Faculty of Health: Medicine, Dentistry and Human Sciences

School of Health Professions

2014-07-01

The After Caring Service: Interim Evaluation Report

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http://hdl.handle.net/10026.1/3167

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RESEARCH WITH PLYMOUTH UNIVERSITY

The After Caring Service

Interim Evaluation Report July 2014

For Torridge Voluntary Services

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ACKNOWLEDGEMENTS

Our grateful thanks must go to all the participants who completed questionnaires, interviews or took part in focus groups. Their honesty, openness and willingness to give of their time and to share their experiences has afforded the research team a unique opportunity to present what we hope is a vivid picture of the needs of older carers and former carers facing transitions in their caring role and of the aspirations of all those who are contributing time, skills and expertise to services which aim to introduce new ways of supporting those who find themselves in need of help. It has been a privilege to be offered such insight into the power of volunteers to achieve change in their communities.

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1.0 INTRODUCTION

1.1 Background to the Study

This study builds on the completion of three earlier evaluations involving older people and those who are carers in Devon (Donnellan and Giarchi, 2012; Donnellan et al, 2011; Donnellan, 2009). For clarity and to avoid repetition, 'carers' here refers specifically to older people, aged 50+ years, who are looking after someone in an unpaid capacity who could not manage without their help and includes those 'former carers' following bereavement or transition of the person they are caring for into long term, residential care.

After Caring is a three-year project running from 2012 – 2015, funded by Comic Relief, managed by Torridge Voluntary Services (TTVS), which is being delivered across Torridge and North Devon districts. After Caring provides peer-led support to carers who are facing periods of transition and change linked to the ending of their caring role, either because of bereavement or transfer of the care recipient into long-term, residential care. By recruiting, training and supporting a range of former carers and older people with experience and/or understanding of the caring role as volunteers, After Caring is able to provide intensive, time-limited mentoring and befriending support to help carers at key stages in the end of care pathways, including the end of life of the care recipient.

The importance of information and support for carers facing change and transition in their caring role has been highlighted in a number of recent studies, focussing particularly on end-of-life care (Bainbridge et al. 2009; Andershed, 2005; McMillan, 2005). However a report published by NHS Devon in 2012 pointed to a paucity of information about what is provided, when and by whom to people outside of hospital, particularly in the last year of life and it is worth noting the implications of wider research which continues to confirm that those with certain chronic conditions such as lung disease, cardiac failure and especially dementia represent 'the disadvantaged dying' compared to those with terminal cancer (Robinson et al, 2005, p. 135). A range of both national and international studies suggest that when a caring role ends, carers face a range of challenges which may be traumatic and stressful including a wide spectrum of emotional issues associated with the grief linked to loss and bereavement (McNamara and Rosenwax, 2010; Wright et al. 2008; Waldrop, 2007); practical issues such as housing and finance as well as understanding and navigating through the range of care options (Davisson and Mosher-Ashley, 2008; Ryan and Scullion, 2000; Zarit and Whitlatch, 1992); physical issues which may arise as the carers' own health is neglected or deteriorates (Holley and Mast, 2009; Haley, et al, 2008; Stroebe et al, 2007); and issues that arise as carers find themselves with new roles and responsibilities (Larkin, 2008; Payne, 1999; McLaughlin and Ritchie, 1994). All of these challenges are further compounded for older carers by the complexities of ageing, changes in social roles, reducing or more dispersed family and friendship support networks and increasing loneliness particularly for those living alone in isolated and more rural communities (Larkin, 2008; Yeandle et al, 2007; Ford, 2008).

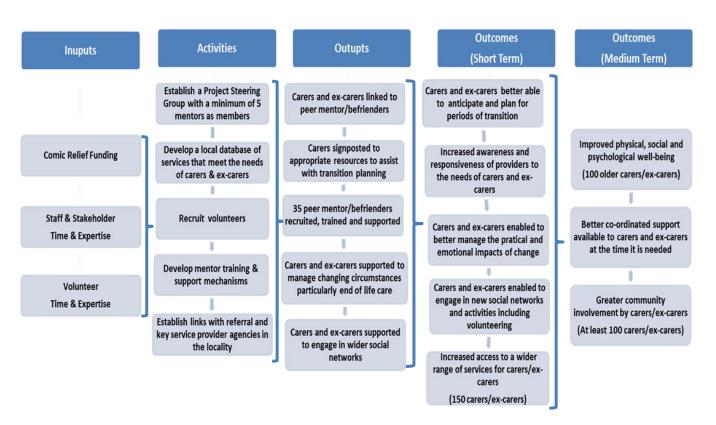
The National End of Life Strategy (DH, 2008) emphasises the role of informal, family caregivers throughout its 'Six-Step Care Pathway' with particular reference to an agreed and regularly reviewed individual care plan including an assessment of the

needs of carers (*Step 2*); the strategic co-ordination of care (*Step 3*); support for carers in the days pre-bereavement (*Step 5*); and emotional and practical care and support which extends into the period post-bereavement (*Step 6*). Drawing on this national guidance, there is recognition within Devon's local strategy (NHS Devon, 2011) that carers are often not assessed and that health professionals frequently neglect bereavement services. Indeed there appears to be a lack of knowledge about what services are available and how they may be accessed so that provision can be poorly co-ordinated and may be confined to those individuals who are already known to services whilst the deceased person was alive.

General risk factors for low life satisfaction and well-being are known to include informal caring in addition to poverty, ill health, living alone or in poor or disadvantaged communities. Importantly, social interaction and community participation appear to be among the most significant factors influencing high levels of life satisfaction (NICE, 2008, NHS Scotland, 2012; Skills for Care, 2010; Age UK, 2011; Foresight, 2008) and it is at this level that After Caring aims to make a positive impact in supporting older carers and former carers to prioritise the issues that can positively affect the quality of their lives as they face transitions and change. The evaluation offers the opportunity to explore the relationship between some of these risk factors, carers' needs and the range of characteristics of those carers, volunteers and stakeholders who engage with the services and activities managed and delivered by After Caring.

2.0 STUDY DESIGN

Figure 1: The programme logic model



2.1 Aims and Outcomes

The evaluation aims to identify some of the key elements of the After Caring service that contribute to improving the quality of life and well-being of older carers and the ways in which they can be supported and assisted to better plan for and manage change and can be encouraged to engage in new social networks and activities including volunteering. The theory or logic model underpinning the design of the study is shown in Figure 1, to depict the project 'as intended'.

2.2 Methods

Data has been gathered concurrently from three contrasting perspectives: carers using the service; volunteers providing services; and project co-ordination and management in order to evaluate project processes and outcomes (Rossi et al, 2004). The study is using a mix of methods drawing on both quantitative data from survey questionnaires and more in depth qualitative data drawn from key themes emerging from individual interviews and focus group discussions. Consideration from a number of perspectives in this way provides the opportunity to compare and contrast the findings and to corroborate and enhance their validity.

2.3 Participants

Participants, identified and grouped into four categories, were invited to join the evaluation study as follows:

- Carers using the service
- Volunteers
- Steering group/stakeholders
- Paid project delivery staff

All participants were provided with an individual information sheet. Agreement to take part in the study was assumed for those who chose to return postal survey forms and confirmed in a signed and countersigned consent form for all those choosing to take part in interview and focus group sessions.

2.4 Process

(a) Carers using the service – Initial self-completed postal survey

Carers received a sealed research pack from the project co-ordinator, acting as gatekeeper for recruitment into the evaluation study. Packs were offered as soon after entry into the project as considered practicable by the co-ordinator, given the potential vulnerability of individuals facing life changes which may be stressful. In addition to an individual letter of invitation and information sheet, the research pack comprised:

- A locally-designed postal questionnaire for self-completion and return anonymously in a 'freepost' envelope direct to the research team at Plymouth University, gathering demographic data and information about participants' background and individual circumstances. This local questionnaire had direct input from, and was piloted by, a group of carers and former carers.
- A General Health Questionnaire (GHQ28) which was returned separately to the research team. This was used to measure perceptions of stress and wellbeing. This is a validated instrument particularly suitable for the measurement

of change in four domains of well-being which has been used successfully with informal family caregivers in wider research as well as in prior studies in Devon by members of the evaluation team (Donnellan et al, 2011; Blakely and Donnellan, 2009). The use of a validated instrument is helpful in enhancing confidence in the robustness and reliability of the data generated.

