.

*It's a combination of the person with the life limiting condition and also the carer, because there are some clients who we support for respite particularly, from a carer's point of view, who otherwise wouldn't be able to go out and have a break from their caring role. But equally there are those with life limiting conditions who want to have somebody to speak to that isn't family.*  
Service Manager

*It's more for the carer, I would say, than the [terminally ill] individual. It's psychological support for the carer...because very often they daren't leave the house in case something happens whilst they're away, whereas if they know they've got someone coming that gives them a lot more reassurance.*  
Referrer, Nottingham

In addition to providing emotional support, service managers also saw the aim of the service as providing practical help. They said that the service is intended to support terminally ill people to stay at home, not only by providing respite for their carers, but also by providing practical help, through signposting other services and helping clients to obtain aids, to

improve their quality of life. It should be noted, however, that whilst referrers also saw this as an aim of the service, the helpers themselves placed less emphasis on this aspect and there was little discussion in the helper group of issues such as signposting other services. This suggests that helpers may need more support to deliver these practical aspects, if they are thought to be key to the service.

*We can go in and identify need. Things like bad backs, we can identify that you might be able to get a hoist. And it's things like that that people know are out there but [we know] the quick fix.*

Service Manger

Referrers, terminally ill people and their carers also focused on practical help in terms of everyday tasks. They thought that the service can help people continue to live their lives through assistance with simple tasks such as washing up or shopping. However, there was some uncertainty as to the extent of the support that the helper was supposed to provide.

*Well I haven't even asked whether this is an option but some people struggle with a little bit of light housework and...I can't remember whether that was an option or not. Things like changing light bulbs.*

Referrer, Somerset

In general, there was a shared understanding of the aims of the service amongst the different audiences. However, there were small but distinct differences of emphasis between them. While this may not represent a problem, these differences, if left unchecked, could lead to misunderstandings and missed opportunities in the future.

## 3. Benefits and factors for success of the service

This section sets out the benefits that the service brings – primarily for terminally ill people and their carers. There are also benefits for referrers and helpers that are discussed here. In addition, this chapter explores the success factors for the service: what are the key features that mean it is successful or otherwise?

### 3.1 Benefits of the service for terminally ill people and carers

The helper service aims to provide a range of support to maximise the wellbeing of terminally ill people and their carers. Participants were asked about the support received within the following areas and how the support had made a difference:

- emotional support
- companionship
- practical support
- carer respite
- providing information about services.

#### Emotional support

For many of the terminally ill people and carers, the emotional support provided by the helper service was where they saw it as being distinctive to the support they received from other services. While the medical needs of the terminally ill person were met by a range of health professionals, the helper was someone they could talk to and confide in on a personal level. The helper was often seen as being there to listen to the terminally ill person's hopes, fears, concerns and frustrations – things they felt a medical professional may not have the time or inclination to listen to. There were also some things they simply did not want to discuss with their health professionals.

*She rings me once a week, yeah, I'm okay, you know, listens to my whinge, you know.*  
Terminally ill person, Nottingham

As noted in the previous chapter, the provision of a 'listening ear' was considered to be a key means of emotional support for those with terminal illness who were socially isolated. However, participants also thought this support was equally important where they did have friends and family they could speak to. The helper was someone who had volunteered to be there, who they could speak to frankly and openly, without having to worry about their feelings or that they were impinging on their time, as they might with a family member. They could also provide an objective point of view and act as a sounding board for the terminally ill person.

*Being able to speak to someone in an alternative manner that I can't necessarily with my dad... The best bit is being able to talk with someone who is not exactly in the same situation.*  
Terminally ill person, Somerset

*I've had money worries and [helper] was a great help, I could chat to her about these things because of course she didn't know my relatives so I was able to get a sort of impersonal view of all these worries that I had.*  
Terminally ill person, Somerset

Equally, carers welcomed having the opportunity to speak to someone other than the person they were caring for about their concerns, whether these were related to the terminally ill person or something else.

*I mean I get carers coming in four times a day but they're not here for long, you can't have a general conversation with anybody so basically I'm on my own all the time which gets a bit boring at times, so it's nice to be able to sit and talk to somebody for a change so in that way it's quite good.*  
Carer, Nottingham

### Impact of the support provided

The support provided by helpers to the terminally ill person was seen as having a positive impact on their emotional wellbeing. The helper was sometimes able to provide reassurance on specific concerns raised, but more often, simply talking about their worries enabled the terminally ill person to cope better with their situation.

*I feel really down. Really down. That's why they asked [helper] to come and see me...So he helped me for talking to me you know...and trying to boost me up a bit.*  
Terminally ill person, Nottingham

*A type of liberation... a type of freedom...*  
Terminally ill person, Somerset

In some cases the concerns discussed were specific issues around their medical care, or their family, or practical matters, but in others they were more substantial and related to the overall situation the terminally ill person found themselves in, and the reality of their condition. For example, one helper described how their client opened up about his fears for the future. This was something he had not been able to do with anyone else, and illustrates clearly the impact of the emotional support provided by the helper role.

*And in the second session, he just broke down. He literally just sobbed and just before I left he regained his composure. And on reflection I just feel that he needed to do that, and maybe I was the person who he needed to offload. And I think it kind of dawned on him that with his condition, he's not going to get better, and I think that was a heavy burden which he needed to release and since then he's been more jovial.*  
Helper, Nottingham

*I don't like the prospect of having suddenly to come to terms with the fact that I may be dying and to have somebody intelligent and sympathetic to chat about these things is a great help.*  
Terminally ill person, Somerset

However, one helper warned that the desired 'impact' should not always be seen as 'cheering up' the terminally ill person (or the carer). Empathy – gauging their moods and listening to them – were thought to be key to providing emotional support.

*As much as I hope I'm always cheerful you've got to gauge what they're like. You're not just there to cheer them up, you're there literally just to sit and listen, it's their feelings at the end of the day. So they're allowed to vent and let it all out. They don't have to worry about upsetting you or worrying about what we're thinking.*

Carers also reported similar benefits where they were able to talk to the helper about their own concerns. Having a space to vent their feelings with someone neutral and not involved with the terminally ill person's formal care helped them feel less overwhelmed. Helpers highlighted that the carer's needs could often be overlooked during a family member's terminal illness and were aware of the benefit that their relationship could have for a carer's mental wellbeing.

*I do feel chirpier...I feel a lot better through having [helper] here to talk to, to whinge to if I want to...It's been really good having her here.*  
Carer, Nottingham

*With my particular carer sometimes she wants to let off steam because he's terminally ill, she's got cancer and she's getting over it and she gets so aggravated with all the care situations which seem to change... So sometimes I always find part of my job is to sit there for half an hour or so and just listen to her let off steam.*  
Helper, Nottingham

One helper highlighted the importance of the conversations that took place with the carer in helping her to think about the future. The emotional support provided here was less about dealing with existing problems, but more about preparing her for life without her husband.

*So, quite often we'll spend a significant amount of time talking about him, but then I'll say 'How are you? How did you doctor's appointment go? Did you see the royal wedding?' You know, little things that bring her back into the present, but also talking a bit about the future, what happens after he's gone, because we know that he's going to go...what else is happening in her life, that sort of thing.*  
Helper, Nottingham

In addition, the carers often benefited simply from knowing that the emotional needs of the person they were caring for were being met.

## **Companionship**

In many cases, the helper role was described in terms of the companionship it provided. The nature of relationships between terminally ill people and their helpers – the detail of what comprised that companionship – varied widely depending on factors such as the terminally ill person's mental and physical capacities, as well as their and their carer's general expectations from the relationship. For example, one carer in Nottingham was caring for her husband who was unable to speak due to his illness. The helper's role here was to sit with him and do little practical things to help him while the carer was out (for example, to answer the phone or change the television channel).

Some terminally ill people and carers very much valued having a relationship closer to a friendship, someone they had things in common with and could talk freely with. For them, companionship was about easing the social isolation that often went with their condition.

*He enjoys a game of cards and we do have a little kind of man's talk about things.*  
Helper, Nottingham

*It's knowing that I have a friend to talk to and will come... We just get on, we feel that she's part of the family.*  
Terminally ill person, Somerset

*We had a gentleman come who could sit and talk to [my husband]... I was quite happy because [my husband] is a person who likes a little chin-wag.*  
Carer, Somerset

*To have someone sensible and intelligent to discuss books with and to look at my family photographs with.*  
Terminally ill person, Somerset

Where the health of the terminally ill person allowed, the helper would accompany them on trips outside the home, in the way that a friend would do so. For example, some helpers had gone for meals with their clients or to sports matches, where that was something they both enjoyed.

