

**AGE UK:  
Supporting Older Carers  
of Those Nearing the  
End of Life**

**LANCASTER UNIVERSITY  
EVALUATION OF SIX PILOT  
PROJECTS  
*Final Report***

Commissioned by Age UK  
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## Executive Summary:

This report presents findings from an independent evaluation commissioned by National Age UK through the Department of Health *Supporting Older Carers of Those Nearing the End of Life* Programme. Six local Age UK organisations in England were funded to provide practical and emotional support to older carers, and to establish the potential role of trained volunteer delivered interventions in this area.

In this report we identify a number of important issues for the provision of specialist volunteer support services for older carers of an older family member who is nearing the end of life. These are posited within the context of a small scale service evaluation, and as such point to emergent and interesting areas for further research in third sector older carer support provision.

The findings are principally organised into six main areas that expand on key messages in each of the finding sections. These sections cover two principle elements of the pilot work: *older carer support* and *volunteer delivered* support services at the end of life. Recommendations arising from these key messages are directed to key stakeholders and offer guidance for organisations providing support services to older carers, to organisations planning provision to meet local needs in this area, and at a national policy and funding level.

In summary:

### OLDER CARERS OF THOSE NEARING THE END OF LIFE:

- **Older carer's often have complex and multiple needs** that co-exist with their cared-for relative's complex health and welfare circumstances
- **Reciprocal and changeable caregiving** may often exist within same household caring relationships
- **Multiple caregiving roles** exist whereby older carers can be supporting spouses, siblings, their children or their sibling's children, within their own households and in other households
- Older carers may have **lifelong and shifting carer roles** for now aged family members with enduring health conditions or disabilities
- **Emotional support** often emerges as a **secondary dimension to practical assistance needs**
- **Befriending and friendship** support provide assistive contact, while enabling older carers to share the value of mutually meaningful relationships with coordinators and volunteers
- Maintaining **soft contact with older carers over time** enables contact or re-engagement at the point of increased need, and following loss and bereavement particularly for some carers

### Implications and recommendations:

- Older carers require their **health and social needs** to be addressed *alongside* those of their family member to feel comfortable about accessing and accepting services
- Assessment of older carers should take account of the multiple and mutual needs that co-exist between them and their cared-for relative. Individual **carer**

**and couple / partnership needs** should be addressed because carers want to know that their family member does not lose out when they take a break from caring

- Older carers may need time to accept offers of support. **Timeliness of support** and **soft contact over time** are important to allow individual carers to accept support at a time appropriate to them, and/or to allow a trusting relationship to develop with support workers that they can then call on when needed
- Befriending and friendship services should provide **meaningful support** for cared-for people to allow older carers to feel able to leave their family member to gain respite

#### **LOCAL LEVEL ORGANISATIONS PROVIDING SPECIALIST END OF LIFE VOLUNTEERING SERVICES TO SUPPORT OLDER CARERS:**

- Equal importance of **service user needs and volunteer needs** where volunteers deliver specialist end of life services
- Potential mis-match in timing of **volunteer readiness** and older carer support needs in the start-up phase of establishing services. Lead-in time to volunteer readiness can have implications for **short term funded projects**
- Links with specialist trainers can enable **integrated working** between health and third sector organisations
- A strong, planned strategy for **supervision and support** is fundamental for volunteers working in the area of end of life. **Group training** opportunities facilitate volunteer cohesion and offer **peer support**
- Coordinators **signpost to a range of health, social care and voluntary services**. They are especially well placed to access other services provided by local Age UK organisations
- **Open Intervention Model** facilitates long term support and soft contact to build rapport and trust. Coordinator and volunteer delivered older carer support **Timed Intervention Model** regulates demand and protects the intensive EOL supporting relationship. Primarily volunteer delivered older carer support
- **Volunteering 'spousal teams'** provide mutual volunteer support and enable the needs of older carer / cared-for couples to be met in an inclusive, mutually beneficial way
- Establishing early **external referral pathways** and maintaining these through regular updates to health and social care teams. Internal services provide important **referral sources**. Dual coordinator roles boost referral links between projects
- Early, planned, organisation-wide **volunteer recruitment strategies** to ensure an established, ready volunteer base to match with individual older carers. Anticipation that EOL may be a **sensitive area of volunteering** to an older age cohort of volunteers

#### **Implications and recommendations:**

- Volunteering at the end of life should be recognised and promoted as a specialist service, whether it is a dedicated or embedded service. **End of life volunteering** should involve specialist training, contact with peer volunteers working in the same area, and robust mechanisms for supervision and support
- **Referral pathways** with external organisations and **volunteer recruitment** are interconnected priority tasks and should be instigated soon after project

start-up to enable matching of service providers (volunteers) to service users (older carers)

- All service types that aim to meet needs at the end of life, including practical, financial and social, should include a component that **supports older carers on an emotional level**, to lesser or greater degrees
- **Time managed support** approaches can protect volunteers from intense involvement with older carers. **Couples volunteering** may provide a successful way of supporting spousal/partner couples who both require support at the end of life
- **Interpersonal communication** in the last few months and weeks of life between the triad of patient, family carers and Age UK support staff and volunteers is crucial but poorly understood and researched. Healthcare **conversations around end of life** care topics are challenging for staff and volunteers, and they need to feel comfortable addressing emotional issues, in addition to undertaking practical support tasks
- There is a need to address the growing demands on staff and volunteers working with older people and their carers in homes, communities, and day services. End of life needs is not the domain of specific services, because older people and their carers require a range of individualised support. **Organisation-wide training and knowledge exchange in end of life** issues, needs and support should **bridge ALL service areas**

#### **STRATEGIC AND POLICY LEVEL PLANNING FOR SPECIALIST END OF LIFE VOLUNTEERING SERVICES TO SUPPORT OLDER CARERS:**

- Development of **sustainable end of life services** can be achieved by 'adding-on' this area as a distinct element of work for existing services, or 'embedding' an end of life component into all existing services
- **Flexible service development** accommodates locality older carer population specific needs
- Self-evaluation, internal audit, and independent external **evaluation** place additional layers of responsibility and demand on coordinator positions

#### **Implications and recommendations:**

- Building sustainable older carer support requires funding programmes that allow local organisations to be flexible in how they **embed or add-on end of life services** to their existing provision
- **Evaluation** of service interventions should be **collaborative and cooperative** to facilitate working relationships with project coordinators and other staff members, including volunteers. Evaluation tasks compete with service delivery requirements, which place additional demands on individuals and host organisations
- End of life specialist services involving volunteers should be conceived of as both **service user and volunteering services**, to recognise that both **service users and volunteers have specific support needs**. These services should be resourced and underpinned with clear funding elements and delivery requirements for *both* components
- **Minimum periods of funding** for pilot volunteer services should be established. Outcomes for funding periods of less than 12 months are limited

- Working relationships with third sector organisations who provide specialist end of life services, enhance patient care through their carers receiving support in their own right. **Investment in supporting these services provides opportunities for integrated work** and care provision
- Cross-over in local organisation's geographical areas and spheres of work is inevitable as ageing and informal carer populations grow. Providing services in similar areas and with similar carer populations at the end of life offer **opportunities for service planning and development**, joint working, and sharing of resources e.g. training, volunteer support and supervision

## Contents

	<b>Page</b>
<b>1 Background</b>	1-2
<b>2 Aims and objectives</b>	3
<b>3 Caring at the End of Life: context and background</b>	4-6
<b>4 Methods</b>	7-14
4.1 Data collection	8-11
4.2 Data Analysis	11-12
<b>5 Pilot Project Profiles</b>	13-15
5.1 Summary details	13
5.2 Older Carers supported	14-15
<b>6 Findings</b>	16-52
6.1 Carer benefits: impact areas	16-19
6.1.1 Older carer perceptions of support received	16-18
6.1.2 Emotional, practical, information and advice support	19
6.2 Complex, multiple, mutual needs	20
6.3 End of Life Support: emotional, befriending and bereavement support	24-32
6.3.1 Befriending, friendship and signposting services	25-30
6.3.2 Bereavement services	30-32
6.4 Volunteer Services for End of Life Support	33-39
6.4.1 Sustainable volunteering	34-37
6.4.2 Supporting specialist End of Life and bereavement volunteering	37-39
6.5 Coordinated services: models of older carer support volunteering services	40-44
6.5.1 Open intervention model	41-42
6.5.2 Timed intervention model	42-44
6.6 Obstacles and challenges	45-52
6.6.1 referrals & collaborative / partnership working with health	46-49
6.6.2 volunteer recruitment and attrition	49-50
6.6.3 sustainability of older carer specialist support services.	50-52
<b>7 Conclusion</b>	53
<b>8 Recommendations</b>	54-56
8.1 Recommendations to support older carers	54
8.2 Recommendations for Age UK organisations supporting older carers	54-55
8.3 Recommendations for Age UK head office	55
8.4 Recommendations for key stakeholders	55-56

<b>9</b>	<b>Acknowledgements</b>	57
<b>10</b>	<b>References</b>	58-59
<b>11</b>	<b>Appendices</b>	60-61
	<b>1. Carer questionnaire</b>	

## Tables

		<b>Page</b>
<b>Table 1</b>	Pilot Programme, Evaluation framework, and data collection structure	1
<b>Table 2</b>	Evaluation data sources	8
<b>Table 3</b>	Qualitative data analysis coding framework	12
<b>Table 4</b>	Pilot projects: local team composition, funding period, referrals received, volunteers recruited	13
<b>Table 5</b>	Age, Gender, Ethnicity	14
<b>Table 6</b>	Age self-reported disabled, registered carer with GP, living same address	15
<b>Table 7</b>	Older carer perceptions at the time of receiving support from <i>Supporting Older Carer</i> pilot services	17
<b>Table 8</b>	Older carer perceptions of aspects of their caring role and lives <i>without</i> support from <i>Supporting Older Carer</i> pilot services	17
<b>Table 9</b>	Older carer perceptions of help received through <i>Supporting Older Carer</i> pilot services	18
<b>Table 10</b>	Spheres of support of pilot projects	19
<b>Table 11</b>	Emergent emotional support needs	28
<b>Table 12</b>	Volunteer training topics and sessions delivered by pilot projects	35
<b>Table 13</b>	Total referrals to pilot projects with area EOL population data	46
<b>Table 14</b>	Referral challenges and issues	47
<b>Table 15</b>	Volunteers: recruitment and attrition	49

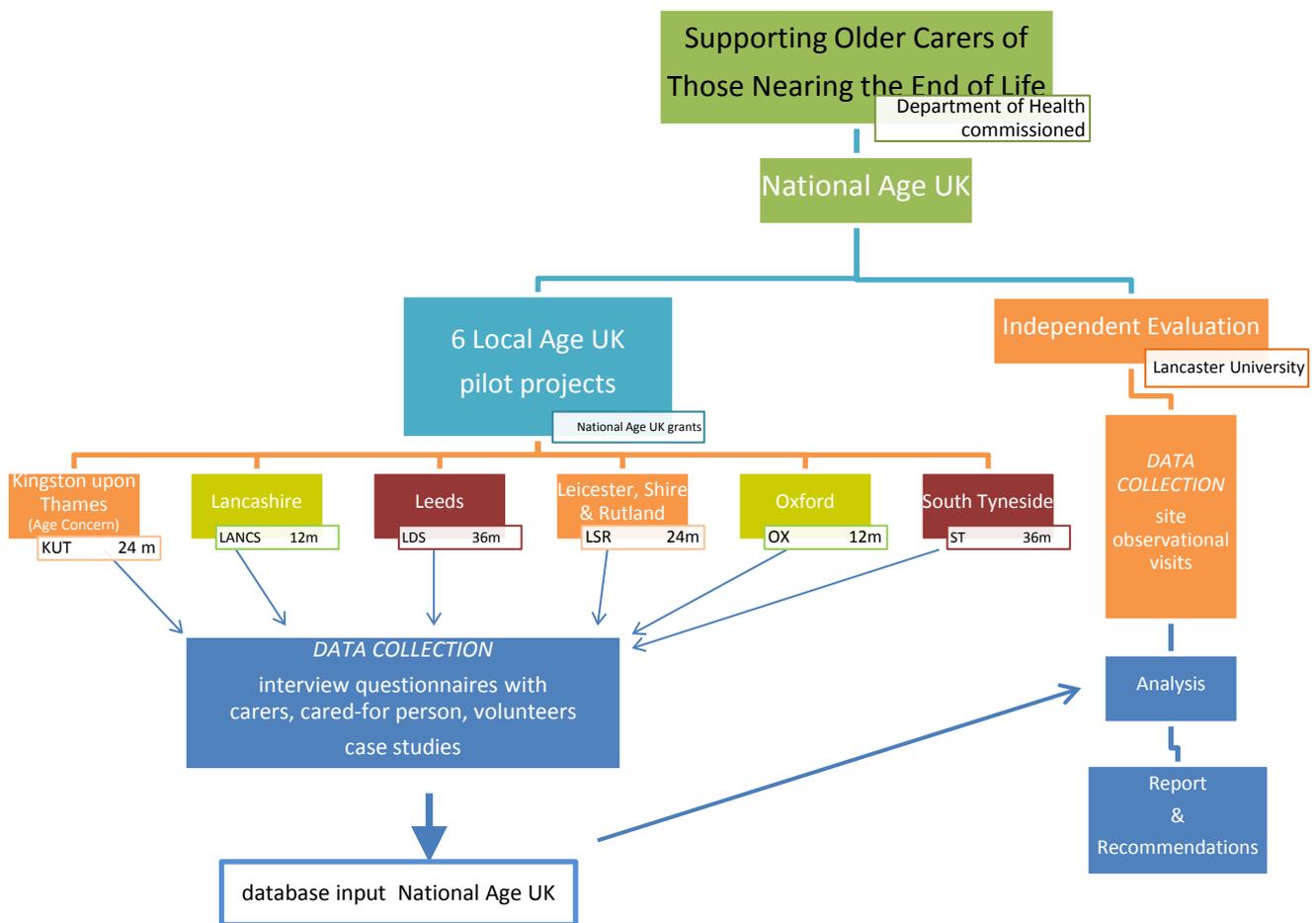
# 1. Background

This is the final report of an external independent evaluation of the Age UK *Supporting Older Carers of Those Nearing the End of Life Programme (Supporting Older Carers)*. It presents the results of research undertaken by the International Observatory on End of Life Care (IOELC) within the Faculty of Health and Medicine at Lancaster University, between September 2011 and August 2013.