All responses are confidential and anonymous with one important exception. The GHQ form is identified by a sequential research reference number, recorded separately in a checklist maintained by the After Caring project co-ordinator as each research pack is distributed so that in circumstances where an individual carer's responses to the GHQ are unacceptably high, there is a mechanism through which the evaluation team can alert the After Caring co-ordinator to track back and make contact with the individual carer either directly or through their mentor in order to agree an action plan to best protect the carer's health and well-being;

In the period 1st April 2013 to 31st March 2014, of the 17 registered carers using the service and receiving individual project support and mentoring, completed questionnaires were returned anonymously direct to the research team by 9 participants (53% response rate).

(b) Project Volunteers – Initial self-completed postal survey

In a similar process to that outlined above for carers, an individual letter of invitation, information sheet and locally-generated postal questionnaire was distributed by the project co-ordinator in a sealed research pack to all 11 active, volunteer mentors in May 2014, to gather their initial perceptions, understanding, preparedness and aspirations for their volunteer role. Completed questionnaires were returned anonymously in a 'freepost' envelope direct to the research team by 8 participants, representing a 73% response rate.

(c) Steering group/stakeholders - Focus group

All members of the project steering group (8) were provided by e-mail or post with an information sheet and individual letter of invitation to attend a focus group meeting in May 2014. A total of 3 members took part (38% response).

A topic guide was used to gather in-depth perceptions and opinions of the service, and what is needed, offered and delivered from the perspective of each participant. A buffet lunch was provided and the focus group lasted for approximately 1½ hours. With the permission of all those taking part, an audio-recording was made which was transcribed for the purposes of analysis.

(d) Project delivery staff - Individual telephone interviews

The project co-ordinator and line manager were provided with an information sheet and invited to take part in an individual interview in order to gather the initial perspectives and aspirations of the project delivery team. Both members of staff agreed to take part in the study and interviews, lasting 60 and 35 minutes respectively took place in April and May 2014. With the permission of each participant, an audio-recording was made which was transcribed for analysis.

3.0 DATA COLLECTION

It is important to note that it was not the intention to collect personal data in any of the study activities. All records were anonymised, using a sequential research reference number, and all responses were forwarded direct to the evaluation team at Plymouth University. Plymouth University researchers used appropriately encrypted laptop or personal computers which were also password protected for the collection, analysis and storage of all data.

3.1 Ethical Considerations

As part of the standard procedures within Plymouth University and to provide validation of the evaluation team's commitment to the principles of equality of opportunity, anti-oppressive practice and the right to confidentiality of those involved at all levels in the study, the proposal was reviewed and approved by the university's Faculty of Health Human Ethics Sub-Committee. All those working directly on the study had up-to-date Criminal Records Bureau (CRB) checks in place.

3.2 Informed consent

Full informed consent from all participants to their involvement in the study was sought through the provision of an information sheet and opportunities to ask questions and seek further advice from either the university research team or the project co-ordinator before deciding whether to take part or not. Individual informed consent was confirmed in a signed /countersigned consent form immediately prior to participation in an interview or focus group.

3.3 Confidentiality

Plymouth University is fully compliant with all requirements of the Information Commissioner's Office. In accordance with good research practice, the research team recognised the data protection principles set out in the Data Protection Act 1989, and operated within the spirit of the law:

- Using data only for the purposes originally specified
- Collecting accurately only that which is actually needed
- Retaining data no longer than is necessary
- Keeping data securely in a locked cabinet and on specified computers only with encryption and password protection on computer-held records
- Prohibiting distribution of any data to other organisations.

3.4 Data Analysis

Quantitative data was coded and analysed using the Statistical Package for the Social Sciences (SPSS). Digital recordings from interviews were transcribed for collation and manual coding. Initial categories identified from focus groups and interviews were sorted, compared and refined as data sets were built up. Emerging trends and themes were extracted, to inform the findings and recommendations for inclusion in the report.

3.5 Limitations

This is a small empirical study undertaken with groups of self-identified carers using the service, volunteers and project staff. In considering the findings, no assumption

can be made that the participants comprise a representative sample of the whole project population.

It is important to note that this interim evaluation has gathered initial perceptions at the point at which those carers and former carers who have decided to take part in the study enter the programme. Although response rates are acceptable, the numbers of individuals taking part in the study is small, obviating any meaningful statistical analysis at this stage.

The number of participants in the range of categories explored has been expressed as a proportion of the sample using percentages but these need to be interpreted with caution. At this stage, the evidence is illustrative rather than representative but does give a helpful, early insight into emerging trends and outcomes.

4.0 FINDINGS AND DISCUSSION

For clarity and to avoid repetition, 'carers' has been used to refer specifically to older people, aged 50+ years, who are looking after someone in an unpaid capacity who could not manage without their help and includes those 'former carers' following bereavement or transition of the person they are caring for into long term, residential care. The report brings together all of the themes which have emerged from analysis of both quantitative data as well as the more qualitative material drawn from individual comments and opinions in interviews and focus groups and is illustrated by verbatim extracts taken from transcriptions. The findings are reported in three sections as follows:

- Perspectives of staff and stakeholders
- Perspectives of volunteer mentors
- Perspectives of carers using the service

4.1 Perspectives of staff and stakeholders

The findings in this section draw on an analysis of transcriptions of semi-structured, telephone interviews with two members of staff and a focus group discussion with three members of the project's Steering Group, two of whom were volunteers and one a paid employee representing a Devon county-wide service for all carers.

Project management and delivery arrangements

Motivations

There was unanimous agreement amongst all participants that the project was addressing an important need. They were motivated by a strong desire to make a difference by improving the range, depth and quality of services available to carers facing transitions, as the following extracts demonstrate:

"It's just such an important service to have, because of the isolation [in a caring role]." [Steering Group member]

"Well, yes, it's a journey that people travel along you know and everyone's journey is different and that does make it difficult but it makes you feel the depth of it and it

makes you think that we have to try to come up with something what works best ... meets as much as possible." [Steering Group member]

Some participants had personal experience of caring and bereavement and this served to heighten their motivation, enthusiasm and long-term commitment to the project from its inception as the following extract from the focus group makes clear:

"And their [volunteers] example of how it was for them is making them come forward to help others." [Staff Participant]

"... and I really thought I wished this was something I could have had myself... because there's just such a whacking great hole when you've been caring for someone for so many years, and I think that it really needs to be looked at." [Steering Group member]

Roles and tasks of the steering group

The steering group reported generally meeting on a quarterly basis. The range of skills, knowledge and contacts offered by different members of the steering group – some as unaffiliated volunteers and others in paid positions formally representing local stakeholders and organisations connected with caring - provided a rich resource for project development. In the planning and early implementation stages attendance had been good and although engagement had been variable, it was reported that latterly interest and regular participation in meetings was noticeably improving. Whilst the benefits of a wide and inclusive membership were acknowledged, it was also noted that representatives with decision-making authority would be needed to move the project development on to the next stage:

"I think the intention was to have as many interested parties ... but also interested parties who can actually make a difference in terms of knowledge, contacts, ideas, whatever...." [Steering Group member]

Participants all had a clear understanding of the strategic aims and objectives of the project and of their own specific roles, tasks and contribution to the expected outcomes. Members of the steering group clearly felt that they belonged to a team in which they were encouraged to express individual opinions, ideas and approaches, each drawing on their very different backgrounds and experiences to act as a 'sounding board and support' to the project co-ordinator in a range of tasks most recently including for example the design of promotional materials; duration of mentoring support; the discontinuation of old or implementation of new activities; or the deployment of volunteers. An extremely high level of co-operative working, based on frequent, open communication in meetings, e-mail and telephone contacts and joint, democratic decision-making, together with a flexible approach to working practices was clearly evident, expressed as follows:

"[The co-ordinator] is very inclusive and to have a leader that's all embracing, accepts people's limitations and can find a role for everyone who knows my strengths and knows my weak points I think that's vital" [Steering Group member]

"But I mean, she is good at working at relationships and working on how are we going to crack this rather than flying in there with this is what I want, if that makes sense?" [Steering Group member]

Staffing

The part-time co-ordinator working 4 days per week is the only paid member of staff involved in the direct delivery of the project, although some paid hours are available for financial and budget monitoring. In addition, staff supervision together with strategic oversight of the project is provided through TTVS.