### Impact of the support provided

Again, the impact of companionship centred on the emotional wellbeing of the terminally ill person. The helper often filled a gap left by the absence of friends and family (either where these did not exist or were unable to visit). Several participants mentioned the gender of the helper as making a real difference to the terminally ill person – meaning that the relationship was more like that of a friend.

*I used to play golf three times a week and I had my golfing friends, my men friends, and it was a chap's time together, you know, a bit of a crack...so for me it has replaced that gap which appeared in my life.*  
Terminally ill person, Nottingham

Terminally ill people (and carers) talked about the pleasure they got out of the visits – they enjoyed the time they spent with the helper and looked forward to visits. As noted above, many said that the helper had become a friend and someone they wanted to spend time with.

*And when [the helper] arrived I thought [my husband] wasn't all that well that morning and was maybe a bit too tired to go out but as soon as he saw [the helper] he perked up and said right, we are going, shall we go down and have coffee.*  
Carer, Somerset

*I really have enjoyed her being here.*  
Carer, Nottingham

The focus on companionship (rather than medical care) was seen as providing a release from being a patient, an 'object', to being able to feel 'normal' and lead a normal life, engaging in everyday conversations and activities. Where the terminally ill person and the helper undertook activities in or outside the home, they said they regained a sense of independence. They talked about relief at not being reliant on their carer. The helper was also seen as a link to the outside world – something that some felt they had lost as their health had deteriorated.

*A little bit of normality in my life.*  
Terminally ill person, Nottingham

*She's actually taken me shopping once and she took me to hospital and it's lovely because I feel independent. You know, you just feel like you're going with a pal.*  
Terminally ill person, Nottingham

*She tells me, "oh the road is up and so and so", so she keeps me up to date, like a little newsletter.*  
Terminally ill person, Somerset

Where the carer was the primary client, they also talked about the enjoyment they got from having a friend to spend time with and talk to. Where the helper was primarily there to support the terminally ill person, the carers also felt they benefitted through knowing their loved one was in safe and congenial company. They gave them peace of mind.

*I thought well it's a great idea because whilst somebody's with her, if she does have a fall or an accident, there's somebody there. It helps my stress levels, knowing I've not got to worry quite as much.*  
Carer, Nottingham

## **Practical support**

Practical support could range from doing small things to make the terminally ill person or carer's life more comfortable – such as helping with shopping, washing-up or other small ad hoc tasks around the house. The extent of the practical support provided varied from case to case. As noted earlier, there was some uncertainty from terminally ill people, carers and referrers about what a helper was permitted to help with. One service manager also raised the issue of personal care – something that not all helpers saw as their role.

*It's been a bonus that we've been able to start pushing wheelchairs and making cups of tea. The difficulty I think is the toileting side of things, I don't know how we'd get round that because helpers might not want to be able to take someone to the toilet.*  
Service manager

*She'll come and she'll wash up dishes or anything like that for us, or do any other little task that she feels is necessary.*  
Carer, Somerset

*And then I'm still not sure what their role is you know... I know they know what they can't do and what, you know, what they're not allowed to do, but I don't know what they are allowed to do.*  
Terminally ill person, Nottingham

In some cases, the helper took the terminally ill person shopping or to medical or other types of appointments (e.g. hairdressers). This could occur simply because the individual needed help in getting there or because they wanted the moral support, perhaps during medical appointments. Even where they didn't accompany them, they sometimes provided practical advice on how to deal with specific issues relating to their medical care or other aspects of their life.

## Impact of the support provided

The practical support provided enabled the terminally ill people and their carers to do things they said they would otherwise have struggled with. For example, they talked about the challenges they faced in completing some everyday tasks, such as unpacking the shopping or taking the washing out of the washing machine. The helper's assistance made their lives a little bit easier. In some cases, the helper's support meant that they were able to do things they simply would not have been able to do otherwise. This in itself had an impact on their lives, but it also provided reassurance and peace of mind that there was someone they could rely on to help them with these things.

*He helps me do routine things which I can't do like go to the bank...go to the shops and takes me to the hairdressers. Things like that which I can't do myself because, though I can still just about drive, I can't get in and out of the car by myself. I need someone there to help me and put me in a wheelchair and wheel me round.*

Terminally ill person, Nottingham

*I don't worry now about how I'm going to get shopping in. It's like the television blew up and she took me to buy a new television.*

Terminally ill person, Nottingham

Where the helper accompanied the terminally ill person to medical appointments, this had a number of benefits. In addition to driving them to the clinic or hospital, they also sometimes acted as a 'second pair of ears', someone more detached and able to take in information, and ensure that the terminally ill person asked the right questions.

*She did remind me about something [during the appointment].*

Terminally ill person, Nottingham

*My first client she was diagnosed, she said 'they throw all this stuff at you and I saw this person and that person' and I said 'do you want me to come with you?' 'No, no, I'll be fine.' I said 'why don't you take a notebook and just write down all the little bits, what they tell you and ask their names. Stop them and say what's your name, who are you, you know just write it down 'cause you get very confused or do you want me to come along and write it down.' And just giving them sort of little tools to give them that confidence to broach things or record things.*

Helper, Nottingham

## **Carer respite**

The analysis presented above shows that in some cases there were direct benefits to the carer as the primary client of the helper. For example, the support provided meant they had someone else to talk to other than the person they were caring for, or a companion to spend time with, or someone to help with practical tasks. In addition, where the support was primarily provided to the terminally ill person, the carer received respite from their caring duties. This was one of the most common benefits cited by carers, with the greatest impact on their lives. Some carers used the time to do basic tasks like shopping, going to the bank or attend medical appointments. This assisted them on a practical level, but also gave them a sense of normality and allowed them to think about themselves for a short time.



*Very often when patients are at the end of life the carers daren't go out, they daren't leave the house in case something happens while they're away, whereas if they know they've got someone coming in to sit that gives them a lot more reassurance to do that.*

Referrer, Nottingham

*I was tied to the house... I felt like I was about to have a nervous breakdown.*

Carer, Nottingham

*I went to hospital on Monday so she made a special visit to come down and stay with my wife whilst I was in the hospital.*

Carer, Somerset

As with some of the terminally ill people who had close relationships with their helpers, the visits and calls could help the carer to feel less isolated. This was the case where the relationship was mainly between the carer and helper, or equally between the helper and the terminally ill person and carer.

*It's nice to be able to sit and talk to someone for a change.*

Carer, Nottingham

### Impact of the support provided

In addition to providing carers with peace of mind about the wellbeing of the person they cared for, the helper visit also allowed them to get on with their own lives. The impact for the terminally ill person was that the carer would feel less stressed, and more able to focus on them and care for them effectively. One carer described how draining it could be, having to constantly attend to her husband even during the night. She felt the demands on her were starting to affect the quality of the care she was giving her husband.

*And to tell you the honest truth, I don't think I've really recovered from it yet. I'm still very tired because I don't seem to be able to catch up.*

Carer, Nottingham

*I wasn't getting any help at all. I was struggling on my own. So you can imagine how grateful I am for the help I get from Marie Curie.*

Carer, Nottingham

### **Providing information about services**

As described above, some helpers have established a role in supporting terminally ill people and carers in dealing with paid carers and professionals. Some also provided information about different services, generally about what was available (hospices, for example) and who to contact. However, as noted in the previous chapter, the helpers were less likely to see this as a core function of their role.

Similarly, the provision of information about services did not emerge as an element that terminally ill people or carers thought was a significant part of the helper's role. They often did like to discuss issues around medical care and support with the helper, but more often to 'let off steam', as previously discussed.

*I know all that I need to know about the disease, to be perfectly honest. And there's the internet and my team at the Motor Neurone Disease Centre in Nottingham, they're very forthright. They tell you exactly as it is. So I don't need more information.*  
Terminally ill person, Nottingham

However, helpers were prepared to provide information about other services, or find out what was available on behalf of their client. They said that the service managers were a key source of information for them and they would direct their queries to them, confident that they would be able to help.

*If you're in trouble you've just got to ring up [the service manager] and she will point you in the right direction. She is a very experienced lady.*  
Helper, Nottingham

### Impact of the support provided

While there were few examples of this type of support being provided, where it did happen, it meant that terminally ill people were able to benefit from services they would not otherwise have been aware of. The helper acted as a 'lifeline' to these other services.