The Department of Health (DOH) funded Age UK to undertake a Programme which involved setting-up, developing and running six pilot projects run by local Age UK organisations and one Age Concern (see note below regarding definitions of local Age UK pilot projects). A staggered funding approach was taken whereby grants were awarded for 36, 24, and 12 months, with two pilots funded in each time bracket. Lancaster University commenced the evaluation in year two of the Programme. See Table 1 for overall framework of the funded Programme, evaluation and data collection structure.

The pilot projects were located in England in: Kingston upon Thames, Lancashire, Leeds, Leicester, Shire and Rutland, Oxfordshire, and South Tyneside. See Table 4, page 13 for project profiles.

Table 1: Pilot Programme, Evaluation framework, and data collection structure



The following definitions were used in the *Supporting Older Carers* Programme:

**Older Carer:** An individual over 50 years\* who provides support to the cared for person. They are neither paid nor professionally trained to provide this help. They may not recognise their 'carer' status, viewing themselves as a helpful family member, friend or neighbour.

**Cared for:** An individual who receives emotional or practical support from the older carer, at the time of nearing the end of their life

Hereafter, family, friends and significant others providing informal care are referred to as '*carers*' or '*family carers*'.

**Local Age UK pilot projects:** for ease of reference through this report the *Kingston upon Thames Age Concern* pilot project is included when reference is made to *local Age UK pilot projects*, except where we refer directly to their specific service

\*Exceptions within this definition were made to promote inclusivity e.g. a carer with Gypsy heritage where lower life expectancy was recognised, or to extend the reach of pilot work at times of low referrals.

## 2. Aims and objectives

The overall aim of the evaluation was to:

*Evaluate models of support funded through the Age UK 'Supporting Older Carers of Those Nearing the End of Life' pilot Programme, to support peoples' choice to be cared for, and die with dignity at home or a place of their choice, through providing support for older carers.*

Age UK Pilot Project objectives were to:

- Develop appropriate, high quality, integrated services that will improve the quality of life for older people at the end of their lives
- Support the identification of carers, promote carer assessments and provide practical support to older carers in a service model that is integrated with and delivered seamlessly with health/social care
- Enable older carers to access bereavement support.
- Identify potential roles for trained volunteers in providing practical and emotional support
- Reduce acute hospital bed usage
- Develop and test service models that can be rolled out nationally
- Provide best practice information for all commissioners and providers of End of Life care services in England

Assessment of a number of objectives as they were implemented by the five local Age UK and one Age Concern projects sought to evidence the effectiveness of the pilot Programme by addressing the following areas:

- Analysis and interpretation of quantitative and qualitative data collected by each local Age UK/Age Concern
- Assess how effectively the pilot sites had delivered on their aims and objectives both individually and comparatively
- Make recommendations on generalising the results to a national service model

### 3. Caring at the End of Life: context and background

#### *Context and background to caring in the UK*

Around six million people provide informal (unpaid) care and support for a spouse, other family member or friend who is frail, ill or disabled across England and Wales (ONS, 2013). Informal care giving can vary from a few hours a week undertaking fairly simple tasks such as shopping, cooking and cleaning or providing at-home respite for another informal carer, to those who provide care for 50 hours per week or more, undertaking more intensive care-giving tasks such as bathing, dressing, toileting and medication. The extent of this informal care-giving has been estimated to save the UK economy more than £119 billion a year (Carers UK, 2013). Given the ageing of the UK population, and policies focused around ageing in place, this economic saving will increase substantially in coming decades – indeed, Pickard (2008) estimates that the demand for informal care will more than double in the next 30 years. Informal care is thus a critically important social policy issue, with successful ageing (and dying) in place, relying significantly on the availability and willingness of people to undertake this informal care. This not only places them at the centre of future health and social care strategies, but indicates that in the UK, informal carers should be viewed as partners in the care of their family member. This, combined with a focus on the home as the preferred site of care, highlights an increasing complexity of relationships between formal and informal care-givers and care recipients focused on the home (Milligan, 2009).

The concept of care with which policy makers are concerned explicitly links care to the place in which it is performed and the social relations through which it is carried out (Milligan, 2009, 27). Informal care is seen as a task that is performed largely (but not exclusively) within the private sphere of the home and through the social relations of kin and community. Often promoted as a 'labour of love', there has been – and continues to be – a gender bias to care-giving. Hence, policies that promote familial responsibility for the care of frail and disabled people can have a disproportionate effect on women. Recent analysis of census data for England and Wales for example, illustrates that overall, the picture remains one in which more women than men undertake informal care, particularly in the 50-64 age groups, and that this can have an adverse impact – not only on their own health and wellbeing, but also on their employment chances as many give up paid work to care (or go part-time). Returning to paid work once the care-recipient has entered residential care or has died can prove problematic – particularly for women in this age group – with knock-on effects for their own socio-economic well-being in later life. Interestingly, this gendered picture shifts amongst those aged 65 and above, where recent figures demonstrate that slightly more men than women undertake a caring role (ONS, 2013).

There are also spatial and socio-economic inequalities attached to informal care-giving (Milligan, 2009). Geographically, Wales and the north of England have the highest numbers of informal carers across England and Wales whilst London has the lowest (in part due to its young age demographic). The south west of England has seen the highest percentage increase in the last decade (ONS, 2013). However, even within these broad regions there is marked geographic variation in who cares and where, that will have a significant impact of the demand for services to support carers.

### *Context and background to End of Life caring*

Family carers provide care to patients during advanced illness and through the process of dying. It is widely recognised that these people have an essential role in providing physical care, emotional and social support, financial resources, advocacy and anticipatory care, and in negotiating and co-ordinating care during the final phases of life (Hudson and Payne, 2008, Grande et al, 2009). The presence of family carers who are able and willing to provide care is essential to facilitate important patient choices, such as place of care and place of death. It is a challenging and demanding role, which few people aspire to, but which many will have thrust upon them, in often difficult circumstances and following a 'crisis'. Undertaking this role may have physical, psychological, social and financial consequences for carers which outlast their period of care and may influence their bereavement. The Department of Health commissioned *Supporting Older Carers Programme* pilot work reflects this recognition and consequently focuses on carers over cared-for people in this grant programme. The challenges carers experience may stem from witnessing the last period of a patients' life with the potential for vicarious distress and suffering, from the direct physical and emotional demands of being a carer or from their own emotional and social changes in bereavement. This creates a complex and 'messy' picture to capture in research.

The Government's *Next Steps for the Carers Strategy* for England, maintains the vision over the next decade, that:

... carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring ... (DOH, 2010:5)

This assertion can be viewed as a national imperative as well-rehearsed demographic changes see people living longer with increasingly complex and multiple health and social care needs. Within the specific context of palliative and end of life (EOL) care the World Health Organisation calls for provision to be extended to families, ensuring their quality of life, ability to cope and bereavement phase are addressed alongside the health and wider needs of patients receiving end of life health services (Hudson and Payne, 2011). Alongside the management of conditions, symptoms and provision of information for people approaching the end of life guidance issued by NICE also acknowledge problems faced by carers at this time:

Families, including children, close friends and informal carers, also experience a range of problems at this time. They play a crucial role and have needs of their own before, during and after the person's death: these too must be addressed.  
<http://publications.nice.org.uk/quality-standard-for-end-of-life-care-for-adults-qs13/introduction-and-overview#introduction>

While the important work that carers contribute is recognised, there is increasing evidence that they are often unprepared for the many demands they might face and that they experience considerable physical, psychological, social and financial challenges (Hudson and Payne 2008). Hence both practical and emotional areas of support were of importance to capture through the carer questionnaires devised for this pilot Programme. Overlying these demands is the dual, and what can be competing, positions for many carers of being both the providers of care, and also the

recipients of services and support (Payne, 2010; Payne and Grande, 2013). Such that the circumstances of family carers and households that are the site of end of life care, are complex locations of personal and emotional distress, familial and social support, and advanced health care provision. Ultimately this dual experience for carers as care providers and receivers is marked by the competing demands to attend to their own health while supporting another with theirs. Within the work of *Supporting Older Carers* there have been many such examples, and also of carers and cared-for people who may alternate in these roles. So strong is this dual experience that it can at times be difficult to identify which person is categorised as carer or cared-for.

The possibilities of a more affirmative experience of family caring, is predicated on carers being able to access a greater number of resources and possessing personal resilience characteristics that support their coping mechanisms (Hudson and Payne, 2011). Increasingly recognised too, is the crucial importance of professionals' communication with carers to ensure their informed, supported and respected involvement in their family member's EOL care (Neuberger, 2013). Without these key components of good communication carers are exposed to distress and what should be avoidable misunderstandings at a poignant life phase for them and their family member.

New models of working with, and offering support to, family carers of those near the end of life are not readily accessible to people designing and developing services, with the result that service providers are often disappointed with the up-take of specific services, or fail to design support that is acceptable, appropriately timed or flexible enough to meet the diverse needs of family carers (O'Brien et al, 2010). Moreover, even when new services appear to be 'successful', the lack of rigorous evaluation and publication means that other providers do not have access to the lessons and important knowledge is not transferred. This potentially wastes limited third sector organisation resources and disadvantages family carers. Recent research has highlighted that despite the implementation of a range of policies, little impact or improvement in the experiences of carers has come about (Hanratty, 2013). There is therefore an urgent need to further inform third sector providers about how best to work with, and for, family carers of those facing the end of life. In this respect the *Supporting Older Carer Programme* placed a strong emphasis on gaining feedback from carers and cared-for people on the services they have received, and from local Age UK workers and volunteers on their provision of such services.

#### 4. Methods

A mixed methods approach provided the organising framework to examine the effectiveness, implementation and maintenance of the *Supporting Older Carers* Programme through Years 2 and 3 (see Table 1, page 1).

Lancaster University research ethics committee approval was gained (21<sup>st</sup> February 2012) for the evaluation following retrospective amendments and adjustments to Age UK designed data collection tools, project information, and the provision of additional supporting documentation. Project monitoring reports were amended and data backdated following these required changes to ensure consistency of information collected across projects from those commencing earlier and later in the funded Programme. Resource implications of ethical approval processes for small scale evaluations are commented on in the concluding section of this report.

The evaluation draws on a range of stakeholder views and experiences, including: older carers and their cared-for family members or friend, Age UK volunteers, pilot coordinators and their managers. A self-evaluation approach to data collection was employed in the six pilot localities with pilot coordinators and volunteers administering questionnaires to older carers, their cared-for older person, and volunteers. Interview questionnaires were completed by a total of 83 individuals in the following breakdown:

Stakeholder	Total in <i>Supporting Older Carers</i> Programme No.	Completed self-evaluation questionnaire No. & %
Older carers	243	58 (24%)
Cared-for person	249	13 (5%)
Volunteers	73	12 (16%)
<b>TOTAL</b>	<b>565</b>	<b>83 (15%)</b>

Observational visits were made by a Lancaster University researcher at which primary data was collected in each location from: 6 pilot coordinators, 6 Age UK managers, and 7 volunteers.

#### 4.1 Data collection

##### *Internal and external data sources:*

A range of data collection and documentary sources were identified to feed in to the evaluation analysis. With the exception of site visit notes and reports, which were compiled by the University researcher, all data were collected and supplied by national Age UK and coordinators and managers of the six pilot projects.

**Table 2: Evaluation data sources**

<b>Data collected by Age UK</b>	<b>Data collected by IOELC</b>
<b>quarterly monitoring forms</b> <i>compiled by pilot project coordinators and managers</i>	<b>reviews with coordinators, volunteers, and local managers</b> <i>conducted by the University researcher</i>
<b>interview questionnaires with older carers and cared-for people</b> <i>completed by pilot project coordinators and volunteers</i>	<b>site visit logs and summary reports from the six pilot projects</b> <i>compiled by the University researcher</i>
<b>interview questionnaires with volunteers delivering interventions</b> <i>completed by pilot project coordinators</i>	<b>agenda, minutes and notes from quarterly national project meetings</b> <i>compiled by the University researcher</i>
<b>case studies on carers supported</b> <i>compiled by pilot project coordinators</i>	<b>conversations with key stakeholders and other local Age UK personnel</b> <i>undertaken by the University researcher</i>

This table shows data sources and data collection responsibilities for the *Supporting Older Carers* Programme. In order to meet the evaluation requirements coordinators needed to become familiar with and administer 18 sets of data collection documents that included:

- For CARERS, BEREAVED CARERS, CARED-FOR PEOPLE and VOLUNTEERS:
  - Information sheets
  - Consent forms
  - Introductory invitation letter
  - Demographic data sheet
  - Questionnaire / interview sheet
  - Guidance paper on conducting questionnaire / interviews

In addition, case study templates were completed profiling their work with older carers and cared-for people, preparation and arrangements for observation site visits were made, and feedback given to validate evaluation summary reports.

*Site visits to pilot projects:*

One site visit to each of the pilot projects was undertaken over one working day per site, at which the researcher met with the project coordinator and their line manager, or other appropriate local Age UK officer, to review the project's inception, management, development, achievements and challenges. The overall purpose of the visits was to build a picture of the projects' local working and organisational context, and to understand individual project development and delivery of support services to older carers in their locality. Coordinators were provided with an outline of the purpose and objectives for the site reviews prior to the researcher's visit, and had the opportunity to provide feedback on the visit schedules. Each post-visit summary report was validated by the coordinator and/or Age UK locality manager.

Site visits were organised and conducted in a manner that reflected the underpinning emphasis of the evaluation as collaborative, participatory, ethically sensitive and constructive (Ingleton et al, 1998). Project coordinators were contacted by email and telephone to ensure arrangements for the day were planned and manageable. Pre-visit schedules were forwarded to ensure expectations were clear, and coordinators were invited to feedback their experience of the visit to fellow pilot coordinators, at whole group project meetings, and to the Programme manager.

Following each site visit a detailed narrative was produced, which provided the context, highlights of the extent to which the pilot project's outcomes were being or were likely to be achieved, identified evidence of the role of volunteers in supporting older carers, reviewed evidence of sustainability, described examples of carer support enhancement, and documented challenges encountered. Account was taken of local needs, specific local priorities and policies, and national Age UK priorities in examining and presenting results of the site visits.