It should be noted that the first co-ordinator appointed at inception left the project after approximately 14 months. There was a short hiatus before the new appointee came into post and consequently, no direct 'hand-over' was possible. Although the steering group did not feel that development had been adversely affected, other staff more closely involved in the day-to-day delivery did report a 'dip' in project performance as follows:

"So I probably didn't start by hitting the ground running It took quite a bit of a while to sort of get my head around what would be required from the post and I think probably the project could have lost a little bit of momentum because of that to start with" [Staff participant]

"Obviously, we've had a change of staff which always, always brings a dip in terms of inducting a new member of staff and there's sometimes a gap between you know people in post so that did have an impact." [Staff participant]

The steering group described project co-ordination as 'a tough job' given the size and rural nature of the district and the range of responsibilities attached to the post. Maintaining a proper work-life balance and identifying time for development work to move the project forward rather than simply maintaining the 'status quo' was often challenging.

Lone working had raised some specific issues in relation to supervision and the need for additional support to deal with the extra stresses and emotions engendered by work involving bereavement has been recognised. Access to what is sometimes termed 'clinical supervision' has been highlighted as crucial in a project where staff, particularly those who do not have access to other professionals or members of a co-located team, are involved in dealing with the grief, pain and loss frequently associated with bereavement, expressed as follows:

"Because I mean if you're dealing with the bereavement side of it, it can be quite emotionally draining...... "

"As a manager it has occurred ... the realisation that the member of staff needs that extra support in that they're dealing with bereavement and loss and quite high emotion you know ... and I think that's taken time as the project's developed ... and now Well, we are trying We are offering extra support in addition..." [Staff participant]

The steering group and/or the chairperson also took on a key role, acting as a source of support to the co-ordinator.

Getting established

Confirmation of need

All participants were enthusiastic about the project's remit, were pleased with the progress that had been made to date and felt that the need for the service had been amply demonstrated, illustrated in the following extract:

"You know, we've got referrals coming in and we've also had people coming forward as volunteers who got no support for their own experience in the end of a caring role or in transition and their stories are so powerful." [Staff Participant]

Members of the steering group commented on the self-sufficiency of many communities in North Devon with a long-established tradition of 'managing alone' and in these circumstances, there was a sense in which the sheltering of a new service such as After Caring beneath the umbrella of TTVS, a well-known and trusted local organisation, had brought benefits to its early development exemplified as follows:

"I think in North Devon, I don't know what the others think but I think it's not resistance but you've kind of got to prove it's worthwhile before people will accept it and run with it." [Steering Group member]

"Possibly rather than physically having an office itself, it's being under the umbrella of TTVS because people locally will, a lot of people anyway are familiar with TTVS and when I go in and say are you happy to take these leaflets, it's part of TTVS, as soon as they hear that, they know it and Oh, yes, that's OK." [Staff participant]

Asked about the benefits of the service, participants reflected on the difficulties of quantifying the outcomes, beyond 'a gut feeling' and 'hoping that we are doing the right thing'. Monitoring systems appeared to be in the early stages of development and there was an underlying resistance to engage fully with what could be described as a more 'managerialist', target-led culture yet a pragmatic appreciation of the necessity to maintain a focus on the service remit, whilst 'humanising' the targets, expressed by participants as follows:

"You have to satisfy what the funders are funding you forthat's the whole crux of it, because if you don't get your funding, then there is no project and nobody is helped then." [Staff participant]

"So you know when people say you're just after targets, well unfortunately, to some extent, that is the way it has to be. But hopefully those targets are people and we are helping them and supporting them." [Staff participant]

Marketing and promotion

Marketing and promotion were clearly areas of sustained and substantial activity within the After Caring project. All participants were able to identify a wide range of activities undertaken to raise awareness of the project including:

- New, recently revised leaflets and posters in libraries, Citizen's Advice Bureaux, shops, supermarkets and carers centres as well as distribution by hand to individuals and groups via personal links and the volunteer network;
- Articles and advertisements in parish magazines and local newspapers;
- A dedicated website for After Caring available at www.aftercaring.org.uk;
- Multi-media display on screen in at least one local GP practice waiting room;
- Participation in relevant local events e.g. Torrington Care Forum
- Visits, talks and presentations to relevant stakeholders (for example the hospice, Devon Carers, Alzheimer's Society, memory cafes, churches and faith-based support groups) across the locality.

Overall, there is an impressive range of organisations either actively involved or aware and informed of the project, its aims and objectives. It is disappointing to note therefore that written requests from the co-ordinator to make a short presentation to care teams in all GP practices in Torridge and North Devon districts had produced just two positive responses. With GP practices heavily incentivised to undertake particular pieces of work, staff acknowledged the difficulties inherent in attracting interest to third sector projects such as After Caring as follows:

"The GP surgeries are notoriously difficult to get in to It's almost as if you have to establish yourself before you can go ahead and do that, if that makes sense" [Steering Group participant]

"I think if there is no incentive then there is probably no motivation unless you've got someone who's had a personal experience, you know it comes down to people then rather than policy" [Staff participant]

Similar difficulties were reported in either establishing or maintaining productive links with other statutory agencies within the NHS and social services including for example complex care teams. These relationships remain what a member of the steering group described as a largely 'untapped resource' in relation to referrals into After Caring.

Building links

When asked about awareness-raising activities, there was wide agreement that although a range of media were employed to good effect, word of mouth was one of the most powerful promotional tools, expressed as follows:

"Dropping little things in conversation with people, they catch the vision and come and ask a bit more and by the time you finish, they jump on the bank wagon and offer their services and then off they go!" [Steering group participant]
"And that's what the bottom line is. It gets spread by word of mouth. It really is! It's about people talking to people and people having good experiences...." [Steering group participant]

There was a sense in which establishing links across the locality had a dual purpose, reflecting two sides of the same coin. Links to other local stakeholders were valued to build up the repository of local information for signposting carers using the After Caring service to other local resources whilst also functioning to raise awareness of

what After Caring is able to provide, with a view to stimulating referrals in to After Caring.

Working with volunteers and carers using the service

Identification and recruitment

Asked about the sources of volunteer applications, it appeared that personal contacts and networks delivering individual invitations, mainly by word of mouth, was a key mechanism. The links between other voluntary projects embedded in TTVS also facilitated the sharing of suitable volunteer recruits. The impact of competition amongst a range of organisations to recruit volunteers was noted and they were regarded as an increasingly valuable and scarce resource, especially in times of budget cuts, statutory service reductions and financial austerity. There was wide recognition of the particular range of skills, personal attributes, and 'readiness' needed by After Caring volunteers, and personal confidence to come forward to take on the role was seen as a particular barrier for some potential mentors.

"For most ordinary people, to think 'Do I have the confidence to put myself into that situation?' And that's a thought process that people will have to go through before they agree to do it or not" [Steering Group member]

At inception, there was an aspiration to draw mentors preferentially from those carers who had themselves been bereaved but experience had shown that mentoring sometimes raised unresolved issues in their own journey for the volunteers, expressed as follows:

"You've got to make sure your volunteers are ready. And some are more honest about that. Some don't realise perhaps until after they start that they aren't ready." [Staff participant]

"For the mentors, they've been there themselves so there's an element of exploring your own emotions so there could be a quite difficult journey for you yourself" [Steering Group member]

In these circumstances, After Caring responded sensitively to each individual situation by offering additional support to continue or time away or switching to other activities to assist the project but away from front line delivery/mentoring. Staff became very aware of a permeable boundary between the roles of service user and volunteer:

"One other thing is that the beneficiary group are both the volunteers and the service users but I have found that some people come wanting to be a volunteer but end up being a service user. They're not quite ready and they want to help out volunteering but they're not quite ready to mentor. so some people sit on one side of the fence and cross to the other and vice versa. And some people, I don't know which side of the fence they're on really." [Staff participant]

Although regarded on the one hand as a strength, the flexibility of this approach also resulted on the other in some difficulties in relation to management and monitoring

"It's very difficult really because they sort of drop out and say we don't need mentoring and then they'll phone up to have a chat And then the people who are volunteers are probably also using the service in some way as well so" [Staff participant]

Matching

After Caring has emerged as a relationships-based service and the evaluation evidence has suggested an early focus in the initial stages of the project on one-to-one support for bereaved carers. It is predicated on not just making a relationship but on its quality, based on empathy and understanding between equal partners, which research has identified as an important aspect in peer support (Diamond et al, 2012). It is perhaps not surprising therefore to find that matching the right mentor with the right service user was regarded by all participants as both a key priority and a key strength in After Caring.