*Anything I need like that she will get it for me.*  
Terminally ill person, Somerset

*You can always get that information and sometimes it's the family who haven't got access to that and they just don't know what to do. So we are a point of contact.*  
Helper, Nottingham

There were limits to signposting though. Some helpers emphasised that they could only suggest things or even just leave information. Carers could sometimes be quite resistant to this type of support.

*You can't live their lives for them you know.*  
Helper, Somerset

In summary, the findings suggest that the emotional support provided by the helper service, whether that was talking through concerns or simply sharing some enjoyment with a friend had a positive impact on the lives of the clients. They also benefited in numerous ways from the practical support provided, but could sometimes struggle with the boundaries of the role. The signposting function of the helper's role appears to be slightly less important for recipients of the service, though it has proved useful for some.

## **3.2 Benefits for other audiences**

While the study was primarily intended to consider the impact on the terminally ill people and carers, the research revealed further benefits for the referrers and helpers.

### **Referrers**

The helper service was widely seen amongst referrers as a vital additional resource for them to use locally. It filled a clear niche where some non-medical relief and respite was needed. The regular visit from helpers without the need for new appointments each time made it particularly useful for referrers when they identified a carer with a need for regular respite or support.

*When you refer to say [Marie Curie Nursing Service], there's no guarantee that you can get a booking on a set day, whereas with the helper service it usually works that they have a regular input on a set day. For instance I have a chap and his wife wants to go out and do her shopping on a Monday, so she now has her Marie Curie volunteer every Monday.*  
Referrer, Nottingham

For one key referrer in Somerset, the advantages of the additional service were particularly welcome where cutbacks had resulted in reduced funding for the provision of 'sitting' services. The referrer suggested that the helper service filled that gap, alleviating some of the pressure on carers.

*[Our organisation] as a whole used to be able to provide free sitting services, that is gone. It is difficult times.*  
Referrer, Somerset

### **Helpers and Volunteer Assessors**

Helpers and Volunteer Assessors (who had started as helpers) tended to be motivated by a desire to help other people, to make things easier for them at a difficult time. Some of those who had experienced bereavements themselves, meanwhile, felt that they could have an impact on someone else's experience so that other terminally ill people and their carers could have a better experience than their loved one. Their role as a helper appeared to give them a level of satisfaction that they were able to help someone in need.

*When my father died 10 years ago, he was diagnosed and died within five weeks and it was a bit like bang, bang, bang and people came and went and there wasn't anything like this. And this is when I read about the helper service in the Evening Post two years ago and thought what a brilliant idea because if someone wants to die at home we could have really done with that support because we didn't have anywhere to go, or know what to do.*  
Helper, Nottingham

### **3.3 Success factors**

In order for the relationships between the helper and the client to succeed, and the service to deliver positive impacts for carers and terminally ill people, a number of factors were identified in discussion with the different audiences. When these factors were in place, the service worked at its best.

#### **Finding common ground**

Terminally ill people and their carers emphasised the importance of finding common ground between the parties. This could be shared interests, but could also just be a shared sense of humour, similar approach or outlook. Helpers also recognised the importance of building rapport between the parties. Being the same age and gender could help, but rapport could transcend these factors and was more important. There were examples of relationships where the helper and terminally ill person were quite different ages.

*We go to garden centres, we go around sight-seeing, we both have an interest in the flora and fauna. She loves her birds and so do I and we admire the autumn tints, and we generally have a rapport.*  
Terminally ill person, Somerset

*I've had the one where I'd just got no rapport at all. I'd phone and it was very difficult to get a conversation going.*  
Helper, Nottingham

*My client was 24 and I am 58 and you are thinking, this is not a very good mix, I could be his dad, but [service manager] mentioned about his music, so you have a link straight away so that actually takes you right into quite a close friendship.*  
Helper, Somerset

## Quality and calibre of helpers

The personal qualities of the helper were also seen as important. Terminally ill people and carers singled out qualities such as being a good listener, easy to talk to, straightforward, kind and gentle.

*Having the opportunity to chat every week to a congenial person with whom I hit it off. I can talk to her about my medical tests.*  
Terminally ill person, Somerset

*Empathetic, obliging, helpful, she was very helpful*  
Terminally ill person, Nottingham

Trustworthiness and integrity were an important consideration for some. One terminally ill person described how they were reluctant to have people in their home, and so trusting the helper was a key requirement for them. Several interviewees referred to the large number of people that come into the home when someone is terminally ill. They often found the presence of all these strangers intrusive and stressful. This made it all the more important that their helper was someone they felt comfortable with.

*Someone I can talk to, that's part of it... She's honest, a very honest person.*  
Terminally ill person, Nottingham

*To tell you the truth I would rather not have people I don't know around the house where I can't see what they're doing. I was well aware that people have been known to rummage about and help themselves to what happens to be around.*  
Terminally ill person, Somerset

Whilst such qualities were important, so were more active, 'positive' skills, especially the ability to make conversation and take the lead in creating the all-important rapport. Helpers were particularly conscious of the skills they needed to make the relationship work and the emotional input that was required of them. They understood that they would be entering people's lives at a difficult time and so needed the skills and attitude to be able to cope with this.

*It's sometimes feeling the way, approaching topics like with my first client it was soaps. I started talking about soaps and I could almost hear a click and her go oh yeah she's alright and then we go on to other topics and you feel your way.*  
Helper, Nottingham

*[Ability to] hold a good conversation as well. You know, trying to find an area you can hold a conversation about.*  
Helper, Nottingham

*You need to have quite a mature and adult attitude to dying and death which is not easy. It's still quite a taboo subject isn't it?*  
Helper, Somerset

## **Commitment**

The extent of the helpers' commitment to the role was clear from some of the feedback from clients. Within the parameters of the service, helpers were flexible, considerate and thoughtful, putting the terminally ill person or carer first. Clients sometimes talked of the helper as being a very close friend or even like a member of the family.

*When [the helper] goes on holiday she sends a card like she would any friend and then comes to visit as soon as she comes home. At the moment she does feel like one of the family.*  
Carer, Somerset

In both Somerset and Nottingham, volunteers need to commit at least three hours per week. Most seemed to do at least this much. Visits and calls tended to be regular but flexibility was often seen as very important. One of the key benefits of the service was that it could adapt to clients' needs. Clients were aware of this, and referred to how timings and activities had been discussed and agreed with their helper. This flexibility was greatly appreciated by clients. The ability of helpers to take their clients to hospital, go for a coffee with them, or pick up some shopping for a carer if they are not able to go out made a tangible difference to them. However, this flexibility also reaffirms the importance of clearly setting out boundaries early on, to ensure that carers and terminally ill people do not become confused about the exact purpose of the helper.

*I fit in with my carer, the wife, because it's her that needs a break because she's with him 24/7... I used to go Monday because that was better for her but she thinks Thursday's better because the food's fresher on a Thursday [shopping].*  
Helper, Nottingham

*He made the world of difference to me when he took me out on a Wednesday. And he didn't mind where he drove. And I did say that I would like to go out and have something to eat, because it saves me getting a meal.*  
Terminally ill person, Somerset

Helpers also highlighted the importance of continuity to clients. From the clients' perspective, medical staff can come and go, and having that consistent point of contact, someone to talk to about themselves, regardless of what else is going on around them, was seen as valuable.

*Family and friends will sympathise with you and then get on with their lives, and because I've been calling her for over a year she'll say 'you're the only one who rings me regularly and you ask me about me'.*  
Helper, Nottingham

## **Professional attributes**

Helpers sometimes brought experience from the workplace and other volunteering roles. For example in Nottingham, the two volunteer assessors were recruited partly with their professional backgrounds in mind. The service manager believed that their previous experience would be valuable to them.

*One lady is an experienced helper, she's been doing it over a year now and also she has a legal background so it's in terms of knowing about confidentiality, risk assessments. She's also agreed to train up on welfare benefits as well. The other lady is retired, she's got a lot of time on her hands but she's also a volunteer at the hospice that's in the area where she's going to be assessing, so she's got a wealth of experience with outpatients.*  
Service manager

Previous experience was also noted as valuable by some clients. Despite the fact that terminally ill people welcomed the fact that the helpers were distinct from medical staff, some of the qualities garnered from a professional medical background were appreciated.