*Questionnaire and survey development:*

The carer's interview questionnaire format utilised for the evaluation was based on the Adult Social Care Outcomes Toolkit (ASCOT), with questions derived from a carer's survey designed by the Personal Social Services Research University (PSSRU) at the University of Kent. Age UK's adaptation of these tools for the older carer's interview questionnaire kept in place the original ASCOT categories and questions relating to carer health and well-being (domains). The adaptations, together with further adjustments following piloting by two projects, resulted in these data collection tools being extensively redrafted. While the changes enabled the development of an appropriate carer's interview questionnaire for the *Supporting Older Carers* evaluation, there was a significant departure from the original validated ASCOT tool and carer's survey. However, confirmation was received from PSSRU that the adapted version utilised many of the survey domain areas and as such they were satisfied that the carer's interview questionnaire could be acknowledged as drawing from the original survey tool. Of particular importance was the retention of the ASCOT style of questions i.e. *consider your situation now, consider the support Age UK has provided, now imagine what would your situation be like without that support?* This was felt to be an

appropriate approach in order to capture impact and outcomes of pilot support for older carers, and where possible attribute change and/or improvements to service intervention.

In utilising a self-evaluation approach to data collection a number of issues are highlighted that impact on data collected by this method. An awareness of these allows incomplete and inaccurate collated data to be anticipated, understood and accommodated. Principally these issues arise through multiple coordinator and volunteer completion of interview questionnaires, and where these data are completed by non-research trained staff. *Supporting Older Carers* project coordinators, who were responsible for collecting all older carer and related stakeholder data in their localities, spoke about the challenges of implementing the range of Programme specific designed interview questionnaires. There was some difficulty in appreciating the relevance of all the carer/cared-for profile questions and coordinators referred to feeling awkward about asking some carers, bereaved carers and cared-for people particular questions, i.e. about sexual orientation and religious beliefs. (National Projects Meeting notes, 16.11.11).

A complex coding schema was introduced mid-Programme which necessitated retrospective coding of all carers supported from the outset of each pilot project. This required the 4 operational projects at the time to retrospectively code carer information. The schema was in place when the final 2 pilot projects joined the Programme. Fulfilling the evaluation requirements was a standing agenda item for national meetings. There was an impression that the evaluation requirements were a burden to the coordinator role in that Age UK workers understandably wished to prioritise their work with older carers and not on completing evaluation tasks. However, there was also an appreciation of the longer term gains of capturing the work of their project service. The following issues were raised and experienced by coordinators in varying degrees:

1. Conflict and awkwardness in the *dual role* of conducting *service feed-back* interviews with users, while being *providers* of that service
2. Variable *approaches* to data gathering, and variable *completion* of interview questionnaires
3. The *range* and *complexity* of interview questionnaires
4. The complexity of *coding* of carer scenarios and relationships

#### *Database development:*

An Access database was designed by the Lancaster University researcher and Information Officer for IOELC, to capture and collate pilot project, volunteer and carer/cared-for demographic information, service provision data, together with Programme progress, milestones, and outcomes. Quantitative and qualitative data from each of the 6 pilot projects was received and entered by national Age UK staff. The database as an evaluation output also serves as a whole Programme dataset allowing the funders to extract information, scrutinise Programme elements, and

undertake further analysis beyond the limitations of the small scale independent evaluation. See Appendix 1, page 61 for Access database structure.

Database value (for evaluation funders):

1. collation of whole Programme data and information (qualitative and quantitative) into a single software database (Microsoft Access)
2. retrospective scrutiny of whole Programme data for Service and Policy development
3. database model available as template for future national service evaluations

Database limitations (for evaluation research):

1. *complexity* of the database to enable multiple interview questionnaire data input, which was not possible to anticipate prior to the commencement of the Lancaster University evaluation
2. self-evaluation approach reliant on pilot collected data by non-researchers with gaps, inconsistencies and *limited contents to open-ended question* areas giving rise to limited qualitative data material
3. development and employment of a *large cross-comparative database* for analysis in a small-scale evaluation

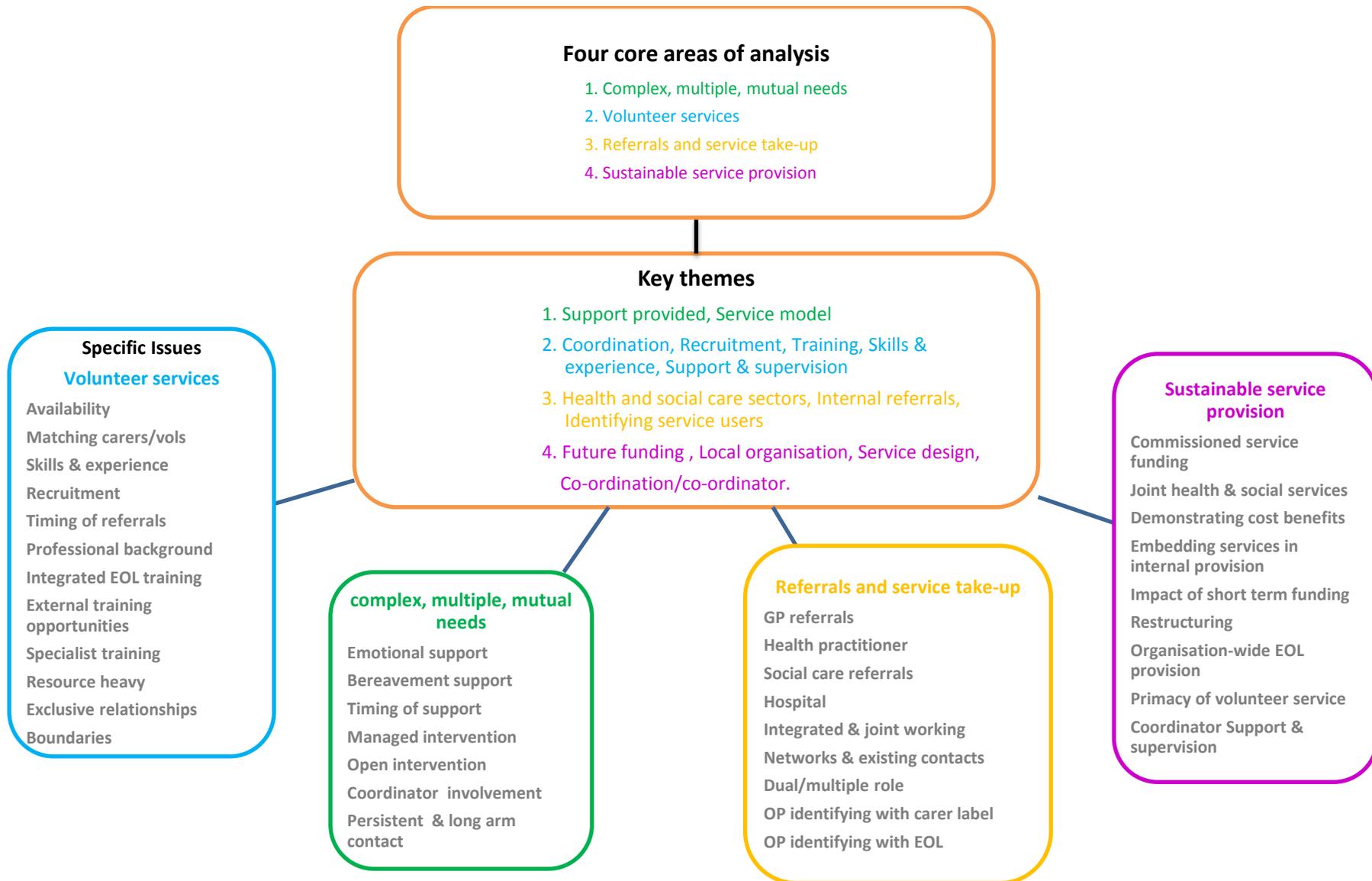
#### *4.2 Data analysis & integration*

Data analysis gave primacy to qualitative data and findings, with secondary supporting quantitative analysis. This approach reflected the importance placed on in-depth understandings in order to privilege older carer experiences of end of life support. This pragmatic approach also aimed at achieving balance between the quality and complexity of data collection tools within the size and scale of the funded evaluation.

Quantitative data collated in the above multiple project Access database was exported to SPSS to provide cross-comparative descriptive statistical analysis of whole Programme data. This enabled presentation of pilot project and service user profile data (for older carers, cared-for people and volunteers), and services delivered through the *Supporting Older Carers* Programme.

Synthesis and analysis of qualitative data was undertaken on a range of data sets and sources (see Table 2: *Evaluation data sources*, page 8), at individual pilot project level and across-cases at Programme level. This captured: project context, activity, and older carer, cared-for and volunteer outcomes. Initial and emergent areas of analysis were identified through the examination of: a priori issues, evaluation site visit summary reports, evolving project/Programme dialogue, and supplementary documents. An analysis framework was constructed within which thematic content analysis identified: *core areas of analysis* and *key themes*. Within these *specific issues* were identified and *empirically illustrated*. See coding framework below in Table 3.

**Table 3: Qualitative data analysis coding framework**



## 5. Pilot Project Profiles

### 5.1 Summary details

**Table 4:** Pilot projects: local team composition, funding period, referrals received, volunteers recruited

Project name & Location	Local Age UK pilot team	Funding period (months)	Older Carer Referrals received (n)	Volunteers recruited (n)	
Kingston upon Thames (KUT)	Pilot coordinator (21hrs wk) Business Support worker (10hrs wk) Line manager	24	19	6	
Lancashire (LANCS)	Pilot coordinator (21hrs wk) Line manager	12	19	6	
Leeds (LDS)	Pilot coordinator (17.5hrs wk) Line manager	36	60	29	
Leicester, Shire and Rutland (LSR)	Pilot coordinator (18hrs wk) Line manager	24	72	9	
Oxford (OX)	Pilot coordinator (variable part time hrs wk) Line manager	12	20	12	
South Tyneside (ST)	Pilot coordinator (17.5hrs wk) Line manager	36	53	11	
<b>TOTALS</b>			<b>243</b>	<b>73</b>	

## 5.2 Older Carers supported

**Table 5:** Age, Gender, Ethnicity

	Carers		Cared-for		TOTAL	
	(n)	%	(n)	%	(n)	%
<b>Age</b>						
Under 50	16	6.6	5	2.0	21	4.3
50-64	84	34.6	31	12.4	115	23.4
65-74	51	21.0	50	20.1	101	20.5
75-84	64	26.3	102	41.0	166	33.7
85-94	26	10.7	53	21.3	79	16.1
95+	2	0.8	6	2.4	8	1.6
Missing data	0	0.0	2	0.8	2	0.4
<b>Gender</b>	(n)	%	(n)	%	(n)	%
Female	126	51.9	76	30.5	202	41.1
Male	54	22.2	106	42.6	160	32.5
Missing data	63	25.9	67	26.9	130	26.4
<b>Ethnicity</b>	(n)	%	(n)	%	(n)	%
Asian	1	0.4	2	0.8	3	0.6
Black	3	1.2	3	1.2	6	1.2
Mixed	2	0.8	3	1.2	5	1.0
White	233	95.9	229	92.0	462	93.9
Any other	4	1.6	7	2.8	11	2.2
Missing data	0	0.0	5	2.0	5	1.0

Within the *Supporting Older Carers* Programme approximately half of older carers supported by the pilot projects were aged between 65 and 84 years (47.3%), with more than one quarter over the age of 75 years (26.3%), and of these 28 carers were over 85 years. Over half of the total number of cared-for people supported by older carers were 75 years and above (161 in total). Of the carers and cared-for people worked with, 4.3% were under the age of 50 years (see footnote page 2). A total of 8 carers and cared-for people were over the age of 95 years; 2 carers and 6 cared-for people.

A majority of older carers were female (51%), with 22.2% being male\*. A slightly larger proportion of cared-for people were male (42.6%) than female (30.5%\*). The pilot projects predominately worked with older carers and cared-for people from White ethnic background/s, while a total of 2.4% of carers and 3.2% of cared-for people were classified in Asian, Black or Mixed ethnic groups.

\*Missing data should be noted in the categories of gender and ethnicity.

**Table 6:** Age self-reported disabled, registered carer with GP, living same address

	Carers		Cared-for		TOTAL	
	(n)	%	(n)	%	(n)	%
<b>Disability</b>						
Yes	35	14.4	155	62.2	190	38.6
no	208	85.6	94	37.8	302	61.4
<b>Registered Carer</b>	(n)			%	(n)	
Don't know	4	1.6	0	0.0	4	0.8
No	40	16.5	4	1.6	44	8.9
Missing data	199	81.9	245	98.4	444	90.2
<b>At same address</b>	(n)			%	(n)	
Yes	196	80.7	216	86.7	412	83.7
No	47	19.3	33	13.3	80	16.3

Reported disabilities were low in the overall carer and cared-for total, with 38.6% in total classified as having a disability; 14.4% of carers and 62.2% of cared-for people. Where recorded, older carers were noted as not registered by their GP as a carer. The majority (83.7%) of carers and cared-for people lived at the same address, although a total of 47 carers in the Programme did not.

## 6. Findings

This section begins with descriptive data showing older carer reported perceived benefits of receiving support from the Age UK pilot projects. The areas and range of these services are also presented. Following this service evaluation findings are presented within four overarching themes:

- The complex, multiple needs of older carers accessing specialist end of life support services
- Priorities and responsibilities for volunteer provision of specialist end of life support services
- The benefits to users of specialist end of life support services for older carers and their cared-for family members
- The obstacles and challenges faced by local Age UK groups and organisations in establishing and developing specialist end of life support services

A key emphasis from the findings is the particular and related nature of the support needs of older service users *and* the volunteers engaged by each pilot project to work with them, in the area of end of life support. While varied in their duration of operation and service provision approach, each pilot project acknowledged the complex and special needs of older carers facing the end of life of an older family member. In a similar way, volunteers working in this area had particular support needs, and local Age UK organisations experienced challenges in setting up and maintaining volunteer involvement in this sphere of their work.