"But in terms of actually matching someone who would work well with a certain person ... you don't just put someone with a certain person and just hope that match works ... you do try and think well, do they have anything in common? Are they the right personalities? You know, would they get along?" [Staff participant]

Interestingly, one participant highlighted the way in which carers and mentors rather than project staff had identified age as an important criterion in the matching process.

"And age is an issue actually! The carers and volunteers distinguish for themselves between someone who's 60 and someone who's 85. You know, they see that they're too old or too young for them. You know ... so that's a distinction that they've made which you know, perhaps we haven't considered." [Staff participant]

The size of the locality, its rural geography and sparse population outside the two or three main town centres, presented delivery staff with several difficulties. For the coordinator, the focus on a robust matching process entailed extensive travel to make an initial personal visit and assessment with each new service user referred into the service, regardless of location but this was regarded as an essential part of the delivery programme and one in which the co-ordinator demonstrated considerable skill.

Although it was possible to identify carers and volunteers across the patch, having them sufficiently near to each other to minimise the extra burden of travelling to and from visits, yet sufficiently separate to allow a good working relationship to develop, was a particular challenge.

".... And we've got a few towns but the others are rural areas and when you're recruiting volunteers, you've not only got to get the right person and train that person, they need to be in the right place from where you get the referrals." [Staff participant]

Training and support

Viewed as an area of particular strength and an activity that had been well-received, an extensive range of induction days, information sessions, training days and workshops – 9 in total during the last 12 months - made available to volunteers, carers and members of the steering group was reported by participants. A wide variety of subjects had been addressed from project processes and monitoring to mental health and well-being, to wills and legal powers of attorney.

"But if you look at the workshops and training that the volunteers themselves have been given, I can tell you that I'll bet there are commissioned services whose volunteers haven't been given those opportunities." [Steering Group member]

"And the lovely thing for the people doing the caring was that everyone gelled as they walked into the hall. By the end of the day, they were all exchanging telephone numbers Can we meet up for a coffee? ... it just happened ... the tone and atmosphere in the room" [Steering group participant]

An additional benefit of the training sessions noted by participants was that they allowed groups to come together, exchange ideas, discuss dilemmas and difficulties and develop a range of peer support networks. The benefit of sessions involving for example relaxation techniques and positive attitudes on the personal development of volunteers was also noted as follows:

"Yes. We're having more training sessions for all of the volunteers so they can meet each other; so they can support each other; and they know that they are not alone. And they bounce ideas off each other so I think that is helping them to feel more confident in the role they're doing. They're also picking up some of the skills from things like the workshop ... to use in their personal life so that's a benefit to them too" [Staff participant]

For carers using the service, although company and the reassurance offered by regular contacts were undoubtedly having positive impacts, benefits had sometimes also been related to more practical issues, described as follows:

"I think the positives are, sometimes it's been practical in that they've just wanted some advice perhaps about bereavement benefits or legal powers of attorney or just what to do when somebody goes into a care home or they die and we've got that information pack. It's an end of life pack, well it's really information for when you need it." [Staff participant]

This rather more 'low level' help has been shown in other studies (Wimpenny, 2006; Nelis et al, 2007; Arthur et al, 2011) to be an important part of the journey through bereavement for the majority of people and is therefore a valuable aspect of what After Caring is able to offer. Indeed, the information pack has become the repository of a range of local information, guidance and advice brought together by After Caring through some of the marketing and promotional activities already considered above, into a large A4 folder given to mentors as they join the project. Timing the provision of information is important (Nelis et al, 2007) and rather than overwhelming carers with too much information at the wrong time, After Caring mentors are able to take

the lead from carers themselves, selecting whatever is appropriate from the pack when it is called for and can either offer the written pages or join direct discussion around particular issues as they arise.

Service user boundaries had raised some concerns for staff in managing the project delivery and while mentors had received training and generally understood the difference between a friendship and a 'mentoring relationship in a professional environment', managing carers' perceptions was more difficult, expressed by one participant as follows:

"People are quite vulnerable and you know, if they feel isolated and then someone's visiting them, it's like putting that person on a pedestal. I think this happens sometimes with counselling relationships, that they sort of idolize the person and I wonder if that happens sometimes. I think it can be a little bit tricky and I think you have to be careful that the professional boundaries are kept, that this is a professional relationship not a friendship as such." [Staff participant]

Development and sustainability

All participants involved in project management and delivery wanted the service to continue, to become self-sustaining in some way.

"I think the key challenge is how we sustain the project, because we've moved into the final year ... and it's three-year funding and it never seems quite long enough" [Staff participant]

Two years into current project funding, participants from the steering group found difficulty in making an overall assessment of the programme's effectiveness, reporting that the project was in the early stages of development, 'had not been running for very long' and 'needed more time to see how it's panning out'. Staff were understandably focussed on what they saw as the project's core remit and the challenge of responding to need and managing the balance between supply and demand, exemplified as follows:

"The main thing that I am working on, well there are two things really. One is to get more referrals but before I build up the referrals I was hoping to build up the volunteer base that's really well, that's really what the project's all about so yes" [Staff participant]

There was commitment to use the final year of the current project funding to consider a range of options for the future and tentative suggestions from participants included:

- Integrating After Caring into a county-wide strategy for Devon;
- Guiding After Caring to become a commissioned service, which was nevertheless accompanied by some concerns around the loss of meaningful local input into decision-making and the positives that had emerged from the current model of delivery;
- Mainstreaming After Caring within another established organisation;
- Fund-raising to maintain After Caring as a separate entity serving northern Devon;
- Integrating After Caring within another part of TTVS.

4.2 Perspectives of volunteer mentors

The findings in this section draw on responses to a postal survey in May 2014 of a self-identified sample of 8 (out of 11) currently active volunteer mentors. The general characteristics of those who chose to take part in the study are summarised in Figure 2 below.

Figure 2: Background characteristics of volunteer mentors

		Study sample n=8
Gender	Female	75%
	Male	25%
Age	40 – 54 years	13%
	55-64 years	25%
	65-74 years	50%
	85+ years	13%
Ethnicity	White British	100%
Access to transport	Car driver	88%
	Walking	13%
Employment status	Employed part-time	25%
	Unemployed, looking for work	13%
	Retired	63%
Volunteering commitment	0-1 hours each week	63%
(Average per week)	2-5 hours each week	38%
Number of carers with whom	1 carer	50%
mentor has been matched	2 carers	50%

Participants were all white British, reflecting the lack of ethnic diversity across North Devon. In line with much other research involving volunteers (McCulloch, 2012; Nazroo and Matthews, 2012), the majority of participants in this study were women (75%) and those in early retirement (63%). All participants were currently matched and actively working with at least one service user although half (50%) reported experience of working with up to 2 other carers. Research (Burnell, et al, 2012) has suggested that peer supporters in a similar role to that of the After Caring mentors may need up to 6 months in their role before they begin to feel confident in carrying out their tasks and it is interesting to note (See Figure 3 below) that 1 in 4 participants is in this early stage of registration as a mentor.

40% 35% 30% 25% 20% 15% 10% 5% 0% 0-6 months 7-12 months 13-18 months 19-24 months

Figure 3: Length of time in the volunteer mentor role with After Caring

Motivation

Asked about the ways in which they had found out about volunteering with After Caring, participants identified a wide range of sources of information from advertisements in local papers (2), links with employment or other volunteering roles (2), and personal contact with the project co-ordinator (3).

It is interesting to note that altruism – helping others, making a difference and giving something back - appeared to provide the strongest drivers for the vast majority of volunteers rather than focussing on themselves. The proportion of respondents giving the highest score – strongly agree – in relation to each of six statements is reported in Figure 4.