*I thought she was a very pleasant person, very well dressed and very well spoken and like a nurse, previous nursing experience.*  
Terminally ill person, Somerset

### **Robust processes**

Service managers in particular emphasised the importance of robust recruitment processes and training for volunteers. Getting the right volunteers, with the right qualities and motivation, was not easy. Insisting on quite a lengthy commitment was thought to help secure the right people and dissuade less suitable ones.

*I have to be aware that some people unfortunately just want the training to go on their CV or if they're job hunting etc, you know, and I say, that's why I think it's really good we ask for a commitment of a year up front and I think that sorts out the wheat from the chaff.*  
Service manager

The training for volunteers lasts two full days. It covers in detail the aims, ethos and boundaries of the service – what helpers can and cannot do in relation to their clients. The helpers described how useful they found the training and particularly the role play exercises. These were designed to equip the helpers with the knowledge of what to do and what not to do in certain difficult situations that could arise.

*That pointed out a lot of stuff to me, role play. Such as making decisions that it wasn't my business to make.*  
Helper, Somerset

Finally, participants also mentioned the assessment and matching process as key to the success of the service. At the assessment stage the service manager or assessor would think carefully about which volunteers would be most likely to form a good, long-term relationship with the terminally ill person and carer.

*I explain to them that I will come back with a helper if they feel they could not get on with the helper in a month of Sundays, they tell me and we start again. I absolutely do not agree with just matching people for the sake of it. You've got to be right.*  
Service manager

This emerged as a key part of the service: it allowed rapport between helpers and clients to be built more quickly, and essentially for the quality of relationships to be maximised.

Overall, there are a number of key success factors for the helper service, many of which relate to the skills, personality and commitment of the volunteer. Attracting suitable candidates to the role is a significant challenge and it needs to be supported by robust

recruitment and training processes. These challenges are considered more fully in chapter six of this report.

## 4. Understanding and expectations of the service

This chapter discusses initial reactions from terminally ill people and carers on learning about the service, as well as their understanding of what was being offered and their expectations of their helper. It then goes on to look at helpers' and referrers' understanding of the helper service.

### 4.1 Initial reactions from terminally ill people and carers

When first informed about the Marie Curie Helper Service, most terminally ill people and carers reported positive reactions. Both audiences said that their initial reaction was that the service was a good idea, and that they could see how they could benefit from it. For terminally ill people, this anticipated benefit lay in the possibility of seeing a new face, companionship and having someone new to 'natter' with. For carers, the service opened up the possibility of respite from caring, whilst also providing peace of mind that someone was with the person they care for, should anything happen. Indeed, many terminally ill people and carers said that they had no reservations at all about using the service when they initially heard about it.

*My feelings were it sounded a wonderful suggestion, to have a break and know that somebody was here who would call me if need be.*  
Carer, Somerset

*I didn't realise there was such things about...Everything that was being suggested I've gone along with, because I know it's for my own benefit.*  
Terminally ill person, Somerset

However, although these positive reactions were common, some terminally ill people and carers were more hesitant when first told of the service. This hesitance was sometimes a result of nervousness about letting a stranger into their home, or a perception on the part of the terminally ill person that they could cope on their own and did not want or need to be 'babysat'. In addition, one carer felt guilty admitting that she was not able to cope on her own. However, these participants also said that these concerns were addressed, by the referrer or by the service managers or volunteer assessors, when they made contact, and that once the helper service was more fully explained to them they decided that it sounded like a good idea.

*I felt guilty at first, admitting I couldn't cope. But the nurse convinced me, she said if I was depressed I wouldn't be as much help to my husband as if I allowed myself a break.*  
Carer, Nottingham

These reservations also arose in interviews with service managers and referrers, who said that guilt or a need to protect their relatives sometimes makes carers reluctant to accept the service. They also noted that terminally ill people were sometimes hesitant to accept help due to their pride, a reluctance to accept their prognosis or an unwillingness to accept help from anyone other than their carer.



## 4.2 Understanding and expectations of the service

### Terminally ill people and carers

At the time of the initial contact by Marie Curie, understanding of the service offered and expectations varied considerably. Some terminally ill people and carers had a clear idea of what was being offered and understood what helpers could and could not do; others had a general idea that the service provided companionship but little notion of what was involved beyond that; and a third group had no awareness at all of the service, and may not even have known that they had been referred. It should not be inferred, however, that everyone in this third group was not informed of their referral, or asked if they would like the help; some terminally ill people recognised that because of the number of people they saw in relation to their illness they may not recall such a discussion. That being said, some assessors did feel that the referrers were not always providing information to clients, and that it was quite common for them not to know anything about the service when assessors first speak to them.

*Some of them don't even know they've been referred...And they know nothing about it because the referrers haven't given them any information.*  
Volunteer assessor, Somerset

These varied levels of early understanding mean that it is important the service manager or volunteer assessor clearly sets out the nature of the helper service, what is included and its limitations before a helper is assigned, so that clients have a clear idea of what is being offered and what helpers can and cannot do. It does seem that the message is largely getting through at this stage; regardless of their early understanding of the service, several terminally ill people and carers noted that it primarily provided companionship for the terminally ill and respite for carers, and that whilst helpers could take people on trips, they were not meant to undertake housework, or personal care or that they could not accept the purchase of items such as a cup of coffee. In addition, a couple also mentioned leaflets about the service that they had received which set out the boundaries of the role.

*The worst [assessment] was when she didn't seem to be listening to start with. She just said 'I need this, I need that'. And a lot of it wasn't ours. But by the time we left she realised that we would do limited amounts.*  
Volunteer assessor, Nottingham

*I know I shouldn't ask her to do any personal things, like doing my hair or washing... You have to learn the boundaries for everyone.*  
Terminally ill person, Somerset

Whilst many clients did understand the nature of the service before their helper started, a small number were still unsure, in particular of the limitations on what their helper could do at this point. Indeed, one terminally ill person said that they still did not have a clear understanding of this.

*I'm still not sure what their role is...I mean I carry oxygen for instance, and I don't know if you've noticed when people are lacking in oxygen they can't always get the oxygen machine on. If I was with a helper, would that helper be able to do it, help me?*  
Terminally ill person, Nottingham

Concerns over how well, in practice, some clients understood the nature of the service were also raised by one of the volunteer assessors, who questioned whether terminally ill people always understood that helpers do not have a medical background.

*I sometimes think, is it fair to somebody who is so ill to be left with this person...have they really realised that we're not medical people?*  
Volunteer assessor, Nottingham

Those clients who are not fully aware of the limitations of the service rely on their helpers to tell them if their expectations go beyond the limitations of the service. Indeed, in the Nottingham helper group, it was noted that questions relating to what helpers could or could not do were common. Helpers seemed to be clear that they were there to provide both companionship for the terminally ill person and respite for the carer, and they were largely aware of the limits of what they could do in terms of practical help. It also should be noted that the interviews with carers and terminally ill people, and indeed the helpers themselves, suggest that helpers do sometimes go beyond the strict limits of their role, for example by performing household tasks.

*You don't do anything in the house...you can't actually, apart from making them a cup of tea or tidying their blankets.*  
Helper, Somerset

*You bend the rules a bit... I gave one of the gentlemen my mobile number because he had a hospital visit and I'm not far from the hospital so I said well I'll go home and you just give me a ring when you're free.*  
Helper, Nottingham

Whilst they were generally clear that they could not help with personal care, there was also confusion amongst some helpers over whether they were permitted to do some very small tasks, such as making a cup of tea. It seems that this confusion may have arisen as a result of changes in the regulations, and issuing clarifications would help to eliminate it.

## **Helpers**

Helpers saw themselves as providing both respite for carers, and also as providing the terminally ill person with an independent person to talk to, who is not a medical professional and is outside the terminally ill person's family. In this sense, they expected that they would provide support for both the carer and the terminally ill person, regardless of which of these was the primary client.

Helpers expected that they would be provided with training, and that they would be given ongoing support by their service manager. In terms of their role, they expected to spend a few hours a week with their client, either in their home or on a trip somewhere, but also recognised that the arrangement was flexible.

*When we did our training we were told sort of three hours which we could break up if we wanted, it depends how far you are going.*  
Helper, Somerset

## **Referrers**

There were two main expectations of the service amongst referrers. Whilst some expected that the helpers would primarily provide respite for the carers, with companionship for the terminally ill person a secondary benefit, others thought that the main role of helpers was to provide companionship and support for the terminally ill person. As noted in chapter two, referrer perceptions appeared to be affected by the referrer's own role and whether this was focused on patients or carers. One referrer had no firm expectations of the service, and emphasised its flexibility in terms of what the helpers do.