The staggered funding duration of the *Supporting Older Carers of Those Nearing the End of Life* Programme saw differential project start-up approaches and evolving, individual timeframes to service take up and delivery. Across the pilots however, common experiences were identified in the challenges faced, particularly in the areas of volunteer recruitment and referrals of older carers for support.

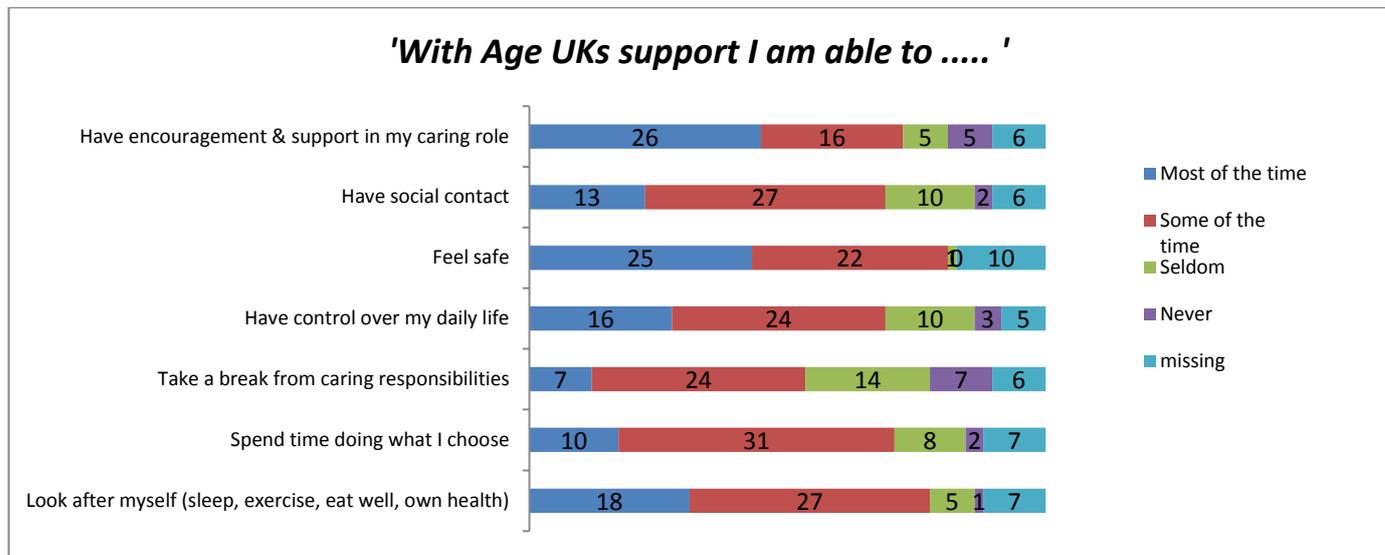
Case study examples are drawn upon to illustrate the points and issues raised in this section. Names used in these, together with direct quotations, have been changed to maintain anonymity of research participants.

### 6.1 Carer Benefits: pilot project impact areas

#### 6.1.1 Older carer perceptions of support received

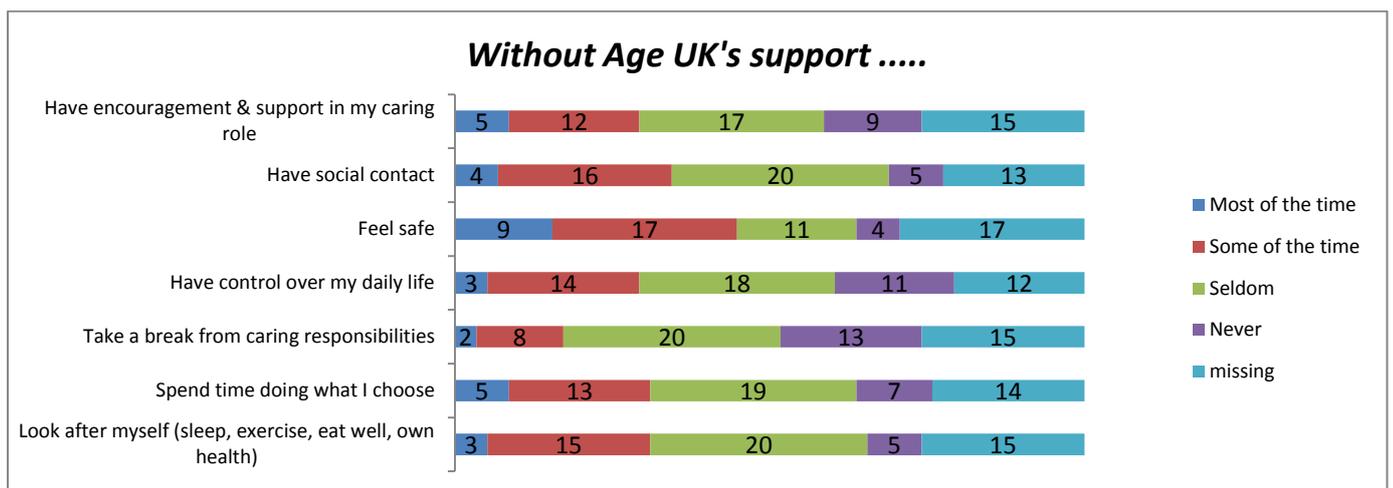
Data from interview questionnaires administered to 58 older carers show how local Age UK projects supported older carers in the seven domains originating from the ASCOT carer survey. Table 7, captures carer perceptions and experiences in these areas at the time of receiving support, and Table 8 shows responses to a reflective question covering the same domains, had the carer been without Age UK support. A final Table 9 shows older carer's views on whether Age UK's support helped them.

**Table 7: Older carer perceptions at the time of receiving support from *Supporting Older Carer* pilot services**



Through receiving Age UK's *Supporting Older Carers'* service the majority of older carers responded positively to feeling supported in the seven care related domains for most or some of the time, particularly in feeling encouraged and supported in their caring role, feeling safe, and being able to look after aspects of their own needs. To a lesser degree older carers reported being able to take a break from their caring role, or to feel control in their daily lives.

**Table 8: Older carer perceptions of aspects of their caring role and lives *without* support from *Supporting Older Carer* pilot services**

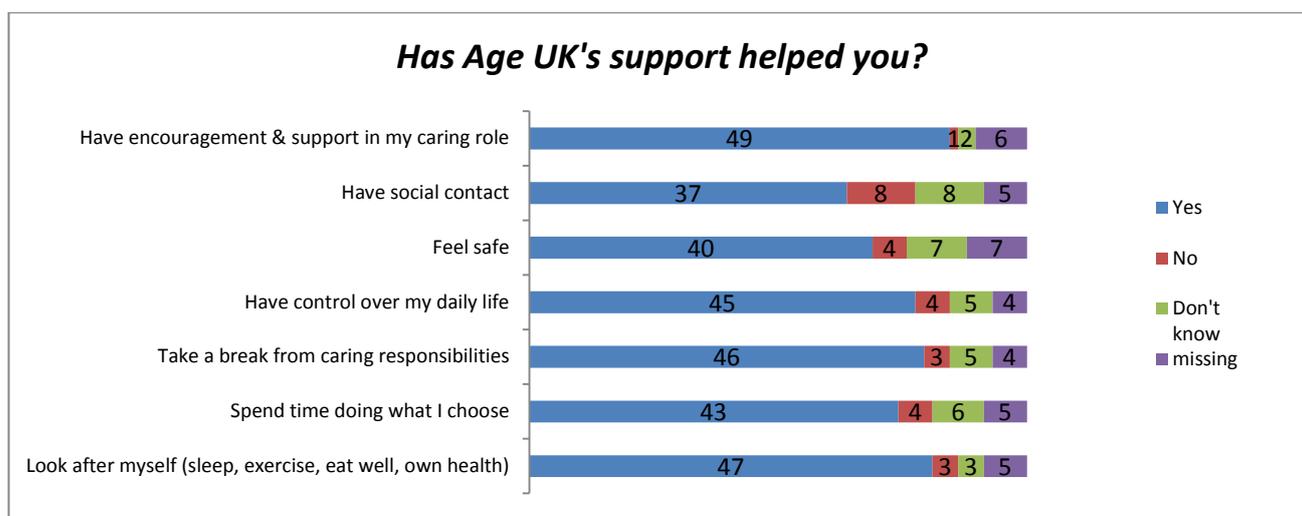


The above table shows older carers responses when they considered their caring roles and lives without Age UK support. In the main it shows they would feel less supported, believing they would for most, some of the time, or seldom be able to look after aspects of their own needs. Similarly, older carers reported that they would be less able to take a break from their caring responsibilities, choose how they spent their

time, or have control over their daily lives, without the *Supporting Older Carer's* service.

The final table below indicates how older carers responded to the question *Has Age UK's support helped you?* again in the seven questionnaire domains. Overwhelmingly it can be seen that older carers believed they had been helped, and as a result benefit has been experienced in the range of aspects to their caring roles and lives.

**Table 9: Older carer perceptions of help received through *Supporting Older Carer* pilot services**



6.1.2 Emotional, practical, information and advice support

Support provided by pilot projects was broadly categorised into three spheres as set out in the *Supporting Older Carers Programme* objectives. Table 10 lists the range of the main support activities undertaken by coordinators and volunteers across the six local Age UK organisations.

**Table 10: Spheres of support of pilot projects**

Sphere of support	Range of support described by pilot projects
<b>Practical</b>	Falls prevention advice; transport assistance; respite sitting service; referral to handy person scheme, seated exercise, health trainer, Time 4 You, I & A, GPs, district nurse teams, occupational therapist, Stroke Association ; Christmas hamper scheme.
<b>Information and Advice</b>	Welfare benefits check; Disability benefits advice; Pension credit advice; Attendance Allowance applications; Welfare benefit appeals; Carers grant applications; Council Tax advice; care charges, Appointeeship; Power of Attorney; signposting to external services; health care complaint; residential care charges; Advanced Directives and care planning; volunteering opportunities.
<b>Emotional</b>	Telephone support, home visits, befriending; coffee morning groups; bereavement support groups; bereavement support 1:1; introduction to social groups; Christmas lunch; advocacy.

## SECTION 6.2 SUMMARY KEY MESSAGES

- Older carer's often have complex and multiple needs that co-exist with their cared-for relative's complex health and welfare circumstances
  - Decline or crises in health prevents older carers from fulfilling their caregiving role
  - Reciprocal and changeable caregiving may often exist within same household caring relationships
  - Multiple caregiving roles exist whereby older carers can be supporting spouses, siblings, their children or their sibling's children, within their own households and in other households
  - Older carers may have lifelong and shifting carer roles for now aged family members with enduring health conditions or disabilities
- 

### *6.2 Complex, multiple, mutual needs*

The needs of older carers supported by the pilot projects can be characterised as complex, multiple, and in many incidences, co-existing with the cared-for person's needs. Older carers accessing the pilot projects experienced a range of health related conditions or difficulties, well-being issues, or social problems.

Multiple older carer needs existed in relation to the cared-for person's own health and well-being needs. It was commonly the case that older carers accessing the end of life pilot projects for support in their caring role can be described as having their own specific health needs. These impact on different areas of their lives, while at the same time existing in relation to, and within the context of, fulfilling a carer role for an older family member.

#### Case 1

Two brothers living together, the younger brother Mr C has a primary caring role for his older brother Mr D of 73 years of age. The older brother has a diagnosis of cancer and attends the local hospice regularly. The carer brother has diabetes, a chronic organ disease requiring surgery, and joint problems causing considerable pain, with imminent planned joint replacement surgery. Mr C is prescribed specialised treatment that cannot be obtained from his GP or local hospital and he travels by taxi to another hospital at some distance to obtain this. Mr C experiences sleep problems and feelings of being unable to cope as his own and his brother's health deteriorates. He has been asked to complete an employment assessment form to evaluate how his illness will affect his ability to work, which is also causing him further stress and worry. Mr D takes a caring role for Mr C during periods of his health improvement.

*(ST, Dec 2012)*

### Case 2

Mr B is 73 years and is primary carer for his wife who is also 73 years of age. Mr B is awaiting heart surgery and struggles with mobility because of his heart condition. Mrs B has terminal cancer and symptoms of dementia. She is in hospital awaiting discharge to their new home. The pressures of caring have added to Mr B's own health concerns leaving him feeling very stressed, which compounds his health issues.  
(LDS, Sep 2011)

A further case example illustrates how older carers' health needs may develop to a level of seriousness that prevents them from fulfilling their caregiving role. The example portrays the complex circumstances of multiple need for some older carers who maintain the 'carer' title and status for a family member, while this role may be suspended by virtue of their own health or treatment requirements. There were further examples within the pilot projects of similar scenarios where older carers were supported in establishing care for their family member, while they themselves accessed services e.g. for hospitalisation.

### Case 3

Mrs A, 85 years, is long-term carer for her partner of 87 years of age. He suffers from depression and mobility difficulties. Mrs A has visual impairment and a diagnosis of lung cancer for which she received a course of chemotherapy. Mr A had respite care during her treatment period. This was a source of great distress for Mrs A. Mr A died within a few months of Mrs A's own health declining, when she was in receipt of hospice care.  
(KUT, Sept 2012)

The following case example illustrates how carer roles can be mutual and shift in their giving and receiving dimensions through fluctuations in the health needs of each individual.

### Case 4

Mrs E has cared for her husband Mr E who has dementia, for approximately 2 years. Prior to this Mrs E was cared for by Mr E following a stroke. Mrs E was recently diagnosed with cancer and requires hospital inpatient treatment. Mr E has a planned care home respite stay arranged for the duration of her hospital admission and her recuperation afterwards.  
(KUT, Mar 2012).

Further to the above, older carer needs changed over the duration of support input. It was more usual for increased levels of support from projects to be required over time, although decreased levels of support following initial input was also seen. In one case an older carer of three family members was referred to a seated exercise class to address some health needs and provide time away from her caregiving responsibilities. The pilot coordinator was anticipating that more intense support would be required in the future given the carer demands in this scenario, and the carer was reassured that the service would be there for her in this eventuality. Some older carers developed confidence in project coordinators through initially being provided practical support, which consequently engendered reassurance and trust encouraging further requests for assistance, as the following case example illustrates:

#### Case 5

Mrs I, 71 years, was initially helped by the project coordinator to resolve a plumbing problem. Occasional contact was maintained by the coordinator to enable the older carer to contact her in the future. Mrs I did this when she had fallen in her home and awaited the paramedics she had called. Mrs I was anxious about what would happen to her husband Mr I, who was diagnosed with Parkinson's disease and cancer. The coordinator stayed with Mr I while the GP attended to make an assessment and she was admitted to hospital.