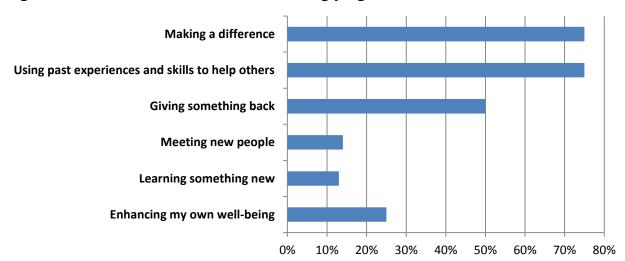


Figure 4: Motivations to volunteer – strongly agree

One volunteer expressed their own motivation as follows:

"To try and help people understand you don't have to be alone with bereavement" [Volunteer]

Time commitment, roles and tasks

As might be expected from the project steering group and staff reports considered earlier in this report, the vast majority of volunteers (75%) were matched with carers who had been bereaved, rather than those caring for someone in a residential or nursing home (25%). Asked about the average time commitment for mentoring, the majority estimated spending on average one hour each week although for some this rose to a maximum of 5 hours per week.

A wide range of roles and tasks were reported, summarised in Figure 5 with talking and listening identified by all. Talking about a lost loved one and the feelings engendered by the experience has been shown to be an important part of the process of bereavement (Milberg, 2008; Burnell et al, 2012) and opportunities to vent and express emotion are particularly important, requiring highly developed listening skills on the part of mentors.

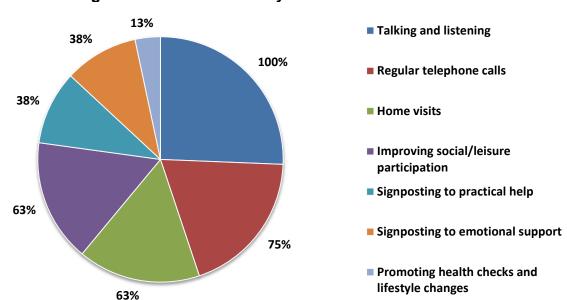


Figure 5: The range of tasks carried out by volunteer mentors

Research tells us that even where people have wide and supportive networks of family and friends, they may often feel unable or unwilling to burden members of these close networks with their own concerns (Arthur et al, 2011), which has a double impact on feelings of isolation and disconnection, which can be a precursor to more serious anxiety and depression (Anderson and Dimond, 1995; Holtslander, 2008). There is evidence from a recent report from the Mental Health Foundation (Swift et al, 2014) and social learning theory (Bandura, 1977) that peer support may be effective where the person providing support is someone with whom the service user can identify, feeling understood and valued, emphasising again the importance of the quality of the relationships facilitated by After Caring and the crucial part played by the programme's 'matching' processes. As with social support more generally, peer support has been shown to directly improve quality of life and well-being by decreasing feelings of isolation, improving mood and promoting more adaptive, positive coping strategies (Dennis, 2003; Burnell et al, 2013)

In addition to the social and emotional support of the one-to-one mentoring, sign-posting carers to practical help was reported by over a third (38%) of volunteers, all of whom had received a copy of the After Caring information pack, which was rated as 'very or extremely useful' by all respondents.

Training and support

Given the sometimes intense emotions that volunteers are likely to encounter in their mentoring role, particularly in working with bereaved carers, the support and training to develop volunteers' knowledge and skills is a crucial element of the project delivery. Asked their opinion of a number of aspects of the training and support offered by After Caring, participants had readily taken up the opportunities available to them and were overwhelmingly positive about their experiences.

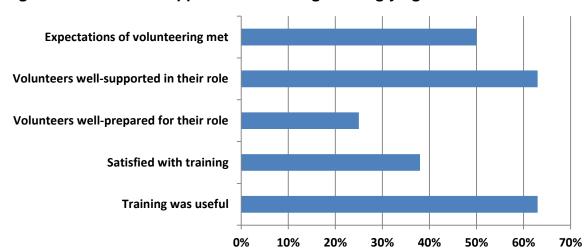


Figure 6: Volunteers' appraisal of training - strongly agree

The proportion of those giving the highest score – strongly agree – to each statement are reported in Figure 6. The usefulness of training and feeling well-supported attracted the highest score from 2 out of 3 participants. The fact that a rather smaller proportion gave highest scores to feeling well-prepared or satisfied with what had been offered may reflect some of the complexity and unpredictability of the task and the fact that a quarter of participants were within the first six months of registration and further time may be needed for them to 'grow into the role', consolidate their skills and knowledge and build their confidence. Some disgruntlement was reported by one volunteer as follows:

"Hearing is difficult (due to my age) at talks and group meetings, especially if there is a background noise. Often speakers talk too quickly to assimilate what is being said" [Volunteer]

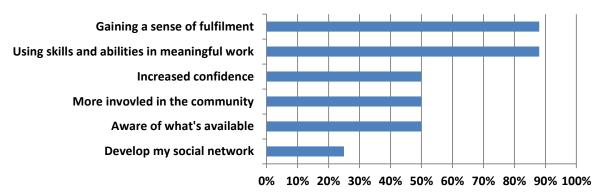
Following up each training event with an evaluation sheet is reaping benefits in identifying particular issues contributing either positively or negatively to levels of satisfaction, supporting a continuing cycle of improvement.

Benefits

As already noted, volunteers were motivated in large part by altruism and wanting to help others, and a similar picture emerged in relation to their perceptions of the benefits of volunteering, summarised in Figure 7.

Nearly all gained a sense of fulfilment from using their skills and abilities in meaningful work. These findings are supported by other studies highlighting the positive impact of volunteering, not only on those receiving the service but also on those delivering it (Borgonovi, 2008; Paylor, 2011; McCulloch, 2012) and it will be important for After Caring to ensure that these aspirations and values are recognised, protected and nurtured as volunteers settle into and develop their roles.

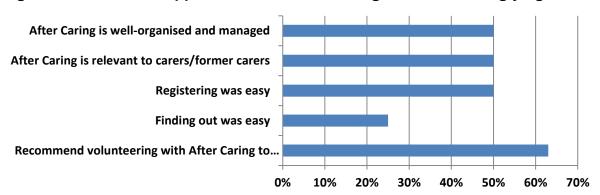
Figure 7: Benefits of volunteering – strongly agree



Satisfactions

Asked their opinion of the After Caring service overall, responses were almost unanimously positive with the vast majority of participants choosing 'agree' or 'strongly agree' in response to each of the statements offered. Indeed, half of all respondents gave the very highest score to each element, as shown in Figure 8, which highlights the one area of disagreement, which arose in relation to the ease with which volunteers had found out about After Caring.

Figure 8: Volunteers' appraisal of the After Caring service – strongly agree



The difficulties of recruiting volunteers were identified by project staff and steering group members and if volunteers themselves are not finding an easy route into the project, this may indicate a gap in the current marketing and promotional activities which often combine information for carers with appeals for volunteers. Advantage may accrue in this area by aiming effort and materials specifically at volunteers.

4.3 Perspectives of carers using the service

It is important to note that findings reported here draw on initial postal surveys undertaken at the point that carers enter the project and begin to receive a service so that no qualitative data, specifically from this study, relating to service satisfaction is yet available.

However, an informal telephone survey undertaken as part of the project's internal monitoring processes in May 2013 has shown high levels of service satisfaction. For example, knowing where to get help 'when I needed it' was identified as an area of high satisfaction by an overwhelming majority (82%) of carers. In addition, over half of respondents reported that After Caring had helped them to adapt to their changed circumstances, had been important to them in getting the support that they needed

and that they were feeling better as a result of their contacts with After Caring - See Appendix A, p. 35 for further details of this separate project monitoring data.

An exit survey, together with a series of focus groups will be undertaken with those using the service during the period 1st September 2014 to 31st March 2015 in order to explore in greater depth experiences of transition, perceptions of the practical and emotional impacts of life changes, the services taken up or barriers to engagement, as well as satisfactions with the After Caring project and suggestions for future improvements.

General characteristics of carers using the service

The general characteristics of the carers choosing to respond to the initial survey are summarised in Figure 9 below.