*The aim of the service is to provide respite for people who are caring for somebody who is in the end stage of life*  
Referrer, Somerset

*Primarily it's for somebody that's very lonely and socially isolated and would like to have somebody who would come and talk to them.*  
Referrer, Somerset

The expectation amongst all referrers was that helpers would, on a regular basis, dedicate several hours of their time, usually weekly, to their client and that during this time they would do things such as spend time with the terminally ill person, take them on trips, or help them or their carer with tasks such as shopping. There was a degree of confusion about the detail of what was allowed and the eligibility criteria; one referrer was not sure if helpers were allowed to carry out small household chores for their clients whilst another thought that only people with a terminal diagnosis of cancer qualified. This has implications for clients, who may be referred to the service with expectations that cannot be met, or who might benefit from the service but are not referred because the referrer does not think that they qualify for it.

Overall, the expectations that terminally ill people, carers and helpers have of the service do coincide. However, greater clarity about the specific functions provided (and not provided) by the service would be beneficial. Whilst it is clearly important that terminally ill people and their carers have a basic understanding of the role of the helper (for example that they are not medically trained and are only there to perform certain functions), it is likely that they will continue to rely on their helper for guidance. This suggests it is important that helpers fully understand the boundaries of their role so that they are able to deal with queries easily and with confidence.

## 5. Service delivery

This chapter describes each of the key stages underpinning the delivery of the Marie Curie Helper Service. It starts with the initial establishment and development of the service in pilot areas. It then considers the recruitment and training of helpers before moving on to discuss the referral process, assessments and matching of helpers and clients.

### 5.1 Establishment of the service

In Somerset and Nottingham the first step taken to set up the service was the identification of the stakeholders with whom the service managers would be working and who would act as referrers to the helper service. Indeed, the reason why Somerset was chosen as the first location for the programme was because Marie Curie was already delivering a programme in that region in 2009, and therefore had already engaged with stakeholders and identified the local services.

In Nottingham the service manager made particular efforts to emphasise to stakeholders that the helper service was not intended as a challenge to their existing role. This issue was not raised by the Somerset service manager, possibly because levels of engagement were already higher.

*We want to show that we are not bulldozing in and that we are a complementary service, rather than a threat to existing services. We don't want to be imposing on their territory.*  
Service Manager

Once the initial process of reaching out to stakeholders was complete, differences also emerged in the promotion of the service. Whilst in both areas service managers contacted stakeholders to inform them of the service, in Somerset the service manager was, and continues to be, very targeted in her use of literature. She expressed concern that widespread publicity about the service could result in a larger number of referrals that could not be met by the number of volunteers. In contrast, whilst there was concern about the number of suitable volunteers in Nottingham, the service manager developed a marketing strategy to attract additional volunteers, rather than manage demand by seeking to limit the number of referrals.

As stated earlier, the service has continued to expand and develop. For example, in 2011 a new role was developed in Somerset, that of volunteer assessor. Although the service manager continues to play a leading role in the assessment process she is now supported by six volunteer assessors. This allows the service manager more time to run the service and provides time to consider how to expand the service. This latter activity involved:

- identifying new referral organisations and making them aware of the service so they signpost their patient to the helper programme; and
- recruiting more volunteer helpers to boost capacity so that the service is able to cater for increased referrals.

In Nottingham, two volunteer assessors have been recruited and were being trained at the time of the research. Again, this was intended to allow expansion of the service.

### 5.2 Recruitment and screening

The recruitment and screening process for helpers takes a significant amount of time and resource but all participants felt it was necessary in ensuring that volunteers were:

- suitable (for example, personal attributes and time commitment);
- equipped (i.e. having an understanding of different life limiting conditions for the role); and
- able to advocate the Marie Curie service.

Service Managers explained they advertise the opportunity of a volunteering role as a helper through adverts placed in the local press or newsletters, leaflet drops or using online websites such as (do-it.org); most helpers in both areas who began volunteering at the project's inception said they were aware of the service as a result of a newspaper advert.

*Anywhere where you can think of putting posters into libraries, dropping leaflets, a poster in the window, up in the office... anywhere where you think that people might have time on their hands, but also where volunteers gather for that kind of information.*  
Service manger

*[I first heard about the volunteering opportunity] in the magazine that you get. I've been, selling daffodils and things for Marie Curie for a long, long time...and it was in the magazine and I thought 'That's something, I'd like to do'.*  
Helper, Nottingham

If interested in becoming a helper, the advert requests that volunteering applicants should make contact with Marie Curie in order to have a brief conversation about the role. Service managers explained that this is one way of limiting attrition by identifying early on those who would not have the skills or time required to volunteer as a helper.

As discussed earlier, attracting high quality candidate was thought to be a key success factor for the service. One helper suggested that running recruitment events where helpers talk through their experiences could be one possible way of ensuring that suitable applicants register an interest.

### 5.3 Training

The next stage of the volunteer recruitment process is an initial training two-day course. This course covers a number of different aspects, including an introductory overview of Marie Curie, focusing on how the helper service aims to complement existing clinical services.

*The formal training course is two and a half days in duration. The first half day is an introductory session. It places Marie Curie Cancer Care and the helper in the context of the organisation and talks about the organisation as a whole. It's an opportunity for the volunteers to meet other volunteers for the first time and then to be given their resource manual which they take away and read which is quite comprehensive.*  
Service Manger

Across the two-day course, training focuses on the different scenarios volunteers may encounter. For example, Marie Curie clinical nurses present information in relation to how individuals and their families are affected by terminal illness, ensuring that volunteers have a level of awareness of the symptoms the terminally ill person may suffer from. Service managers explained this would help the volunteer to feel comfortable around the terminally ill person which in turn helps develop the helper-client relationship.

Helpers in Somerset suggested the training was too focused on risk and health and safety; they understood some of this was necessary but felt that it was given too much emphasis and suggested some would find this off-putting. Helpers in both areas valued the 'how to deal with difficult and challenging situations' course and mentioned it gave them tips in case they needed to defuse family tension.

In general helpers felt the structure, content and format of the training was comprehensive and in a short time it gave them sufficient information to make a fully informed decision regarding their commitment. Although there was no substitute for actually carrying out the role, they explained it also helped them during their initial visits – for example, explaining the distinction between the helper's role and a carer.

*I thought the training was excellent. We had meetings four weeks running.*  
Helper, Somerset

*You have the safety and training issues, social care, assertiveness, listening and a lot of role-play.*  
Helper, Somerset

A one week 'cooling-off' period allows the applicant and the service manager to review and reflect on their suitability for the role of helper. Service managers felt giving space to allow candidates to digest the amount of information across the two-day course was necessary as this enabled them to reflect on whether they have the right attributes or level of commitment the role demands.

## 5.4 Referrals

Referrers were asked about how they made referral decisions and for their thoughts on the referral process itself.

### **Making a decision to refer**

The aim of the Marie Curie Helper Service as understood by referrers was to provide non-clinical support to terminally ill people whose prognosis is less than twelve months. This translated into eligibility criteria used when making a referral decision.

An individual's mental wellbeing was a major factor shaping referrers' decisions about who they should refer to the service. Two considerations lay behind their assessment of wellbeing:

- the social isolation (of the carer or the terminally ill person)
- stress triggered by caring demands or dealing with a terminal illness.

The way in which organisations determined and prioritised 'need' often influenced referrers' decisions, even where this contradicted the eligibility criteria of the service. Indeed some referrers had ignored the eligibility criteria if they identified an individual need. For example, some referrals were made where the need was acute but life expectancy was greater than twelve months. One such example cited was dementia and the impact this had on the sufferer and their carer. Although referrers recognised such circumstances were outside the service's remit, they explained that, in their opinion, it was still in the spirit of the service to help individuals with acute needs where service capacity allowed.

*For some people if they have got Parkinson's, all they need is a bout of pneumonia and they are gone, so also I refer some people that are particularly needy, but could go at any time rather than having cancer which is more defined.*  
Referrer

Regardless of how referral organisations interpreted eligibility criteria, they all welcomed the service and were keen to make use of it. All referrers viewed the service as valuable, particularly in light of service cuts in social care support in the local area. Referrers also added that the service was unique in that it provided a specific service (emotional support) to those at the end stage of life that previously did not exist. Time and again referrers described how the helper service complemented the individual's clinical treatment.