*(ST, Jul 2011)*

Conversely, focused and specific input support for some older carers was sufficient to resolve issues and more limited contact followed. One such older carer looked after his wife who had Parkinson's disease and increasing mobility difficulties. He was anxious about managing shopping trips when she needed to use a wheelchair for such excursions. A project volunteer accompanied them on two such trips, which enabled Mr X to feel confident enough to make further shopping trips unaided.

The complex nature of individual older carer experiences was also seen in the area of family circumstances, dynamics and relationships, indicating that the specific circumstances of older carers providing end of life care do not exist in a social vacuum or necessarily in single-situation scenarios. While in the main, caregiving stories involved dyad relationships, it was not uncommon to hear about older carers fulfilling a carer role to more than one person in their immediate household and/or close family. The complex and multiple demands faced by older carers in such situations are evident in the following case example:

### Case 6

Mrs O, 65 years of age, is primary carer for her husband also 65 years who receives palliative care for a cancer illness, and her adult disabled son who lives at home with them. She is also carer to her mother with a diagnosis of dementia, who is being requested by social services to return home following a recent admission for respite care. In addition, Mrs O supports her brother who lives in residential care.  
(LSR, Mar 2012)

For other older carers there may have been life-long carer roles for family members with enduring health conditions and disabilities. In these situations, older carers may find that they fulfil a care and support role in what are intricate and competing needs of increasing frail parents, siblings, relatives and family members, who may include ageing cared-for people who live with long term disabilities. Two older carer scenarios provide insights into the multi-generational and relational circumstances of some contemporary caregiving roles and relationships:

### Case 7

Mrs F of 88 years is primary carer for her eldest sister of 99 years, another sister of 95 years, and a nephew of 77 years of age. The elder sister, currently a hospital inpatient, will be discharged soon. She, her younger sister and nephew live together, while Mrs F resides in sheltered accommodation. Mrs F is the first line carer contact for all her relatives.  
(ST, Jun 2011)

### Case 8

Mrs G 71 years cares for Ms H, her sister of 64 years, who has a diagnosis of two cancer illnesses. Ms H has learning and physical disabilities and has received life-long care from Mrs G. In addition, Mrs G cared for another sister, also diagnosed with a learning disability, until her death some years previously, and both parents who she more recently nursed through terminal illnesses, until their death.  
(LDS, Sep 2012)

Within a context of these varied, complex, multiple, and sometimes reciprocal caregiving scenarios, it was not uncommon for pilot coordinators to report little existing statutory health or social care services support being in place for older carers at the point of referral to their project. If formal support was in place at the end of life

phase, and projects reported that this was *not* the case for several referrals, there was an emphasis on provision for the cared-for person in isolation of their older carer. One such instance captures the intense and significant needs of an older carer supporting someone at home at the end of life without provision for her husband or herself:

#### Case 9

Mrs J 69 years, primary carer for her husband Mr J of 75 years diagnosed with cancer and acute heart failure, had supported her husband in his decision to discharge himself from hospital as he wanted to die at home. This was a sudden decision and no services were in place on his arrival home or planned for his future care. Mrs J sat up with him every night as he could not be left unattended. The carer was exhausted. The following interventions were quickly put in place by the pilot project: benefits check and completion of Attendance Allowance forms; referral to social services for assessment for a care package; referral to Marie Curie night sitting services; 2 volunteer visits for 2 hours twice a week to sit with Mr J allowing Mrs J some time to herself. Mr J died within a few days of these arrangements having been made.

*LANCS, (Sept 2012)*

With the older carer profiles highlighted in this section typifying the issues and needs worked with, over the lifetime of the Programme pilot projects came to view their service as providing specialist level support. This was the case when supporting older carers in their active care of a family member, as it was also for those older carers previously in the role and now bereaved.

### 6.3 End of Life Support: emotional, befriending, and bereavement support

#### SECTION 6.3 SUMMARY KEY MESSAGES

- Emotional support underpins all forms of contact with older carers
- Emotional support often emerges as a secondary dimension to practical assistance needs
- Befriending and friendship support provided assistive contact, while enabling older carers to share the value of mutually meaningful relationships with coordinators and volunteers
- Coordinators signpost to a range of health, social care and voluntary services. They are especially well placed to access other services provided by local Age UK organisations
- Maintaining soft contact with older carers over time to enable contact or re-engagement at the point of increased need, and following loss and bereavement particularly for some carers

The objectives of the *Supporting Older Carers of Those Nearing the End of Life* Programme proposed practical and emotional support as key areas of provision. As the Programme progressed it was apparent that while practical support may be an area of need addressed by the pilot projects for some older carers, an element of emotional support was required for almost all older carers regardless of the original reason for referral. Services giving practical help, such as help with gardening, may be put in place, however, it was more often likely that this was an initial top layer of need that presented for support, through which further areas of support were revealed upon a full assessment of need.

A range of potential areas of practical support were identified that the pilot projects could provide, including: shopping, ironing, cleaning, small DIY, preparing meals, gardening, befriending and signposting to other organisations. Of this prospective list, befriending and signposting to internal and external services and resources, emerged as key support areas.

#### *6.3.1. Befriending, friendship, and signposting services*

We use the term 'friendship' in addition to 'befriending' in this section to reflect a more recent emphasis on **meaningful supportive relationships** (Age UK, 2009). As a less paternalistic approach this recognises not only the targeted support gained by the recipient, but importantly the sense of value experienced through their contribution to the relationship, as recognised in a recent Age UK evaluation of telephone befriending services:

... for the older people it was the caring attitude of the befrienders and the feelings that this engendered in them, *knowing that they mattered to someone*, which was especially important. (Age UK, 2009:6, our emphasis)

Such *friendship* support may comprise different components, including social support, company, and a 'listening ear'. In this evaluation, an older carer in their own words reflects the value and a sense of mutuality in the relationship they experienced through one pilot project:

***"You have been the hand of friendship ... It's been good to have the phone call and meet for coffee. Truly amazing. Only support I had. You actually cared."***

(Older Carer, ST81)

Through friendship support we see a breadth of ways in which older carers were supported emotionally in different aspects of their caregiving roles, and also in the caregiving relationship between carer and cared-for, as the extended case study shows:

### Case 10

Mrs. X, 71 years, has been the main carer for her husband, who is 73 for many years. He has Parkinson's disease, which has now reached the end stages. He also has ischaemic heart disease. His health has declined rapidly and as a consequence he now lives full time on the ground floor of the house with adaptations to meet his needs. Both Mr and Mrs X are aware of his limited life expectancy, and he is supported by the local palliative care team.

Mr and Mrs X moved some considerable distance to be closer to their daughter. However, it also meant that they were in an area they no longer knew well. Mrs X in particular felt socially isolated and was increasingly aware that her role as a main carer was restricting her ability to get to know the area and to make new friends, which was particularly important as she faced a future by herself. The strain on Mrs X was affecting her mood, which in turn added to Mr X's anxieties, as he felt guilty about the impact of his care needs on his wife's well-being. There were growing tensions in their relationship.

Mrs X identified that she would like to have a break and a chance to leave the home and feel refreshed, while getting to know her local area. Mrs X was concerned however that her husband, a man with a lively and intelligent mind, had more than just a sitting service while she was out. She wanted to know that he was also having an enjoyable time, so that she could enjoy her free space without feeling guilty

A volunteer and service user match was established, whereby shared interests, personalities and lifestyles were assessed as being a 'good fit', and 3 hour, weekly visits organised. Mr X and the volunteer immediately struck up a strong friendship and discovered common interests in art, family history and caravanning. Mrs X, satisfied that her husband was having an enjoyable time with the befriender, used the time to go out, go to shops, and meet friends or her daughter for coffee. Crucially, she had space and time to attend to her own needs instead of her husband's. Her mood improved and she described feeling more like her old self. She was more able to exercise patience in her relationship with her husband, who, in turn, became less worried about his wife and less of a sense of burden to her. The tensions in their relationship lessened.

Mr. X discovered, at a time in his life when he thought he would have very few new experiences that he had made a new friend, realising that he could offer something to a friendship as well as receiving from it.

*(OX, Sept 2012)*

It was noted earlier that an element of emotional support was likely in all aspects of targeted support and intervention, with this often emerging as a secondary dimension to an original referral for practical assistance.

An example is Mrs I's urgent call to a coordinator for assistance following a fall for which she needed to find someone to look after her cared-for husband while she was taken to a local hospital (see case details page 22). A trusting, emotional connection and relationship with the coordinator developed that enabled the older carer to seek support beyond the practical assistance she had originally received, when the coordinator helped to resolve plumbing problems in her home. Mrs I's first thought had been to contact the pilot coordinator, as she had not known anyone else she could have called on in this way. The pilot coordinator had maintained contact with Mrs I over some time, having originally referred her to the Age UK household maintenance service, through an occasional telephone call to check on her circumstances and how she was managing with the care of her husband who had cancer and Parkinson's disease. The coordinator commented:

*"Mrs I expressed how she values the regular contact we have maintained since she accessed the service in January. We have established trust and a good rapport together. This has helped her cope with the emotional rollercoaster she has experienced around her husband's health and the occasions when he has been near to dying."*  
(Case study July 2011 ST)

Instances of similar, emergent emotional support needs following referrals for practical assistance appear in Table 11:

**Table 11: Emergent emotional support needs**

<b>Primary referral for practical assistance:</b>	<b>Subsequent, secondary emotional component to needs:</b>
<p><b>Gas disconnection for safety reasons for a cared-for person with dementia.</b></p> <p><i>Dec 2012, LDS</i></p>	<p>Extra help [daily paid carer visits and hot meals] allowing the carer more time for herself and encouragement to offload her problems to an independent listener.</p>
<p><b>Arrangements for a bed to be installed in a downstairs, accessible room.</b></p> <p><i>June 2012, LDS</i></p>	<p>Volunteer relationship established trust and acceptance, leading to further aids and adaptations being accepted in the home.<sup>3</sup></p>
<p><b>Assistance to register the death of a cared-for family member.</b></p> <p><i>June 2012, LSR</i></p>	<p>Access to interpreter service, support with funeral arrangements, advocacy support with hospital in-patient services, support to access church-led social support service.</p>
<p><b>Assistance to move to a new ground floor flat.</b></p> <p><i>Sept 2011, LDS</i></p>	<p>Supported older carer to liaise with nursing home and with the hospital discharge of cared-for family member with terminal cancer and dementia. Visited carer in hospital following operation, and his cared-for relative in respite care during his in-patient admission.</p>
<p><b>Help with the garden.</b></p> <p><i>Sept 2012, KUT</i></p>	<p>On-going telephone contact and support through cared-for relative's decline in-health and death, and then during the older carer's own increasing debility.</p>
<p><b>Volunteer transport to visit cared-for relative in hospital.</b></p> <p><i>Sept 2012, LSR</i></p>	<p>Older carer recently bereaved when spouse died, now caring for father. Loss of confidence and struggling with further imminent loss. Volunteer accompanies carer on hospital visits and offers companionship. Coordinator gives on-going telephone contact and support. Access to a Carer's Group.</p>

A feature of these scenarios is the **coordinators' continued contact with older carers over time**, whether this was on a regular or infrequent basis, in person or through telephone calls. Often sensitive, careful, and persistent contact maintained a connection with older carers through difficult times, or until the older carer felt ready to accept further support, realising how this could benefit themselves and their cared-for

family member. At two pilot projects (LSR, LANCS) coordinators particularly spoke about having referrals where minimal support was initially requested or taken up.

**Maintaining 'soft' contact over time**, (e.g. occasional telephone or drop-in visits) enabled older carers to re-establish contact at times of future need, for example following bereavement.

Coordinators believed the **timing of offers of support and assistance was of particular importance** too. Instigating contact in close proximity to the end of life of a family member could prove too much for older carers who may already be receiving visits from health practitioners, with a number of professionals already involved in nursing, medical and palliative care. One project manager described challenges of having provided a previous service to older people and their carers in the last 72 hours of life, reflecting that this had been found to be 'too late, too intense ... the wrong time'. The *Supporting Older Carers* project had re-emphasised for this manager the significance of timeliness, and how prior established relationships facilitate support at the time of end of life, if this is needed, and through into later bereavement. The intensity of an end of life phase is evident in the following coordinator's description of an older carer whose wife was receiving hospice care:

*"He spoke of spending all his time at the hospice and also with his daughters. He was naturally extremely distressed but he wanted to be in contact with the [pilot project], but felt he could not take on a new relationship with a volunteer."* (Coordinator, KUT)

Timeliness of support and intervention was evident through the way pilot project's developed their service and how it evolved over the funded period. Further discussion of models of service provision appear in Section 6.5 of this report. In relation to the timing and development of befriending and friendship support, we note the persistent and long arm contact with older carers maintained by coordinators, which also required a flexible, adaptive approach to meet uncertain and changing circumstances characteristic of end of life caregiving. This involvement also recognised the trajectory from active carer to bereaved carer that older carers would likely follow over the course of the pilot involvement in their support. In this way **timeliness**, **'soft contact'**, and **persistence** were elements of befriending and friendship support that addressed a number of purposes. We use the term 'soft contact' to refer to *open, on-going and flexible contact* maintained with an older carer that facilitates later access and take-up of services.

- To establish trust, rapport and a supporting relationship e.g. where a carer was reluctant or felt unable to accept support as a result of their challenged circumstances (lack of entitlement, too exhausted, complying with objections to support from cared-for person)
- To maintain contact while developing future supporting relationships e.g. where support is not currently needed but may be requested following bereavement
- At the request of older carers wanting light touch contact e.g. where the older carer requests occasional telephone contact, but not more active support
- To maintain peripheral contact when existing multiple services are involved, in readiness for bereavement
- To monitor the caring scenario

- To assess change in circumstances, increasing need, social isolation, and onward referrals to other services

Signposting and onward referral to other services and organisations was an important role of the pilot projects. This included referrals to other local Age UK services within their own organisations or to external health, social care and voluntary services. A diversity of services were available at each local Age UK organisation, with pilot coordinators able to refer to home help, gardening and handyman projects, hospital after care and befriending services, and other specific locally funded projects.