Figure 9: General characteristics of carers using the service

<u> </u>	isites of carers using the service	Study sample
		n=9
Gender	Female	89%
	Male	11%
Age	55-64 years	11%
	65-74 years	44%
	75-84 years	11%
	85+ years	11%
Ethnicity	White British	100%
Caring situation	Bereaved	67%
	Care recipient in long-term care	33%
Carer registration	Registered as carer at GP practice	11%
Health	Attending regular health clinic	56%
Transport	Car driver	67%
	Bus	44%
Faith group	Membership of a faith group	63%
Dwelling location	City/Town	33%
	Village	67%
Length of residency	Less than 1 year	11%
	2 - 10 years	11%
	11 – 20 years	66%
	21+ years	11%
Employment status	Retired	100%
Financial resources	Struggling	33%
	Managing	33%
	Comfortable	33%
Length of time in caring role	Less than 1 year	11%
	1 - 5 years	44%
	6 - 10 years	22%
	11+ years	22%
Hours spent caring each	0 – 10 hrs	33%
week	40 – 50 hrs	11%
	50+ hours	56%

The majority of carers participating in this survey (67%) are those who have been bereaved. Most are female, in the early years of retirement, and have lived in a village setting in Devon for over 10 years, indicating a fairly settled community in which it was not surprising to find only a minority of respondents (33%) reporting weak/very weak community networks, adding to the importance of 'word of mouth' as an 'information highway' in the region!

Interestingly, those living in town settings rather than villages were more likely to rate their community networks as 'strong', suggesting that After Caring services are well-directed to more rural locations, despite the logistical problems involved in travelling across such a wide area.

Given that those using the After Caring service must be over 50 years, it is no surprise to find that the majority of participants (56%) attend regular health clinics at their GP surgery which makes the paucity of GP engagement to date with After Caring activities reported variously by staff and steering group members all the more disappointing. In addition, the very small proportion of participants registered at their GP surgery as a carer (11%) also strongly suggests a disappointingly low priority and recognition being given to the needs of carers in these primary healthcare settings.

In this survey, 2 in 3 carers identified themselves as members of a faith group which adds strength to the continued inclusion of parish newsletters and faith-based social groups as an important part of the After Caring marketing and promotion strategy, already outlined in Section 4.1.

We know that caring can have an adverse impact on financial resources and that low income has been shown to negatively influence people's perceptions of their quality of life (Princess Royal Trust for Carers, 2010). It is important to note here that although most felt financially comfortable or at least managing on household income, 1 in 3 respondents reported 'struggling to get by', indicating that an important group has been identified which may be most likely to find positive benefits from the After Caring service.

Caring roles and tasks

The majority of carers using the service (55%) had been caring for up to 5 years and reported spending more than 50 hours each week on a multiplicity of tasks in their caring role, indicating a high level of involvement, leaving perhaps little residual time for other social or leisure pursuits alongside caring.

Nearly all respondents (89%) had been caring for a spouse or partner and research over a number of years has shown that the loss of an intimate relationship of this type is one of the most stressful events in a person's life and can have long-lasting negative impacts in terms of loneliness and depression for those who remain (Bass and Bowman,1990; Beeson, 2003; Burton et al, 2003; Wimpenny, 2006; Diamond et al, 2012). Although these are crucial target groups for the After Caring service, it must be borne in mind, especially when looking for impact that the deep and sometimes complicated grief associated with spousal loss may endure for many years and may never in practice be amenable to peer mentoring (Arthur et al, 2011). In these circumstances it will be important to set limits and/or review the duration of

each After Caring intervention and to support those volunteers involved who may, erroneously, feel personally responsible for a lack of progress and improvement which could erode the more altruistic motivations to undertake the mentoring role so clearly identified by volunteers (See Section 4.2).

Prior help and supports

A quarter (25%) of respondents reported that they did not get as much help as they wanted from either health and social services and these were more likely to be participants who had or were still caring for someone with dementia or Alzheimer's disease rather than other terminal conditions such as cancer or heart and lung conditions, suggesting some of the gaps in services which After Caring is increasingly well-placed to fill.

Asked about the services that provided help in the three months' prior to bereavement or the transition of the care recipient into long term care, a wide range of services was reported as shown in Figure 10.

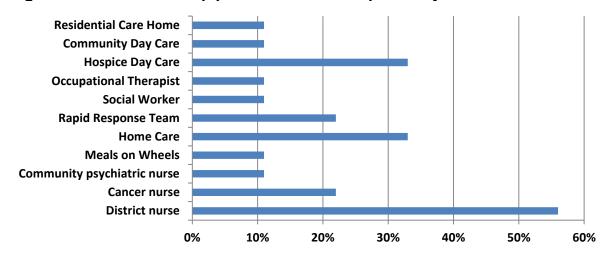


Figure 10: Sources of help prior to transition reported by carers

Although strong links with some of these services have already been established, the list of supports identified by carers in Figure 10 provides a useful checklist for After Caring to ensure that all potential sources of referral have been fully explored.

From this list, home care providers and district nurses clearly have key contact with carers in the period leading up to an important transition and renewed efforts to raise awareness about After Caring and/or establish named contacts specifically with these services may help to enhance referral rates. The part played by care homes in end of life care may also provide an important link for After Caring. Mentioned by a small proportion (11%) of participants in this survey, it has been estimated (Leadbetter and Garber, 2010) that by 2030, 20% of deaths will be in care homes and again, these are providers with whom strong links should be sought and established as part of the service user recruitment strategy.

Physical health and well-being

Although more than three-quarters of carers reported being 'satisfied' or 'very satisfied' with relationships with family, friends and neighbours, at least 1 in 3

expressed some level of dissatisfaction with their lack of energy and motivation to get on with everyday life and take part in hobbies or leisure activities. The amount and quality of sleep was a cause for dissatisfaction for 1 in 4 respondents.

There is a sense in which these carers were not yet willing or able to re-connect with a wider social world, sometimes described in the literature as 'a tendency to hide away' with the result that for a sizeable minority (33%) there was dissatisfaction with their overall sense of well-being and contentment which we know is derived most often from human contact and social interactions. There is evidence that developing hope and positive thinking is effective in assisting recovery following bereavement (Holtslander, 2008) and in this regard, After Caring is well-placed to continue the programme of training, workshops and support focussing on positive coping strategies not only for volunteers but also for carers using the service.

General Health Questionnaires (GHQ)

Participants each responded to the General Health Questionnaire (Goldberg, 1978), which is divided into four domains:

Domain A: Physical strain

Domain B: Anxiety and insomnia

Domain C: Social and personal difficulties Domain D: Depression and mental health

Each domain comprises 7 questions and respondents may choose one from four options, giving a total score from 0-7 in each domain. A high score (5 or more) in any domain is sufficient to trigger a concern in this area of functioning. Questionnaire responses were collated and scored and an initial analysis of the data was undertaken using the computer programme Statistical Package for Social Sciences (SPSS) and responses are shown in Figure 11.

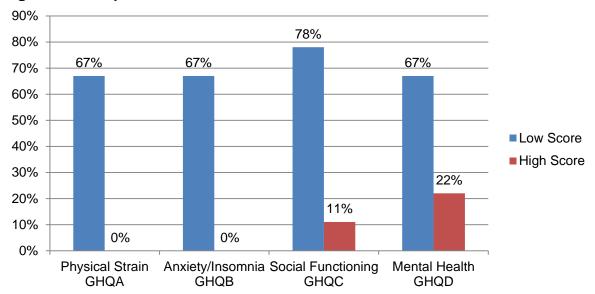


Figure 11: Responses to GHQ in each of the four domains

The blue columns represent the proportion of respondents reporting 'LOW' scores (2 or less) indicating that overall, for the vast majority (67% or more) there were few or no concerns in each of the four domains. However, it is interesting to note that

nearly 1 in 2 felt they were 'in need of a good tonic' (Domain A) and had 'recently lost much sleep over worry' (Domain B), rather or much more than usual.

The red columns represent the percentage of respondents reporting HIGH scores (5 or more) in each domain. Although there were no HIGH scores in relation to physical strain and anxiety/insomnia, ratios in the remaining two domains were at a level to trigger concerns as follows:

Social dysfunction: Overall 1 in 10 scoring HIGH

For example, in this domain, 20% of respondents reported being able to keep busy and occupied 'rather less than usual' and also taking 'much longer than usual' over the things they have to do.