*The volunteer scheme seems to be that step before Hospice at Home if you like and they seem a bit more keen to sort of to accept that... accept somebody like a volunteer into the home rather than a trained nurse or someone like that.*  
Referrer

## **Referral process**

Referrer organisations were very positive about the referral process. They saw the role of service managers in building and maintaining relationships with referrer organisations as an important factor. A strong relationship meant that referrers were able to check whether a client could be supported by the service and that they had confidence that the service would benefit their patient. The pace at which a referral was processed was also praised; in most cases, first contact with the client by the service manager or assessors would occur inside two weeks.

The flexibility of the referral process was welcomed and valued by all referrers we spoke to; as indicated above they could often make a direct contact with the service manager in order to discuss a specific case but could also contact the helper administrator. The value added by these personal contacts and relationships suggest that they should be maintained as the service expands, and extended to new referrer organisations, as a key element of the service.

*If I leave messages they'll get back to me pretty much straight away.*  
Referrer, Nottingham

*I know that I can actually ring her and sound her out about it*  
Referrer, Somerset

The links with referral organisations were seen as an important means of educating organisations about what the service can offer. It also helped limit the number of 'inappropriate' referrals which fall outside of the eligibility criteria although, as noted earlier, these criteria are not always strictly used.

*That's the referrer, the referrer should be aware that the individual has to have a seriously terminal illness. And ...I've had a lady who'll be better in six months. She's not actually dying.*  
Volunteer assessor, Somerset

However, as referrers have become accustomed to the service's parameters, the number of inappropriate referrals has fallen. Although interviewees said there was no such thing as a 'typical' inappropriate referral (since each individual's needs and circumstances are reviewed on a case-by-case basis), cases of obviously wrong referrals were said to have fallen.

Increased knowledge about the service meant that referrers were better placed to make correct decisions about individual cases or to signpost to more appropriate services for individuals falling outside the remit of the helper service.

*I used to refer far more people that were socially isolated and lonely, not necessarily nearing the end stage of life.*  
Referrer, Somerset

Despite decreasing instances of inappropriate referrals, there was a call among referrers for more information on client eligibility criteria and/or the helper's role boundaries to help them to 'understand the service', believing this would allow them to feel more confident in:

- working out whether the service would suit their client's needs; and
- helping them deal with any queries or concerns clients have relating to what is and is not covered by the service.

Referrers did acknowledge that they could make use of their contact with the service manager and rely on helper information leaflets as a way of informing the client and themselves about the service. Even if there was some uncertainty among referrers about whether the service could cater to their clients, this has reduced over time as the partnership developed and more experience of using the programme was gained.

In general, service managers and referrers (those directly involved in the referral process) felt the referral process was working well and any misunderstandings regarding the service remit were dealt with easily. However, in most cases the level of detailed information about the person was limited (name, address, and contact number). Detailed information was only available when the referrer had a prior conversation with the service manager regarding specific issues such as prognosis, lifestyle or familial circumstances. The implications of this for the assessment process are considered later in this chapter.

Some of the referrers also felt that more information could be provided to them after they had made a referral. They currently received little feedback on the person they had referred (for example, whether a helper had been assigned and how it was working out) and thought that this would be useful to them. However, this was not universal and several recognised the personal relationship that would exist between the helper and client, meaning that it was not appropriate for them to receive too much information.

*As long as I know that it's working and it's beneficial then that's good enough for me*  
Referrer, Somerset

### **Publicising the service and increasing the number of referrals**

In general referrers felt that the service was making links with the right types of organisations given the remit of the programme. For instance, referrers welcomed that the service was targeting organisations that catered to the needs of carers (i.e. sitting services) as well as local hospices which serve terminally ill patients.

One referrer did question whether more partnership work targeting local hospitals would help to increase the number of terminally ill individuals and carers benefitting from the service. This view was countered by service managers who said available support was limited by the number of suitably qualified volunteers who could be recruited. They explained that as the service beds in and expands, capacity to meet the needs of more people in the local area



would increase. They would then be able to cope with the increased levels of demand that targeting of other referral organisations would lead to. For example, one service manager talked about delivering a presentation to more than 200 care home managers in order to promote the service, which in turn it was hoped would increase the number of referrals generated.

*I would think that possibly people that attend the general hospital for treatment, or to see the specialist nurses would benefit. I know there are leaflet areas on the wards, but I don't know if [the helper service] has got any leaflets up there... Certainly the professionals should be having leaflets.*  
Referrer, Somerset

## 5.5 Assessment

The next stage of service delivery is assessing the needs of the person who has been referred, whether that is a terminally ill person or a carer. The timing of the assessment depends on whether it is felt the client needs urgent support (defined as acute need). If this was the case then assessment would take place 24 hours from the referral being made. Even where the case was not considered urgent the assessment would typically be completed within one week.

The primary function of the assessment is to gather detailed information about the individual's needs which is then used to help make decisions about the nature of support or whether signposting to relevant services is necessary. Findings from the assessment are also important as they help match the client to a helper and can enable the helper to provide more effective support. For example, a helper may use knowledge about the interests of the terminally ill person or carer to help find 'common ground' on which a relationship can be formed.

*'Helping the helper' - You are there going there for the first time and you're finding out information on behalf of the helper*  
Volunteer assessor, Somerset.

Service managers, volunteer assessors and helpers explained that conducting assessments to a high standard was vital to the effective delivery of the service. They said in order to do this well, the assessor required a good understanding of medical conditions and needed to have the right personal attributes such as empathy and sensitivity, which helps them to make a swift judgement about a client's needs.

*We ask for a bit of their background history, their hobbies, interests and [after the assessment] the assessors will report back to me the type of personality their client has and the conversations they have...All of those things are factored into making a match between the clients and the volunteer.*  
Service Manager

Assessments were therefore initially carried out by the service manager, whose experience also enabled them to gather information in a relaxed and informal conversational style. It was thought that this helped to put the individual at ease and encourages them to talk candidly and openly about how they envisage the service could help them to deal with their situation. The newly trained volunteer assessors in Somerset recognised the skills involved in carrying out an assessment, and performing the role to the same standard as the service manager is something they found quite daunting.

*I will say this [the service manager] is very good.*

Volunteer assessor, Somerset

The role of the assessor is often more varied than gathering important information about the potential client: they also changed their approach to the visit depending on the circumstances. In many referrals the potential client, whether the terminally ill person or carer, seemed to have very limited or no understanding about the service. This was for several reasons:

- the referrer had not fully explained it;
- the individual had been told about the service but could not recall anything about it when the assessor made initial contact; or
- the individual misinterpreted the term 'helper' thinking that the service provided practical or medical support.

*They generally don't have a clue what a Marie Curie helper is...And they know nothing about it because the referrers haven't given them any information.*

Volunteer Assessor, Somerset

As such, assessors viewed one of their key roles as explaining how the referral took place (i.e. naming the organisation that contacted the service) and explaining what the helper role involved and how it benefits potential recipients. The assessment role is also about establishing a rapport with the client. This enables the assessor to reassure the terminally ill person or carer who may be concerned about allowing a stranger into their home. It also allows the assessor to use the relationship to position the service in a positive light.

Signposting to other complementary services was also a part of their role and this typically happened when the assessor felt the helper service was not right for them. For example, an individual may want more practical support around the home, such as preparing meals, which is outside the scope of the service. In such instances, assessors said they would direct them to social services or, in the case of volunteer assessors, seek advice from the service manager.

*If we said it wasn't appropriate for a Marie Curie helper we could then say 'But you might find help from social services.'*

Volunteer assessor, Somerset

Assessors leave behind helper literature (for example information leaflets) so that the terminally ill person or carer(s) can make a decision about whether they would like to proceed. Aside from gathering information to aid the matching process, assessors were keen to point out that effective assessment is a mix of providing and gathering information. Alongside this, they would take care never to apply pressure on the individual to consent to using the service, even if they considered it to be in their best interests.

*I quite liked being the first person they'd met from Marie Curie, and I enjoy, not that's not, I'm using the wrong word so I have to leave it out, it's not selling, but I enjoyed the fact you're putting over a positive image.*

Volunteer assessor, Somerset

## 5.6 Matching

Findings from each assessment are written up into a report or entered onto a client database and reviewed by the service manager within a few days. If volunteer assessors conducted the assessment and considered the needs of the individual to be a priority they would make immediate contact with the service manager to speed up review of the data collected. Volunteer assessors explained feeling confident reporting their findings back to the service manager and thought their views were valued. They were also happy to leave the responsibility of the matching decisions to the service manager.