There was a particular benefit of the pilot project's proximity to financial advice, either through referral to Age UK Advice and Information services, through the coordinator role being closely linked to this sphere of work, or in the location of these services in the same offices. For example, one coordinator had combined coordinator roles working part time for both services, others had previous experience of welfare benefits advice, and all had close liaison and working relationships with the Advice and Information coordinators in their local Age UKs. In addition to welfare benefit advice, and support with benefit claim applications, financial support was also provided in: managing general finances and household bills, pensions, and insurances. Coordinators both referred onto other agencies for welfare benefits assistance and also assisted older carers with form filling and submitting claims, for example Attendance Allowance, disability living allowance and car badges.

Referrals to outside agencies included those within health and social services sectors and to other voluntary agencies. These ranged from specialist palliative care nurses and hospice services, for social services assessments and equipment, church groups, carers groups and respite services, and specific volunteer services e.g. Alzheimer's Society, The Cinnamon Trust for dog walking, and smoking cessation support.

### 6.3.2. Bereavement services

Through the evaluation phase of the Programme *Supporting Older Carer* pilot projects worked with 49 older carers who became bereaved while referred to their service. Support provided included direct bereavement support (emotional and practical), and referral to dedicated bereavement services in the locality. For bereaved carers supported by the pilot projects help with welfare benefits was most often requested. The forms of emotional support older carers identified as the most helpful were having someone to listen, or someone to talk to on the telephone. Fewer older carers requested befriending post-bereavement or to join bereavement groups. The way in which individual support following bereavement was valued is evident in one older carer's appreciative comments about the contact she had with a pilot coordinator:

*"People need this project as other services stop all contact after you are no longer a carer. At this time you need family and friends but you also need the right person to talk to and that's you [COORDINATOR NAME]. I can count on you – you're there for me"*

(Older carer ST215b)

This carer highlights an experience observed by pilot coordinators, that health and social care services that have been in place through the end of life and palliative care

phase cease following the death of a relative or friend. Older carers can find their daily lives suddenly change from the intense time of multiple health professional visits and active caregiving for their dying relative or friend. These losses may also be marked for some by loss of contact with family, neighbours, health and care practitioners that had been in place for the cared-for person. As another carer relayed:

*“If you didn’t come, I wouldn’t see anyone.”*

(Older Carer, ST37)

These experiences reflect similar recent empirical research data, where a carer talked about missing the district nurses when they no longer visited to care for their dying relative. She described having found this very hard having grown so close to them. Recommendations from this research include follow-up bereavement support by a key worker who gets to know carers and family members in order to offer support before death *and* afterwards (Payne et al, 2013).

In contrast other older carers did not wish for post-bereavement contact with the pilot projects explaining they felt they did not need this or that they had help from family and friends:

*“I am a very independent person so I have never asked for any of these things, I am very fortunate to have a fantastic and supportive family.”*

(Older Carer, KUT35)

However, coordinators agreed that an established pre-bereavement relationship was a crucial factor in how post-bereavement support was accepted by an older carer. This is a further way in which the *timeliness* and *maintenance over time* of pilot project contact with older carers can be seen to impact on access to services and support.

Specialist support provided by the pilot coordinators and volunteers again illustrates, as discussed above, the emotional support that results from assistance with practical issues facing some older bereaved carers. One such carer, bereaved twice in 4 months through the death of her husband and a son, was assisted with complex financial and bill payments, and gained crucial reassurance following two losses in such a short time:

*“I’m so grateful to have this service and feel relieved that everything is sorted. It has made a difference as I have felt so worried and afraid.”*

(Older Carer, ST case study Sept 2012)

As the illustrative case study that follows shows, specialist older carer bereavement support can be characterised by the need for help and assistance with practical, emotional and social dimensions of need. The pilot projects enabled this either through direct support and input to an older carer, or through facilitating access to other services. Located as they were within local Age UKs they were especially well placed to directly access and dovetail other services within their organisations to build a wider supportive approach for older carers of those at the end of life. The following case example illustrates a number of the areas addressed in this section, by capturing the benefits of: **pre and post bereavement** contact and **relationships** with older carers; the importance of **maintaining relationships over time**; and the value and meaningfulness experienced by older carers in **befriending and friendship relationships**:

### Case 11

Mr P, 83yrs, cared for his wife, 82yrs, who had been diagnosed with dementia 2 years previously. They regularly attended a dementia club held in the organisation's building. They had also accessed welfare benefit advice, and information about wills and power of attorney from the Information & Advice (I&A) service, in addition to help from the Handyperson and Help @ Home services. Mr P frequently spoke of how invaluable the support was that he and his wife received from these services. Following admission to hospital and a diagnosis of blood cancer, Mrs P rapidly deteriorated and died within 5 days of being transferred to a hospice. Mr P was supported by his children following the loss of his wife, but he kept in frequent contact with the pilot project. Although Mr P was offered volunteer support he felt unable to take on a new relationship at the time and preferred to continue attending the dementia club, where he could talk about his wife with people who had come to know them both over the time they had been part of the group. Mr P again sought assistance from the I&A service with various forms and papers following his wife's funeral. He kept up his membership of the dementia club for some months before joining the organisation as a volunteer himself, feeling that he wanted to give back some of the support he had received. He described this as having been a 'lifeline' and he wanted to be able to help ensure others would have this too. The carer continues to receive bereavement support from the pilot project coordinator, and finds social opportunities in his involvement in the wider organisation.

*(KUT, Dec 2012)*

## SECTION 6.4 SUMMARY KEY MESSAGES

- Equal importance placed on service user needs *and* volunteer needs where volunteers deliver specialist end of life services
- Potential mis-match in timing of volunteer readiness and older carer support needs in the start-up phase of establishing services
- Lead-in time to volunteer readiness can have implications for short term funded projects
- Group training opportunities facilitate volunteer cohesion and peer support
- Benefits and value to organisation-wide training for non-EOL services who work with older people
- Links with specialist trainers can enable integrated working between health and third sector organisations
- Dual role and function of pilot projects in providing a user *and* volunteering service
- A strong, planned strategy for supervision and support is fundamental for volunteers working in the area of end of life
- Maintaining interest and motivation of volunteers during the initial development phases

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A key organisational issue that needs to be addressed is the establishment of a volunteer service to support older carers in an EOL context is that services are required not just for carers but also for the volunteers. This message is of central importance because it conveys the significant support and supervision volunteers required to enable sustainable specialist support for older carers. An overall Programme objective was to: 'Identify potential roles for trained volunteers in providing practical and emotional support'. To fulfil such an approach we would suggest that equal importance and priority is placed on older carer *and* volunteer needs within the service.

One worker articulated the significance she placed on volunteer needs in providing a specialist EOL service to older carers. She described volunteers as a fundamental asset to the organisation, and its greatest resource. Sustaining the volunteer workforce took considerable resources, but without it she believed the organisation would be unable to deliver the range of services they offer to older people:

**"They keep us ticking ... they provide a wealth of support and energy for the organisation ... You can't just get a volunteer in. They need to be looked after and protected. It's not possible to just bring in, match up and send them out ...There are complex needs. Everyone is concentrating on cared-for people. ...My thoughts always turn to the**

*volunteer needs ... [and] ... how we can shape the service by what can be offered by volunteers, rather than volunteers moulding to the service provided."* (KUT, co-worker (our emphasis.)

This highlights how volunteers` presented a demand on pilot projects, alongside the demand of older carers. With this emphasis in mind we present a number of important areas the pilot projects experienced in establishing, developing and managing volunteering in the context of specialist end of life carer support.

#### *6.4.1 Sustainable volunteering*

Pilot projects found there were timing implications to **establishing a volunteering service** where volunteers had undergone recruitment and training processes, and were then in a state of readiness to be matched with older carers. Concurrently coordinators were establishing and promoting their services, with specific efforts focused on identifying referral pathways and receiving referrals of older carers. Coordinators found this process did not follow a linear course, and all 6 pilot projects found at different times that there was a mismatch between volunteer availability and active referrals. It could also be the case that volunteers were in place, older carers were in need of volunteer support, but a 'good match' between both could not be achieved.

In taking up their roles *Supporting Older Carers* project coordinators needed to conceptualise their individual service and envisage how it could be operationalised in their locality. Achieving balance in this multi-faceted timeline to volunteer/service user fit challenged coordinators, and especially those who, although skilled and experienced in the area of EOL, were new to working with volunteers. Working alongside an Age UK volunteer coordinator assisted in this area. One coordinator spoke about the significant amount of time and resources she had put into getting to know the volunteers and to establishing how they would be best employed in the work of the project.

This issue was particularly heightened for those pilot projects joining the Programme later, in years 2 and 3. One coordinator described having an acute awareness of the need to very quickly establish a project that was visible to potential referrers, while meeting the support needs of older carers referred to the project, together with ensuring the growth of a sustainable volunteer base. Another coordinator calculated that it had taken eight months from the point of commencing volunteer recruitment to having volunteers ready for matching to service users. This potential lead-in time has clear implications for short-term funding of voluntary sector services.

Training was a key dimension to **developing a volunteering service**. The pilot projects had differing approaches to training volunteers, but their training schedules all included two broad elements: Induction and relevant, non-specialist training sessions, and a specialist EOL training component. Induction and non-specialist training were mostly accessed via local Age UK in-house provided sessions, while specialist training

was more usually delivered outside of Age UK by EOL practitioners, including hospice, NHS, and voluntary sector bereavement practitioners.

**Table 12: Volunteer training topics and sessions delivered by pilot projects**

Type of training	Topic/Session Description	
<b>Induction</b>	<ul style="list-style-type: none"> <li>- Induction to Age UK</li> <li>- Volunteer Roles &amp; Expectations</li> <li>- Confidentiality</li> </ul>	<ul style="list-style-type: none"> <li>- Health and Safety</li> <li>- Moving and Handling</li> </ul>
<b>Non-EOL specific</b>	<ul style="list-style-type: none"> <li>- Lone Worker Safety</li> <li>- Communication Skills</li> <li>- Communication in later life</li> <li>- Supporting self and others</li> <li>- Listening skills</li> <li>- Co-dependency and coping strategies</li> <li>- Alcohol awareness</li> </ul>	<ul style="list-style-type: none"> <li>- Maintaining boundaries</li> <li>- Reflective practice</li> <li>- Working in people's homes</li> <li>- Safeguarding and using your car.</li> <li>- Safeguard Alerter</li> </ul>
<b>Specialist EOL</b>	<ul style="list-style-type: none"> <li>- Induction to the End of Life Project</li> <li>- 'What is palliative care?'</li> <li>- End of Life</li> <li>- Communication skills</li> <li>- Spirituality</li> <li>- Looking After Yourself</li> <li>- Overview of palliative care-NHS trainer</li> <li>- Principles of End of Life Care</li> <li>- Difficult conversations</li> </ul>	<ul style="list-style-type: none"> <li>- EOL Communication skills</li> <li>- Loss, grief and bereavement</li> <li>- Dealing with loss and grief</li> <li>- Equality and diversity at end-of-life</li> </ul>

Specialist EOL volunteer training also differed in how it was delivered. Two pilot coordinators joined their volunteers for specialist training sessions in hospice settings, and two coordinators co-facilitated EOL training, one with an external provider from a bereavement service and one with an Age UK volunteer coordinator. Value was placed on whole group training sessions as these were seen as team building opportunities for volunteers who may otherwise not meet their *Supporting Older Carer* peers. These were also useful for coordinators who could gauge preparedness of volunteers for working in the sphere of EOL through their contributions and participation. Volunteers fed back that they appreciated joint training sessions that allowed all volunteers to come together and get to know each other. As a result they felt more comfortable about calling on each other for support if they needed to.

It was noted that less formal and opportunistic training arose when volunteers accompany pilot project coordinators on visits to older carers. These could be assessment, support, or introductory visits. One pilot project worked in this way with volunteers 'shadowing' the coordinator specifically to receive on-site training in issues experienced by older carers, and in managing visits.

Wider training opportunities for one Age UK pilot project arose through the coordinator and another colleague working for the *Supporting Older Carers* pilot project, collaborating with a local bereavement service to provide training for in her organisation: see *Training Opportunities 1*. A further pilot coordinator established links with an NHS Palliative Care Nurse who provided specialist training sessions for her *Supporting Older Carers* volunteer group: see *Training Opportunities 2*.

#### *Training Opportunities 1: Kingston upon Thames*

In order for specialist training to be viable within the Local Age Concern a group of volunteers needed to be established. With recruitment difficulties, and in the absence of a larger volunteer cohort to draw on, a specialist training day was devised in partnership with Kingston Bereavement Service, and this was opened up to all Age Concern Kingston volunteers and paid workers to ensure adequate take-up. Two sessions ran over one full Saturday. A further specific training day was delivered to 4 pilot project volunteers who had been successfully recruited to the pilot.

Through promoting the pilot project's work and participating in the delivery of training, the pilot coordinator feels that a greater awareness of end of life issues came to inform her other I&A work within her organisation. She also believes this awareness is filtering into other in-house services through their workers having taken part in the day training on end of life.

#### *Training Opportunities 2: Leicester, Shire and Rutland*

Contact was made with a specialist EOL NHS palliative care nurse who was able to provide 2 days free training for the *Supporting Older Carers* volunteers. 1 day covered palliative care and gave an overview of specialist care, and also covered spiritually and looking after yourself in this area of work. The 2<sup>nd</sup> day's topic was bereavement. Developments through this link with the NHS trainer grew to extend beyond training provision, and within her role she was able to provide coordinator support. This working relationship was greatly appreciated by the pilot coordinator who was able to call on an identified contact who could provide specialist professional practice support and information. The NHS trainer equally appreciated the established link with the pilot project describing this as 'truly integrated working'.

With the emphasis on providing a service for users, a number of aspects of **managing a volunteering service** were unanticipated. As discussed above, we would argue that where specialist user services are provided by volunteers, that equal emphasis is placed on them being a *volunteer service*. Issues in volunteer management ranged from those encountered from the inception of a service, across recruitment (specifically

discussed below in Section 6.6.2), matching volunteers and older carers, support and supervision, and retention.