Mental health: Overall 1 in 4 scoring HIGH

In this domain, nearly one third (30%) of respondents reported feeling that 'life is entirely hopeless' rather more than usual and perhaps most worryingly, the same proportion also reported that the idea of taking their own life 'had crossed my mind'. The prevalence of a high GHQ score, indicating probable mental ill-health in the general population aged 65 – 84 years, is in the range 10 - 14%, compared with 22% reported by the evaluation participants who now have contact with After Caring services providing the supportive interactions which increasing evidence suggests may help to reduce carers' psychological distress (Candy et al, 2011).

6.0 EMERGING THEMES AND RECOMMENDATIONS

Findings from the study have been brought together to produce nine principal recommendations. Some are practical recommendations to improve existing processes and procedures or suggestions to meet gaps which have been identified. Taken together the findings and recommendations are intended to stimulate discussion, inform and influence the way in which partners in the After Caring project can work together to better co-ordinate and improve the support that is available to help carers at key stages in their end of care pathway.

Strengthening the Steering Group

Recommendation 1: to consult widely with relevant stakeholders and review the active membership of the steering group to build on current strengths and continue to engage key organisations at a sufficiently strategic level for the consideration of options for future development, to ensure the inclusion of After Caring in county-wide strategic planning processes over the coming year.

Developing group support

Recommendation 2: to consider the development of facilitated group support for carers and the promotion of peer support groups and social networking amongst volunteer mentors, as an adjunct to the one-to-one mentoring and training arrangements currently in place, as a foundation for the longer-term sustainability of After Caring.

Building knowledge, skills and confidence

Recommendation 3: to continue to offer a range of workshops and training events for volunteers and carers using the service in order to:

- o develop knowledge and skills
- o increase confidence
- o nurture the values and commitment of volunteers

Specific topics could include for example understanding grief; relaxation and sleeping well; listening skills; using positive coping strategies.

Increasing referrals

Recommendation 4: to continue to deliver the full range of marketing and promotional activities, giving particular attention to GP practices; district nurses; home care providers; and care homes, as well as other services identified by participants which are as yet 'untapped resources' for the After Caring service.

Providing co-ordinated and timely information

Recommendation 5: to continue to maintain, up-date and regularly refresh the After Caring information pack which has been a key success and has an enduring central role to play in providing a 'one stop shop' for carers and former carers, to improve their understanding of what is available but most specifically in the way and at the time it is needed.

Improving the volunteer recruitment process

Recommendation 6: to undertake a review of the volunteer recruitment strategy and consider ways in which volunteers can be separated from carers using the service, to ensure that easy, clear and accessible routes to join After Caring are available to all potential volunteer recruits.

Making use of monitoring systems and feedback to implement improvement Recommendation 7: to continue to make regular use of the monitoring systems and feedback loops, for example mentor contact sheets and training evaluation forms, that are now established to assist staff and volunteers to measure their contribution to the service, ensuring that their aspirations and values are recognised, protected and nurtured.

Making best use of co-ordinator time and abilities

Recommendation 8: to review the role of the co-ordinator, particularly as referrals increase, to ensure that the higher-level skills which have been accumulated in recruiting, matching and supporting carer and volunteer 'dyads' are fully utilised. Consideration might need to be given to the possibility of delegating to others some of the now routinized clerical and administrative tasks which might be attractive to volunteers with office skills.

Assessing options for future delivery

Recommendation 9: to consult widely with all stakeholders, to undertake a thorough analysis of the range of other delivery and/or funding options which might become available to After Caring as ways are sought to ensure its continuance and sustainability beyond the first three years.

7.0 REFERENCES

- Age UK (2011) Promoting mental health and well-being in later life: a guide for commissioners of older people's services, London, Age UK
- Andershed, B. (2005). Relatives in end-of-life care: Part 1 a systematic review of the literature the five last years, January 1999 February 2004. **Journal of Clinical Nursing**, 15, 1158-1169.
- Anderson, K. L., and Dimond, M. F. (1995). The experience of bereavement in older adults. **Journal of Advanced Nursing**, *22*(2), 308-315
- Arthur, A., Wilson, E., James, M., Stanton, W., and Seymour, J. (2011).

 Bereavement care services: a synthesis of the literature. London:
 Department of Health / University of Nottingham.
- Bainbridge, D., Krueger, P., Lohfeld, L., and Brazil, K. (2009). Stress processes in caring for an end-of-life family member: Application of a theoretical model. **Aging and Mental Health**, *13*(4), 537 545.
- Bandura, A. (1977). Social Learning Theory. Englewood Cliffs, NJ: Prentice-Hall.
- Bass, D. M., and Bowman, K. (1990). The transition from caregiving to bereavement: the relationship of care- related strain and adjustment to death. *The Gerontologist*, *30*(1), 35-42
- Beeson, R.A., (2003) Loneliness and depression in spousal caregivers of those with Alzheimer's disease versus non-caregiving spouses, **Archive of Psychiatric Nursing**, 17(3), 135-43
- Borgonovi, F., (2008) Doing well by doing good. The relationship between formal volunteering and self-reported health and happiness, **Social Science and Medicine**, 66, 2321 2334
- Burnell, K., Charlesworth, G., Feast, A. R., Hoe, J., Poland, F. M., and Orrell, M. (2012). Peer support interventions for family cares of adults with chronic, mental or physical illness who are living at home. **Cochrane Database of Systematic Reviews** Issue 11 Article No. CD10231
- Burton, L. C., Zdaniuk, B., Schulz, R., Jackson, S., and Hirsch, C. (2003). Transitions in Spousal Caregiving. **The Gerontologist**, *43*(2), 230-241
- Candy, B., Jones, L., Drak, R., Leurent, B., and King, M. (2011). Interventions for supporting informal caregivers of patients in the terminal phase of a disease.

 Cochrane Database of Systematic Reviews, Issue 6. Article No:CD007617
- Davisson, D. B., and Mosher-Ashley, P. M. (2003). Social workers' perceptions of family distress at long-term care placement. **Activities, Adaptation and Aging**, *27*(1), 29-48
- Dennis, C.L. (2003). Peer support within a health care context: a concept analysis. **International Journal of Nursing Studies**, *40*(3), 321-332
- DH (2008) End of life care strategy promoting high quality care for all adults at the end of life, London, Department of Health
- Diamond, H., Llewelyn, S., Relf, M., and Bruce, C., (2012) Helpful aspects of bereavement support for adults following an expected death: volunteers' and bereaved people's perspectives, **Death Studies**, 36(6), 541-64
- Donnellan, H., and Giarchi, G., (2012) The Neighbourhood Links project: Interim evaluation report (unpublished)
- Donnellan, H., Endacott, R., and Grimes, K., (2011), Carers' Health and Well-being Checks Service Evaluation Study Final Report, Devon County Council/DH, retrieved on 20-12-12 from
- http://www.devon.gov.uk/h wbc evaluation study final report august 2011.pdf