*If there's something I feel I can't express on a form then I would speak to Cathy. Such as a case I visited and it's a woman who's trying to balance a husband dying of bowel cancer, a mother who is 87 and living on the other side of town and a son with learning disabilities living in another part of town. She's trying to cope with all this...and they need urgent help. I'm taking the helper this week.*  
Volunteer Assessor, Somerset

It could take as long as one month between the time of the initial referral to a helper being placed with the client. Service managers said whilst this may seem a long time, there were a number of important steps that are necessary for a successful outcome (essentially a good client-helper match). As indicated above, the assessment may occur one week after the referrer passes on their client's details and the time it takes to report back is also taken into account. The potential client is also given time (a few days) so they can review their own situation and decide whether the service is for them. The service manager considers which helper might be suited to the client (and vice versa) as soon as the assessment findings are known but once the client commits to the programme the service manager steps up the matching process.

Service managers said the heart of a successful client-helper relationship was the ability of the helper to quickly establish a good rapport with the terminally ill person or carer. This would mean that they would be comfortable discussing sensitive feelings about the situation in which they find themselves. Spending time on the matching process means stronger, effective relationships are developed which, in turn, improves the impact of the service (as discussed in chapter three). Helpers are selected based on the caring attributes (interest in helping others, empathy, good listening and conversational skills) necessary to build rapport. However, it takes more than this to make a good match. The interests of the helper and client, gender, age, and needs (for example, lifestyle choices such as interest and hobbies) are taken into account by the service manager.

The final stage of the matching process is helper escorted visits, which were valued by both helpers and clients. Given that the assessor had already developed rapport with the terminally ill person or carer it was considered good practice for the assessor to accompany the helper for a short while as part of the helpers' first visit to help make introductions and work as an 'ice-breaker'. In most cases, the assessor only stayed for a short time (c.30 minutes), which limited the impact on their own volunteering commitments.

*If the referral goes forward...then Cathy will make a decision about who the helper will be, along with the helper agreeing...then the assessor will escort them on that first visit...It's a good idea to have that transition...it's a face [the client] knows.*  
Volunteer assessor, Somerset

Overall, the matching process was considered successful by service managers, assessors, helpers, terminally ill people and carers because all clients reported forming positive relationships that they then benefited from. There were a few terminally ill people who were initially concerned their helper was a different gender or was too young for them to relate to.

However, after a few visits, these were alleviated when 'common ground' was found. Regular and on-going feedback from the helpers (both anecdotal and written visit reports) ensures continual improvement of the matching process.

## 6. Challenges

During the course of the research, a number of challenges facing the helper service emerged. This chapter outlines the challenges identified for each role involved in the service in turn: service managers, helpers and referrers.

### 6.1 Service Managers

Service managers in both Somerset and Nottingham have faced difficulties in ensuring that referrals are being made at the appropriate time in a terminally ill person's life. In both areas, the service managers said that they have received referrals in the last few weeks of a person's life. This has meant that the person has subsequently died before a match could be made, or within a very short time of the helper starting. In Somerset the service manager felt that progress was being made and a greater number of referrals are now taking place earlier on. However, it does remain a challenge to be addressed, particularly in Nottingham and the newly established services elsewhere, in order for the service to intervene more effectively so that potential clients benefit from the service. There is a clear need for referrers to be made aware of this point.

*Unfortunately, with end of life, we might get... and we have had clients where they have died before we've been able to match them. Not many, but we have had a few and that is becoming frustrating.*  
Service Manager

Service managers also expressed a frustration that the service may not always reach those terminally ill people in greatest need. They highlighted the fact that many people are referred to the service through hospices or nurses and so those being referred are likely to be people who are both in the healthcare system and comfortable using it. The challenge for the service, therefore, is reaching those people who may be less engaged with the healthcare system, for example because of a previous bad experience, or because they are resistant to accept outside help, and who may have unmet needs. Therefore, greater assistance to referrers in dealing with common concerns that people may have about the service may be beneficial, but there is also a need to focus efforts on how to encourage potential self-referrers.

*There are those people out there who...don't know about service provision and are doing the best they can with minimal support. There are those people who perhaps don't want to engage with healthcare professionals. Perhaps they've had a bad experience in the past...There is a fear point linked with self referral.*  
Service Manager

The amount of paperwork and bureaucracy generated by the service was also identified as a challenge. For example, helpers are required to write a report after each visit. Whilst steps are being taken to address this, such as the creation of a service-specific database, it was felt that the volume of paperwork could still be reduced.

*There's room for simplification of paperwork because there is an awful lot of paperwork that's generated.*  
Service Manager

Service managers also felt that the red tape and risk management built into the system can sometime be frustrating for helpers and this was confirmed in the helper focus groups. Whilst some elements of this have been reduced, for example by allowing helpers to make cups of tea, clients do still sometimes ask their helpers to carry out additional tasks that are not permitted. As discussed earlier in this report, helpers are not always comfortable refusing or sometimes unclear about what they can and cannot do.

Currently, both the Nottingham and the Somerset services are expanding. This raises a series of challenges for service managers, and indeed the service itself. Service managers were already concerned about meeting expanding demand. They were keen to avoid a situation in which their volunteers became overburdened or where they are forced to turn people away because they do not have enough volunteers. Challenges managing demand are exacerbated because, whilst the number of people wishing to volunteer is high, many are found to be unsuitable; in Somerset there were just 44 helpers out of 77 initial applicants. Significant increases in demand would also need to be met without placing excessive demands on the assessors, or indeed the service managers themselves, and would, perhaps, require expanding these teams too. Finally, there is also the issue of how to expand the service without compromising the quality of what is provided to clients. Currently, levels of satisfaction with the service are very high, and service managers understandably wanted to maintain that.

A final challenge identified by service managers was continuing with the helper service in the face of financial pressures. Service managers naturally felt very strongly about the benefits the service offers, in particular in relation to the mental health of clients, and were keen that these should not be underestimated when funding decisions are made.

*We have to have [the helper service] as an essential, rather than a nice to have, and that's the challenge with funding. It's seen as 'You took someone to the park, so what?' But for an individual the benefit could be massive.*  
Service Manager

## 6.2 Helpers

Whilst for service managers the challenges facing the service largely related to procedural aspects of the service and its future, for helpers the challenges related to the way in which they interacted with their clients and the difficulties they sometimes faced when doing this.

These difficulties could arise at all points in the helper-client relationship. For example, when first going into the home, helpers sometimes faced hostility from family members, or resistance from terminally ill people. They may have also unwittingly found themselves in a family dispute. Negotiating these relationships, building trust with both the client and their family, whilst also remaining outside any wider disputes was a significant challenge for some helpers. They often drew on their training and the advice of the service manager to equip them to deal with these challenges and they were aware that they may face them in each new relationship. This demonstrates the importance of the training and support helpers receive from the service manager but also highlights the range of skills that are required by helpers to perform the role.

*I thought there might be a bit of friction [between the helper and the carer] so I trod very carefully and when I went on the first visit I was very much assessing how she was and how he was. And I think I sort of gauged that he wasn't hostile because of me or where I was from but more because he was just a very private person. He didn't want to have anybody else involved and he didn't want her to have anybody else that she'd spoken to.*

Some helpers also admitted that they sometimes struggled to maintain boundaries as the relationship with their client developed. For example, some helpers wanted to do additional tasks for the person they were helping, or spend extra time with them when it was needed. They were also aware of the dependence that could form, and found it hard to refuse additional demands that were outside their role. On the other hand, several terminally ill people and carers said that they would like to buy their helper lunch, or just a coffee, even though they knew the helper would not accept it. In each of these circumstances, helpers faced a significant challenge in maintaining a delicate balance between not offending their client, whilst also behaving appropriately.

*The client I am with now, his wife has lots of problems and she is never back on time. I have been there five hours, because if she doesn't come home you can't leave him.*  
Helper, Somerset

*[A client] had an unpleasant accident in the toilet and the helper did not hesitate, just cleaned her up completely and she tried to give her £10 and the helper said, 'You'll get me sacked, we can't take money.' So she said 'Well you are going to have it', and you can't insult people, so that £10 has gone into Marie Curie's helper pot.*  
Service Manager

Some helpers had faced particular problems where they felt they had insufficient information on the prognosis of the terminally ill person. Some had found it difficult to know how to respond to the terminally ill person or their carer, particularly where they seemed relatively healthy and well. They had also encountered situations where the individual and/or their family seemed to be in denial about the situation. Some helpers felt that more information about the person's illness and prognosis would equip them better to deal with this.