From the point of successful recruitment of volunteers to their pilot project, coordinators needed to carefully manage demands made *upon* volunteers and demands *created* by volunteers. Coordinators recognised that volunteers had varying motivations for volunteering in EOL, and were mindful that these may render some vulnerable in their relationships with older carers with extensive needs. Coordinators needed to judge, monitor and 'hold' volunteer and older carer relationships recognising that volunteers wanted meaningfulness in their relationships with older carers, that they wanted to 'connect' with service users, while ensuring boundaries were observed and they were accessible when needed for support and supervision. Volunteers were described as needing to be 'emotionally sound enough' and knowing where the 'it's gone too far' button was. Pilot project coordinators were tasked with giving volunteers what they sought in their role, while ensuring mutual neediness in the volunteer / older carer relationship was appropriate, and that volunteers were comfortable and protected in their roles.

Coordinators found that the timing of older carer referrals to their service and volunteer availability may not coincide. This was especially the case at the outset of the service where referrals were received prior to volunteers being in place. Conversely, there were times when there were volunteers ready and available to be allocated to older carers, yet low referrals prevented them from being able to work directly with carers. Faced with this situation, pilot projects found volunteers were willing to engage in other forms of support such as distributing project flyers and leaflets, project administration tasks, and covering a stall at a local health fair to advertise the service. On-going allocation issues were anticipated by coordinators given the flexible and responsive style of service all the pilot projects endeavoured to establish. It was envisaged that managing volunteers would form a significant proportion of coordinator resources to oversee, plan and secure this key function of a project alongside the older carer support dimension of their work.

The points raised here provide but a flavour of the myriad issues coordinators tackle in their daily and longer term service planning to establish, develop and manage a volunteer resourced service. These considerable responsibilities for coordinators illustrate our proposition that equal weight is given to both aspects of the role and function of what are more usually conceived of as user service provision.

#### *6.4.2 Supporting specialist end of life and bereavement volunteering*

Individual volunteers brought a mix of skills and experience to their pilot project work. Some had previous relevant professional work histories (e.g. counselling, nursing, social care), or current, relevant experience (two social work students had placements with one project). Volunteer backgrounds were broad, bringing experiences as varied as teaching, domestic cleaning, child rearing, spiritual vocations, and advice work. All volunteers brought life experiences to bear on their roles, including their own losses and bereavements at different times in their lives. Volunteer skill levels contrasted from those with pre-existing and applicable skills, e.g. bereavement counselling expertise, to volunteers bringing few apparent relevant attributes to the role. One volunteering journey illustrates how growth and confidence are acquired from such a starting place:

L1v's development into a dependable and valued member of the team grew from her early work helping in the project office. She had been introduced to volunteering by a friend who worked for Age UK. Initially she had been unconfident and unsure that she would be able to work in this area. L1v had been unemployed and out of work for a long time and described not having confidence in anything. Initially she undertook some typing and administrative tasks in the Age UK office, but with encouragement to become directly involved with service users she made a joint visit with a service coordinator. Following introduction to an elderly woman L1v immediately felt an affinity for the work. She has subsequently gone on to support a number of older people over a period of 2 years, working with frail and unwell people at the end of life and their carers. Over time her confidence and skills have grown and she has acquired a strong sense of the older carers she best works with and she became invaluable to the *Supporting Older Carers* service by providing extra cover for the pilot project when the coordinator was on leave. With self-awareness she recognises how she values feeling needed by the people she supports, and making a difference to someone's day and their situation. Volunteering made her:

*... feel good at the end of the day .... helpful ... the best thing I get out of it is a buzz. I feel like I've done something useful ... I walk away smiling.*  
(L1v, 07.06.12)

This volunteer profile highlights how the pilot project coordinators invested considerable time and resources in enabling volunteers to participate through occupation and meaningful relationships with service users. Coordinators called on volunteers to deliver a service through identifying and harnessing the qualities and attributes they had to offer older carers. While facilitating a 'good fit' between volunteer and older carer, coordinators needed to remain watchful for strain or difficulty in a relationship that was very often intense by virtue of the emotionally fraught life phase they worked in. They also had to ensure that volunteers were engaged, but not overburdened; sensitive, but not overemotional; boundaried, but caring and responsive. Ultimately they needed to ensure volunteers were supported but accountable in their work with vulnerable older carers, bereaved carers, and in their contact with cared-for people nearing the end of life.

With these features of volunteer roles and responsibilities, supervision and support was a priority for all pilot project coordinators. Each had in place a system to ensure they were accessible to volunteers post-visits or for ad hoc contact if they needed this. More formal, one-to-one supervision meetings were scheduled regularly, usually 4-8 weekly. Peer support amongst volunteers was encouraged and three pilot projects arranged group meetings at which volunteers exchanged their work and experiences. All of these approaches were viewed as necessary in order to support volunteers to become and remain involved in relationships that were likely to include the death of a carer's close relative.

Volunteers' own life issues and events were acknowledged as being advantageous to draw on, while potentially unpredictable if triggered through involvement in challenging older carer experiences. With volunteers' ability to connect and empathise with older carers being an important attribute, so too volunteers could find their own needs come to the fore through pre and post bereavement work with older carers. As a pilot project manager commented:

*"... their own 'stuff' can be triggered by a user. It's not necessarily going to be the first user worked with, or the second or the third. It could be the sixth user that a volunteer works with that triggers something in the volunteer that creates difficulties for them."*

(LSR, volunteer discussion group, Oct 2012)

As such, it was imperative that pilot project coordinators were not complacent about individual volunteer's capacity to cope with distress and trauma. Given the complex and emotionally sensitive scenarios cited in earlier sections of this report, volunteer supervision and support when working in such situations was an imperative, key role of pilot project coordinators.

## 6.5 Coordinated services: models of older carer support volunteering services

### SECTION 6.5 SUMMARY KEY MESSAGES

- Flexible service development to accommodate locality older carer population specific needs
- Open Intervention Model facilitates long term support and 'soft' contact to build rapport and trust. Coordinator and volunteer older carer support
- Timed Intervention Model regulates demand and protects the 'intensive' EOL supporting relationship. Primarily volunteer older carer support
- Support provided directly to cared-for people with the purpose to support older carers
- Purposeful targeting of older carers' needs through supporting the cared-for person
- Volunteering 'spousal teams' provide mutual volunteer support and enable the needs of older carer / cared-for couples to be met in an inclusive, mutually beneficial way

Differing approaches to working with older carers evolved over the course of the *Supporting Older Carers* Programme. Locality specific influences included:

- The Coordinator's prior professional background
- Additional roles held by the Coordinator within the local Age UK
- Volunteer availability
- Length of funding for the Programme

Pilot project coordinators professional backgrounds included: qualified nursing and trained social work; counselling; volunteer coordination; adult education; information and advice; carer support services; and dementia support services. Previous positions held had been in a mix of statutory health and social care locations, and in voluntary sector organisations. Three of the coordinators had joint roles in other areas of work in their local Age UK that they undertook together with the *Supporting Older Carers* element of their employment. One coordinator worked outside of Age UK in a counselling capacity. One coordinator was seconded internally to the pilot project for a specified period.

Coordinators were supported by their line managers to develop and promote their projects within the parameters of the Service Level Agreement, with a good degree of autonomy. With the above skill-mix and previous experience brought to their positions, service development was inevitably varied and coordinators styled the service to local need and fit within their larger organisation. Models of provision elsewhere in the

individual local Age UK organisations also informed the best-fit considerations of how the *Supporting Older Carer* services would develop.

Volunteer availability particularly determined coordinator involvement in provided direct support to older carers. During the early phase of project inception and receiving referrals, and in the face of volunteer recruitment issues (see Section 6.6.2 of this report), coordinators had a greater role in direct older carer support than had originally been anticipated for the broader Programme. Sustained reliance on coordinators for this direct service was seen across all pilot projects.

One pilot coordinator, using a timed intervention model described below, suggested that this approach was more suitable for the limited funding period of the pilot that had come on stream mid-way through the Programme. She identified sustainability issues for a small project that would have an increasing service user case load where older carers were supported in an open intervention approach.

The six pilot projects broadly fitted into two models of provision. However, these did not strictly determine how they worked with older carers, but rather reflects the wider framework to their approach. Ultimately support by each pilot project was able to be highly individualised and tailored to the needs of assessed older carers, and so there was a crossover of approaches within the two models outlined below:

#### *6.5.1 Open Intervention Model: coordinator and volunteers jointly providing on-going support services*

Four pilot projects followed this model of provision (LDS, ST, LSR, LANCS): Two were longer term funded pilots, one was medium term funded, and one was short term funded.

##### *Features:*

1. **Coordinator assessment** of older carer needs. The coordinator may provide an initial service, e.g. welfare benefit advice or assistance with practical support. This may then be followed by volunteer support
2. Can have **intense periods of input** when older carers need more support and involvement with the service. This could be on referral to establish practical support or to match the older carer with a volunteer for support visits. **On-going support** follows with an open-ended arrangement that may fluctuate in activity
3. The support arrangement is **flexible and responsive** to older carer needs
4. Support visits undertaken by **coordinator, volunteers, or a joint support arrangement**. The latter may include contact or visits by both workers during the same period for different purposes, or the coordinator may make occasional visits to review the older carer's needs and the support a volunteer may be providing
5. **Soft contact** maintained over weeks or months during different phases (see Section 6.3.1), e.g.
  - a. During intense end of life or palliative care phase when multiple professional services are visiting to provide treatment and support. Older carers may feel an additional further service is too much for them to have involvement with at this time

- b. When end of life or palliative phase is not perceived by the older carer as imminent and they do not feel the need for direct support at the time of initial referral or contact with the pilot service
- c. For older carers who may appear to need support but who are reluctant or unable to accept the offer. Soft contact enabled coordinators to build rapport and trust, and to facilitate a later working relationship with the older carer
- d. To build a relationship with the older carer in preparation for support on bereavement

In the above examples contact is maintained with the older carer, through occasional telephone or home visits to check on any changes in circumstances, and to reiterate offers of support if appropriate.

#### *6.5.2 Timed Intervention Model: volunteers as primary supporters of time-managed contact with older carers.*

Two pilot projects followed this model of provision (KUT, OX): 1 medium term funded pilot, 1 short term funded pilot.

##### *Features:*

1. **Coordinator assessment** of older carer needs. There may be some initial, brief service, e.g. financial and welfare benefits advice or practical services assistance
2. **Focused and specific support** provided, usually to achieve a financial or practical outcome, but included emotional support
3. **Managed, shorter-term contact** arrangements with a specific time-limited framework to support. e.g. one project explored early intervention, 3-6 weekly visits followed by signposting and onward referral to
4. **Coordinator managed volunteer service.** Coordinator has less hands-on involvement with older carers, and primarily manages, supports, and supervises a volunteering service
5. Addresses specific potential volunteering and service provision issues identified by the coordinators working with this model:
  - a. Time boundaries are put in place to older carer/volunteer contact. This may help to protect volunteers who enter what can be intense end of life relationships. Expectations on the limits of the relationship are clear to older carers and volunteers from the outset
  - b. Ensures that older carers who require specialist bereavement support are identified. If carers do not move through their grieving process and require longer term support this may indicate that specialist bereavement support is required over and above that which can be provided by *Supporting Older Carer* volunteers
  - c. Supports access to the service from a continual flow of referrals through ensuring there is volunteer capacity to work with new referrals as they come on stream. Volunteers have a predictable workload that is automatically reviewed as timed interventions are completed

As noted above, within these models variations occurred and coordinators worked flexibly across the approaches, and different ways of working were explored. While the above features of two broad models emerged across the pilot projects, other distinctive ways of working were also identified. These include:

- **Work with cared-for people:** although the Programme's service delivery emphasis was on older carers of cared-for people approaching the end of life, pilot projects also worked purposefully with cared-for people. Where this was the case it provided respite support or reassurance to the older carer. For example, where carers lived some distance from their cared-for relative:

A volunteer regularly visited the elderly mother of the identified carer. Her main role was to provide some company, but she also helped the user with practical jobs that needed doing in her home, this included: getting smoke alarms fitted by the local fire service, and arranging for a plumber to fit a washer for a drip that had been the source of great irritation to her. Referrals were also made to other services within Age UK Leeds. The daughter was greatly reassured by the visits because living some distance away she could not provide this degree of support.

*(LDS 01v, Evaluation observational visit report)*

Also see [Case 10](#) page 26. This pilot project worked with a number of older carer and cared-for spouses providing support services directly to the cared-for person in order to support the older carer. In each case the spousal caregiving relationship had been identified as potentially vulnerable through the stress both people were under. The primary goal for intervention was to prevent carer breakdown.

The key to direct cared-for support in the context of older carers' services is the *purposeful* targeting of older carer needs. It is more usual for support services at the EOL to be directed to the cared-for (patient) and in this case benefits for carers are secondary outcomes. For the *Supporting Older Carers* Programme primary benefit was aimed at older carers.

- **Complex cases:** as discussed in Section 6.2, older carers' health and social care needs were often complex and multiple. Where this was the case 2 pilot project coordinators spoke about taking responsibility for this work. One coordinator explained that she took a lead in more complex and emotionally demanding situations rather than matching volunteers to older carers with these needs. However, at the time she was also aware that her involvement in such cases may need to be reviewed in the event of high demand for the service (LSR). The second coordinator worked alongside a volunteer, who visited an older carer to accompany her on medical appointments and to provide friendship. The coordinator undertook more complex aspects of the older carer's case, including employment assessment forms and will writing (LDS).
- **Volunteering couples:** one pilot project found that 2 sets of spouses volunteered for the service, which resulted in the coordinator matching them each to older carer / cared-for spouse couples. This unique situation provided the opportunity for 2 husband and wife volunteer 'teams' to work together for their visits to older carer and cared-for couples. The coordinator spoke about couples volunteering as a good model of working, whereby they could support each other in what could potentially be isolated and challenging end of life situations. Couples were able to support one another, and this approach also recognised that many carers do not want to leave their looked-after family member alone in order for them to have a break outside of the home:

One spousal couple were visited by a wife and husband volunteer 'team'. Support was provided to the older carer, who also had medical conditions that included heart problems and arthritis. The cared-for person was diagnosed with terminal bowel cancer. Support arrangements include a weekly shopping trip with the older carer while the other volunteer provided company and sat with the cared-for husband.