- Donnellan, H., (2009) **GP Carers' Project Final Evaluation Report**, RE:search South West, University of Plymouth, available at
- www.plymouth.ac.uk/files/extranet/docs/FoH/GP%20Carers'%20Project%20Final%20Report%20May%202009.pdf
- Ford, G. L. (2008). Life after placement: experiences of older rural caregivers after placing a family member into residential care. **Rural and Remote Health**, *8*, 1030-1039.
- Foresight (2008) Mental Capital and Wellbeing Project: Final project report Executive summary, London, The Government Office for Science
- Goldberg, D., (1978), **Manual of the General Health Questionnaire**, Windsor, NFER-Nelson
- Haley, W. E., Bergman, E. J., Roth, D. L., McVie, T., Gaugler, J. E., and Mittelman, M. S. (2008). Long-term effects of bereavement and caregiver intervention on dementia caregiver depressive symptoms. **The Gerontologist**, *48*(6), 732-740.
- Holley, C. K., and Mast, B. T. (2009). The impact of anticipatory grief on caregiver burden in dementia caregivers, **The Gerontologist**, *49*(3), 388-396
- Holtslander, L. F. (2008). Caring for bereaved family caregivers: analyzing the context of care. **Clinical Journal of Oncology Nursing**, *12*(3), 501-506
- Larkin, M. (2009). Life after caring: the post-caring experiences of former carers. **British Journal of Social Work**, 39(6), 1026-1042
- Leadbetter, C and Garber, J., (2010) **Dying for change**, London, Demos McCulloch, A. (2012) **Doing good does you good**. London: Mental Health Foundation
- McLaughlin, E., and Ritchie, J. (1994). Legacies of caring: the experiences and circumstances of ex-carers, **Health and Social Care**, *2*(4), 241-253.
- McMillan, S., C. (2005). Interventions to facilitate family caregiving at the end of life. **Journal of Palliative Medicine**, 8 (Supplement 1), S132-S139.
- McNamara, B., and Rosenwax, L. (2010). Which carers of family members at the end of life need more support from health services and why? **Social Science and Medicine,** 70(7), 1035-1041.
- Milberg, A., Olsson, E.-C., Jakobsson, M., Olsson, M., & Friedrichsen, M. (2008). Family Members' Perceived Needs for Bereavement Follow-Up. **Journal of Pain and Symptom Management**, *35*(1), 58-69.
- Nazroo, J. and Matthews, K. (2012) **The impact of volunteering on well-being in later life.** Cardiff: WRVS
- Nelis, S., Quinn, C., and Clare, L. (2007). Information and support interventions for informal caregivers of people with dementia. **Cochrane Database of Systematic Reviews,** Issue 2, Art. No: CD006440.
- NHS Devon (2011) **Joint Plans for Carers 2011-13, Devon Carers' Strategy** retrieved on 27/02/13 from http://www.devonpct.nhs.uk/Carers/Carers.aspx
- NHS Scotland (2012), **Mental health strategy for Scotland 2012-15**, retrieved on 13-03-13 from http://www.healthscotland.com/mental-health-background.aspx
- NICE (2008) **Mental well-being and older people**, retrieved on 20-12-12 from http://www.nice.org.uk/nicemedia/pdf/PH16QuickRefGuide.pdf
- Paylor, J., (2011) Volunteering and health: evidence of impact and implication for policy and practice: A literature review, London, Institute for Volunteering Research

- Payne, T. (1999). **Picking Up the Threads: A Study of Former Carers**, Melbourne, Carers New South Wales Inc.
- Princess Royal Trust for Carers, (2010) **Broke and broken: Carers and finance survey**, Retrieved 30/05/2014 from http://www.carers.org/press-release/broke-and-broken-carers-battle-poverty-and-depression
- Robinson, L., Hughes, J., Daley, S., Keady, J., Ballard, C., and Volicer, L. (2005). End-of-life care and dementia. **Reviews in Clinical Gerontology**,15,135-148.
- Rossi, P.H., Lispey, Mark, W., Freeman, H.E. (2004) **Evaluation: a systematic approach** (7th Ed), Thousand Oaks, Sage
- Ryan, A. A., and Scullion, H. F. (2000). Nursing home placement: an exploration of the experiences of family carers, **Journal of Advanced Nursing**, *32*(5), 1187-1195
- Skills for Care (2010) Only a footstep away? Neighbourhoods, social capital and their place in the 'Big Society', Leeds, Skills for Care
- Stroebe, M., Schut, H., and Stroebe, W. (2007). Health outcomes of bereavement. **The Lancet**, 370, 1960-1973.
- Swift, P., Cyhlarova, E., Goldie, I., and O'Sullivan, C. (2014). Living with anxiety. London: Mental Health Foundation.
- Waldrop, D. (2007). Caregiver grief in terminal illness and bereavement: a mixed methods study, **Health and Social Work**, *12*(3), 197-207
- Wimpenny, P. (2006). Literature review on bereavement and bereavement care.

 Aberdeen: Robert Gordon University / The Joanna Briggs Institute.
- Wright, A., A, Zhang, B., Ray, A., Mack, J. W., Trice, E., Balboni, T, Mitchell, S.L., Jackson, B. A., Block, S.D., Maciejewski, P.K., and Prigerson, H. G., (2008). Associations between end-of-life discussions, patient mental health, medical care near death and caregiver bereavement adjustment. **Journal of the American Medical Association**, 300(14), 1665-1673.
- Yeandle, S., Bennett, C., Buckner, L., Fry, C., & Price, C. (2007). **CES Report 3 - Diversity in caring: towards equality for carers** Carers, employment and services report series. Leeds: University of Leeds / Carers UK.
- Zarit, S. H., and Whitlatch, C. J. (1992). Institutional placement: Phases of the transition. **The Gerontologist**, *32*(5), 665-672

After Caring Project Consulting with Carers Using Services

Telephone Satisfaction Survey May 2013 EXTRACT FROM SUMMARY RESULTS

A telephone survey comprising 10 pre-set questions was carried out by a project volunteer in May 2013 with a total of 17 carers whose contact details were drawn from the registration schedule maintained by After Caring.

The general characteristics of the 17 carers who took part in the survey are summarised in the table below. The majority (82%) were female and 18% male. The largest proportion were aged over 75 years (41%), followed by those aged 65-74 years (24%). Nearly half (47%) had been in contact with After Caring for the longest period of time, between 7-12 months and one third (35%) had been matched with a mentor. Only a small proportion (29%), were currently caring for someone, with the vast majority (71%) bereaved. In this group, three-quarters were in the first two years since the death of their loved one although for one respondent post-bereavement had extended over 9 years.

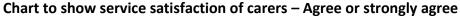
Table to show general characteristics of carers participating in the survey (x17)

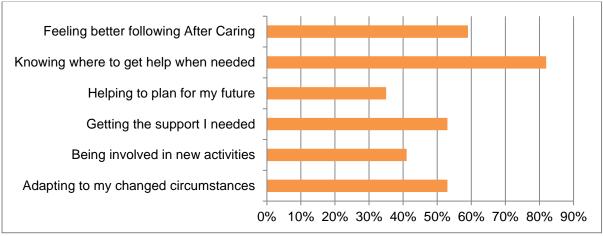
Characteristic		%
Gender	Female	82%
	Male	18%
Age*	50-59 years	18%
	60-64 years	18%
	65-74 years	24%
	75+ years	41%
Caring situation	Bereaved	71%
	Cared for moved to residential care	6%
	Currently caring at home	23%
Length of time since	0 – 2 years	75%
bereavement	3 – 8 years	17%
	9+ years	8%
Length of contact with After	1-3 months	18%
Caring	4-6 months	35%
	7-12 months	47%
Receiving mentor support	Matched with a mentor	35%

^{*}Total exceeds 100% due to rounding

Carers were asked to rate six potential benefits of the After Caring service using a five point scale from 'strongly agree' to 'strongly disagree'. The chart below shows the proportion of participants rating their own experiences positively by choosing either 'agree' or 'strongly agree' with each statement. Knowing where to get help 'when I needed it' was identified as an area of high satisfaction by an overwhelming majority (82%) of carers. It is also important to note that over half of the participants reported that After Caring had helped them to adapt to their changed circumstances, had been important to them in getting the

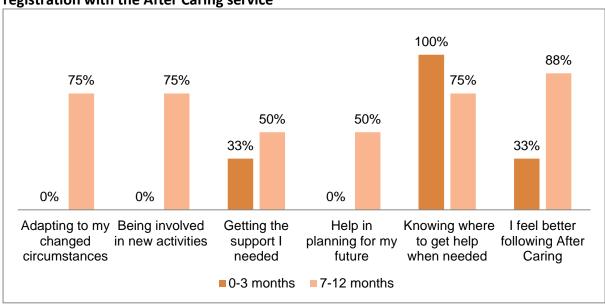
support that they needed and that they were feeling better as a result of their contacts with After Caring.





Although responses did not appear to vary in relation to age and gender, the length of time that participants had been in contact with After Caring did suggest a positive influence on their perceptions as shown in the chart below. Satisfaction increased substantially over time – with only one notable exception - with the majority of those in contact with After Caring for more than six months recording very high satisfaction with all the elements explored.

Chart to show variation in levels of satisfaction (agree or strongly agree) with length of registration with the After Caring service



It is interesting to note that the provision of information - 'knowing where to get help when needed' — was an area of almost instant satisfaction for every participant in the first three months of service receipt, emphasising again the key role played by the After Caring local information pack and the ability of After Caring to respond sensitively with what carers want and need, at an appropriate time for each individual.

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