*He is so convinced he is getting well and he has been so much better every time I go to see him and he is talking about booking a holiday...What I would like to know is if the diagnosis I was given was right or whether maybe he is getting better. I would like to know because I do find it difficult sometimes. If he wants to book a holiday and he has got brochure you can only look at the brochures and say 'Well that looks nice', you can't say 'I don't think you are going to be here.'...I don't want to upset his wife by asking her because maybe she knows he is dying and he doesn't. But I do feel the need to know, for my own comfort zone when I am with him.*  
Helper, Somerset

The death of the terminally ill person placed additional strain on some helpers. They had to deal with their own feelings about the death of that person and support the carer who may have become dependent on them. While supporting the carer into bereavement was often a part of their role, some found it difficult to end the relationship after the allotted three month period.

*It is awful when they do die, even though you know they are going. Nothing prepares you for when it happens. Just normally I feel really, really, sad.*  
Helper, Somerset

*I diarise three months from the person's passing, and then I'll say, 'We really need to be thinking about whether or not we're going to actually stop our service', and I'll have that conversation with the volunteer.*  
Service Manager

Given the many challenges that they face, helpers were aware of the significant support they needed to carry out their role. In many cases, they were able to get this from their service manager, who they could call for guidance. Again, looking towards the potential expansion of services, this support needs to be maintained. Indeed, it may be something that volunteer assessors can work towards providing. However, helpers also said that peer support would also be helpful. This is already being set up in Somerset, and in Nottingham a Christmas event was well-received, but it is important to note that helpers felt that the opportunity to ‘offload’ is valuable to them.

*I made a suggestion that we do more of this getting together...Because you do feel a bit on your own, and there are certain things that occur that you think ‘How do I deal with that?’ or you want someone else’s opinion who’s been through the same thing.*

Helper, Nottingham

Whilst carers and terminally ill people do give verbal feedback to their helper, affirming how helpful they have found them, there was some appetite in one of the groups for more formal feedback. Helpers felt that it would be interesting to know what people think, and it is possible that such feedback would help them develop their skills.

### 6.3 Referrers

As discussed earlier, there was confusion amongst some referrers about exactly what the service could and could not provide. Ensuring greater clarity in relation to this is a key challenge for the service. For example, one referrer was unclear about whether helpers could carry out household chores, whilst another was unaware that terminally ill people with illnesses other than cancer qualified for the helper service. Whilst it was not entirely clear how this confusion arose, one of the referrers claimed they had not received any literature about the service. It is possible, therefore, that targeted literature provision might help to address this, though others had received literature and felt they did not need anything else. This is an important issue to address though, given that referrers are the main entry route into the service, and often shape clients’ expectations. If referrers give out the wrong information or do not fully understand who is entitled to the service then clients may expect more than is offered, or those who could benefit may miss out.

Referrers sometimes also faced problems in persuading potential clients to accept help (this issue is also discussed from the clients’ perspective in chapter four). Referrers said that, even where there was a clear need, there could be resistance from the terminally ill person or carer. Regardless of the cause of the resistance, referrers tried to explain the nature of the service and the potential benefits in the hope that the potential client would accept the help that was being offered.

*Some people just don’t understand why they would meet the criteria of the service because they think they are doing just fine and they don’t need anyone to babysit them, they don’t need that level of support.*

Referrer, Nottingham

In some cases, referrers said that the use of the word ‘cancer’ in Marie Curie’s title had suggested to potential clients that the service was only for people with cancer. Similarly, some referrers felt that some potential clients associated cancer with death. The association between Marie Curie and cancer was therefore off-putting for some potential clients who were unwilling to accept their prognosis. Referrers had no clear idea about what could be done to overcome this, but it was also an issue that the service managers were aware of.



*My only criticism would be that it says 'Marie Curie Cancer Care' and my patients haven't got cancer, so if you say 'Marie Curie' they'll say 'Well I haven't got cancer.'*  
Referrer, Nottingham

Clearly, there are a range of challenges for all audiences involved in the service. In many cases, the support needed to overcome these challenges is already in place, at least in part (for example, the helpers often drew on their training and the advice provided by the service manager). However, the findings demonstrate the importance of this continued support in the future development and expansion of this service. The findings also highlight a number of areas where additional support is needed (for example, in raising awareness amongst referrers and potential clients of the benefits and remit of the service).

## 7. Future development

Future development of the helper service is planned (in existing and additional regions), as mentioned earlier in the report. The qualitative research has highlighted a number of points for consideration as the service moves forwards. The final chapter of this report lists these areas for further thought and potential development.

- **As the service expands, ensure its core ethos is maintained.** Helpers in Nottingham in particular, which is in an expansion phase, were well aware that the service is expanding and that there is much potential demand in the community. They were also aware that too rapid or unplanned an expansion could dilute the voluntary ethos at the service's heart. They were keen not to see the service become a victim of its own success by becoming more professionalised.

*One of the advantages is we're not professional people and I think that's what the charm of it is. If we started to say get more educated as carers, we're turning into like proper Care Workers. I think as it stands it's just about right.*  
Helper, Nottingham

- **Ensure expansion is not at the cost of speed, flexibility and quality.** Helpers expressed concern that the service manager might not be able to cope if the service expanded too rapidly. Maintaining the ability to match was vital, as this is a cornerstone of delivering a high quality service to the client. It is also important that this continues to be done quickly. Often when a terminally ill person comes to the attention of the helper service, they only have a short time left to live.
- **Maintain personal relationships with referrers.** Referrers valued the flexible nature of their relationship with the service manager and the option to call them to discuss referrals to ascertain whether they are suitable. If the service expands, it will be important that this personal contact is maintained for existing referrers and extended to new referrers, so that they too can build their knowledge of what the service offers.
- **Clarify the boundaries of what the helper can do, if that is what helpers want.** In practice, helpers often take a common sense approach and will bend rules slightly, for example doing some dishes or making drinks. Helpers would like some reassurance that this is acceptable. The impression that some receive from the training is that the service is very risk- and health and safety-focused. Some reassurance that rules can be flexible around the edges, and that the helper can be trusted to an extent to use their discretion, would help them in feeling valued and supported. In addition, it is important that helpers are very clear on their role, as they are coping with many questions from terminally ill people and their carers.
- **Think about whether some boundaries can be extended in certain cases.** Toileting is a particularly difficult area. Some visits are long, at least three hours and up to five hours in one case. This is a long time to be with a terminally ill person who needs to use the toilet. Whether or not a helper would feel toileting is an appropriate part of their role is very personal and unique to each carer and each relationship with a carer or terminally ill person that they have. The recommendation would certainly not be to alter the remit of the carer's role regarding toileting, but to allow some flexibility whilst ensuring that it is never something the helper is obliged to do.
- **Improving the provision of practical information by helpers, if this is a key aim of the service.** Helpers, terminally ill people and carers did not see this as a key part

of the helper's role. If the intention of the service is to signpost services in this way, then helpers will need further information and support.

- **Revisit the content of the training.** Some helpers felt too much time was spent on the health and safety aspects of the training. It may be beneficial to revisit the training and ensure that the balance is suitable and beneficial to helpers. For example, while health and safety undoubtedly needs to be part of the training – and indeed possibly cannot be trimmed due to training requirements – it is worth considering whether the balance can be shifted towards those elements the helpers found more useful, for example the role play.
- **Support networking between helpers.** The helpers valued being able to discuss experiences with their clients with each other and give and receive advice – as evidenced at the groups we conducted with them. Experienced helpers were involved in the training of new helpers, indicating that service managers recognised the value of this. For helpers who were retired or worked part-time, informal contact with each other was fairly easy to arrange. However it could be a little more difficult for those helpers with more commitments, such as full-time workers. There was a risk they could be left 'out of the loop' if other helpers were in contact with each other. An expanding service needs to attract a wide range of helpers in terms of age, background and experience to ensure as many good matches as possible. Ensuring those with more commitments (who may also be more likely to be younger) are fully engaged could promote this. Facilitating contact via more pre-arranged gatherings for helpers, at times that suit those with more commitments, could be a way forward.