(LANCS, *Evaluation observational visit report*).

- **Volunteer training:** volunteers could shadow a coordinator for visits as described in Section 6.4.1 above. Joint visits by coordinators and volunteers were more usual for the purposes of matching and introducing both parties for the support that had been arranged. However, one pilot coordinator specifically identified the training objective that accompanied visits also met. Working alongside volunteers in this way enabled onsite, 'real time' training opportunities.

## **6.6 Obstacles and challenges**

Three particular areas have been identified that presented significant challenges for the pilot projects' work. A range of other additional issues were faced by each project, but those expanded on here were common to all six pilot projects in lesser or greater degrees.

### **SECTION 6.6 SUMMARY KEY MESSAGES**

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- Establishing early external referral pathways and maintaining these through regular updates to health and social care teams
  - Internal services provide important referral sources. Dual coordinator roles boost referral links between projects
  - Early, planned, organisation-wide volunteer recruitment strategies to ensure an established, ready volunteer base to match with individual older carers
  - Anticipation that EOL may be a sensitive area of volunteering to an older age cohort of volunteers
  - Development of sustainable EOL services can be achieved by 'adding-on' this area as a distinct element of work for existing services, or 'embedding' EOL component to all existing services
  - Self-evaluation, internal audit, and independent external evaluation place additional layers of responsibility and demand on coordinator positions
-

### 6.6.1 Referrals & collaborative / partnership working with health

**Table 13: Total referrals to pilot projects with area EOL population data**

Pilot Project	Older Carers Referred (n)	Number in PCT population with palliative care needs*		
		#	%	PCT
Kingston upon Thames	19	785	0.46	Kingston
Lancashire	19	3,239	0.71	Central Lancashire
Leeds	60	4,908	0.61	Leeds
Leicester, Shire & Rutland	72	4,512	0.66	Leicestershire County and Rutland
Oxfordshire	20	3,717	0.6	Oxfordshire
South Tyneside	53	1,302	0.85	Sunderland Teaching
<b>TOTAL</b>	<b>243</b>	*Source: Marie Curie Cancer Care End of Life Atlas 17/09/13		

All pilot project coordinators recognised the task of gaining referrals as one requiring dedicated, on-going attention. When referral pathways were established, continued reminders and updates for outside practitioners about the *Supporting Older Carers* service availability were felt to be necessary due to staff turnover and changes in team membership.

Considerable time, resources and effort were invested in establishing referrals with outside agencies early on in the projects' work. All pilot projects had particular difficulties in gaining health practitioner referrals. Table 14 summarises the main challenges and issues faced as reported by the pilot coordinators, together with referral sources. Although health sector referrals are cited here, as reported by all the projects, the majority of referrals were received from within Age UK organisations, from other third sector and community organisations, and from local hospices.

**Table 14: Referral challenges and issues**

<i>Pilot Project:</i>	<b>Referrals:</b> <i>summary of obstacles and sources</i> [Age UK, informal, third & private sector, NHS, social services]
<b>Kingston upon Thames</b>	Few outside agency referrals. Multiple visits made to outside agencies (health service practitioners and voluntary sector e.g. hospice). Majority of referrals received via Information & Advice service and other Age Concern in-house services. <i>Referrals received: Age Concern day centre, Age Concern home visit service, self, family member, neighbour, friend, previous service user, Alzheimer's Society dementia advisor, hospice, occupational therapist.</i>
<b>Lancashire</b>	Large county to cover visits to potential referrals sources. Considerable time spent setting up and attending meetings with groups of professionals. Weekly telephone contact and 2 meetings per week to various agencies. Extended attempts to engage with potential referrers in different sectors including appropriate health care teams and third sector organisations. E.g. Of 150 letters sent out to different organisations, 4 emails from GP practice managers to request visit from the coordinator. <i>Referrals received from: Age UK hospital aftercare team, other service user, hospice palliative care nurse, Alzheimer's Society, Macmillan nurse, Parkinson's specialist nurse, community matron, hospital, GP.</i>
<b>Leeds</b>	Good referral processes from inception due to existing and established relationships and networks with key practitioners developed through the coordinator's previous work in the hospital after care service. Lack of referrals from health sector noted, especially from GP practices. <i>Referrals received from: Age UK advocacy, Age UK befriending, Age UK other, self, family member, hospice, Macmillan nurse, Alzheimer's Society, GP, hospital, hospital social worker, community matron.</i>
<b>Leicester, Shire &amp; Rutland</b>	Significant time investment in networking and establishing referral pathways with NHS and care agencies, via coordinator's previous networks in health and social care work. Referrals took approximately 6 months to generate. Particular efforts to work with social services via the single point of access service. Absence of referrals from local GP surgeries despite contact with over 40 practices in the pilot area. <i>Referrals received from: Age UK I &amp; A, Age UK home service, Age UK respite service, self, friend, hospice, hospital, palliative care team, community matron, dementia support, social services.</i>

<b>Oxfordshire</b>	<p>Low numbers of referrals reflected absence of carers for many Age UK's existing service users, and lack of recording of 'end of life' status. Issue highlighted in identifying 'hidden' carers. Significant time spent marketing pilot via local Age UK's wider services.</p> <p><i>Referrals received from: Age UK Carers, Age UK flexible care, self, neighbour, care home, Carer's Oxfordshire, GP, social services, social worker.</i></p>
<b>South Tyneside</b>	<p>Few referrals from local PCT and engagement from health professionals low, despite significant efforts to make contact and inform of pilot work. GP surgeries targeted with flyer drops. No contact initiated with coordinator by GP surgeries or referrals received.</p> <p><i>Referrals received from: Age UK hospital discharge, Age UK I &amp; A, Age UK time 4 you, Age UK health trainer, Age UK home support, Age UK health coordinator, self, Carer's Association, Places for People, Cancer Connections, hospital, community matron.</i></p>

Two pilot project coordinators identified locality specific reasons why referrals to their service may have been lower than anticipated. One pilot area had particularly well established and recognised bereavement support services within Age UK. This pilot was one of the 12 month funded projects in the Programme. With a short delivery time frame it is not possible to evaluate the impact of existing services already in place on referrals to the *Supporting Older Carers* service.

A second pilot coordinator reflected that very few external referrals had been received from outside agencies. This was a surprise to her given the very positive reception to the project when she initially promoted the service at external talks to groups and practitioners. Of significance in her locality she felt, was the existence of community nurse health practitioners who had support workers working alongside them. These were able to give more time to patients than could be provided by the community nurses themselves. Carers could receive support from the support workers, via the health services that were in place for the patient. This included emotional support.

A factor that boosted referrals to the pilot projects was if coordinators occupied additional roles within their organisations. Where coordinators had a dual role, i.e. working for Advice and Information, and Befriending services, appropriate referrals could be directed to the *Supporting Older Carers* service. This also occurred early on in the life of the projects when external referral pathways were still being established. In a similar way, all six pilot projects received referrals from within their organisations from other projects. Indeed, lessons learned from longer established pilot projects within the Programme led to this approach being a specific strategy for the last two projects to be funded. This recognised that within the 12 month funding period

external referrals may prove less achievable. See Table 14 for the range of internal Age UK referral sources.

### 6.6.2 Volunteer recruitment and attrition

A persistent issue for all pilot projects was establishing a volunteer workforce to deliver the specialist older carer service. Managing and coordinating a dual service to *both* older carers and volunteers has been discussed above (see Section 6.4). A key operational issue described by coordinators was the challenge of growing a user service hand in hand with establishing a volunteer base, while also establishing referral pathways. All three of these project objectives would ideally synchronise to ensure the smooth transition of older carer assessment, followed by matching and placement with an appropriate and available volunteer. However, a streamlined, linear process was often not possible with projects finding a mis-match between numbers of volunteers and older carers needing support.

**Table 15: Volunteers: recruitment and attrition**

<i>Pilot Project</i>	<b>Volunteers</b>		
	Recruited	Left	Reasons for leaving pilot volunteering
<b>Kingston upon Thames</b>	6	2	<i>1. Ill-health. 2. Personal commitments.</i>
<b>Lancashire</b>	6	1	<i>1. To take up paid employment.</i>
<b>Leeds</b>	29	4	<i>1. &amp; 2. Personal reasons. 3. &amp; 4. Information unavailable.</i>
<b>Leicester, Shire &amp; Rutland</b>	9	3	<i>1. Needed guaranteed regular hours. 2. No reason given.</i>
<b>Oxfordshire</b>	12	7	<i>Information unavailable.</i>
<b>South Tyneside</b>	11	4	<i>1. Volunteer died. 2. Ill-health. 3. To take up paid employment. 4. To volunteer for different Age UK project.</i>
<b>TOTAL</b>	<b>73</b>	<b>21</b>	

Although volunteer recruitment varied across the six projects, all had fewer people than anticipated joining their volunteer base. For one project this was a particular difficulty and volunteer recruitment took considerable efforts to address. In this case an additional member of the organisation's staff joined the pilot coordinator to target this aspect of the project's work. Other projects were assisted by their locality Age UK volunteering coordinator who directed potential recruits from their general volunteer pool to the projects. One pilot project undertook recruitment directly, through local advertising, and a further project was able to draw on volunteers already working in related projects e.g. befriending services.

Different factors were proposed as having contributed to the volunteer recruitment issues faced within this Programme:

- The area of *end of life* may be experienced as too challenging for people considering volunteering. The majority of pilot project volunteers were in an age range of between 50 and 84 years. With this age range coordinators considered whether potential volunteers had experiences that were personally too close and uncomfortable to the end of life phase. One coordinator reported that a potential volunteer had been dissuaded from volunteering by a relative who had concerns about the impact on them of highly emotional work in this area. Another coordinator described that while volunteer work was with older carers, the prospect of contact with their dying family members may be regarded as too difficult
- Unpredictable nature of volunteering with older carers may be off putting. Older carers may need flexible, responsive support while in contrast volunteers may want to work specific and regular days and hours
- Large geographical areas may create difficulties for volunteers living in areas where older carers require visits or other specific support where close proximity of volunteers is preferable, e.g. accompanying on medical appointments. Conversely, some organisations operate in smaller geographical areas giving a correspondingly small volunteer catchment area
- Short term funding may give the impression of a temporary or insecure project which is off putting to volunteers who want to commit to working for the organisation

### *6.6.3 Sustainability of older carer specialist support services*

Two specific issues are raised here that emerged through the pilot nature of the Programme work, with implications for developing established end of life services in local Age UK organisations.

The first concerns the value placed on older carer support and services by each pilot project manager and other officers in the local Age UK organisation. Gaps in provision for this specific, specialist end of life sphere of work were acknowledged and the need for this area of their work to continue was fully endorsed. On-going sustainability of pilot project services, largely for funding reasons, however was across all projects identified as presenting difficulties. Each locality had its own funding and service commissioning issues to consider, and all predicted that the project work would not continue in the working / organisational pilot format. Rather, it was hoped that

*Supporting Older Carers of those nearing the end of life* could to be embedded in other services they delivered. This was presented either as strategic planning or as a pragmatic solution to maintaining the work that pilot projects had established.

Short term funding, especially of 12 months duration, was viewed as inadequate for projects aiming at delivering direct user services, when during this time there were expectations to: appoint a coordinator, set-up referral systems and volunteer recruitment and training, market /promote services, receive and assess referrals, allocate volunteers to older carers, monitor and supervise provision, and evaluate delivery. Within the Programme funding models, two year funding was described as the minimum necessary for establishing limited service provision, with three year funding preferable. Ultimately short term funding, it was suggested, should be avoided.

Two options for more sustainable specialist end of life older carer services were identified. Funding should be aimed at:

- **'add on'** specialist components to existing services, e.g. to Befriending, Help at Home, Information and Advice services
- **'embedded'** strategies for all specific provision areas in local Age UK organisations, in order that *end of life* needs are identified and addressed in all service areas

The second issue noted here relates to how pilot interventions, which include evaluation, are resourced and managed at local and national levels. The dual coordinator role of providing older carer *and* volunteer services has been raised earlier. A third significant component to the role can be identified in meeting the requirements and demands of self-evaluation and independent external evaluation. To enable service impact and outcomes to be captured this element of pilot project coordinators' work was crucial, but perhaps unanticipated by them or their host organisations. We would suggest that through a combination of the challenges faced by coordinators (some of which are outlined above), together with a specialised and sensitive area of work with vulnerable service users, that this created circumstances of particular high demand on individual coordinators.

The evaluation tasks created an additional layer to the work of coordinators and while they were aware of the requirement for Programme evaluation on taking up their roles, this element was greater than they had anticipated. Indeed, one coordinator was working on another independently evaluated project at the same time as the *Supporting Older Carers* pilot, which similarly required: attendance at national project meetings, collection and submission of a diverse range of data, and the need to respond to ad hoc requests from the University team conducting the evaluation. These demands clearly have implications for on-going audit of third sector services.

However, when reflecting on their experiences in the evaluation meetings with the University researcher a number of coordinators also expressed the usefulness of this process and in having the opportunity to reflect on the progress they had made. These meetings also gave them the opportunity to view differently and place in context, some of the difficulties they had encountered in their work. In this respect coordinators especially found the lack of referrals of older carers to their projects and the volunteer recruitment difficulties frustrating and disappointing. It was evident that some of the

coordinators had struggled not to see these challenges as reflections on their professional and personal abilities and had been very disappointed in this aspect of their work, as the following quotes relay:

*'Personally I've found support from the programme manager, she's been kind and patient. ... The ball got dropped along the way though, but probably at our end ... key personnel changed, I ended up with a bid I didn't understand. The way that it was, was nobody's fault. So then it's catch-up. When I came to the group meeting ... then I understood what was being asked for ... Would have liked a chat room or some way to liaise with the other projects ... to commiserate and guide each other ... would have been helpful ... to know: ' I haven't got any volunteers ... it's not just me.'*

(Ox Coordinator, November 2012)

*'I'm now weighed down by it. I'm disappointed that it hasn't been established – too great expectations. Really wanted to see a service that was embedded by the end of the pilot ... so that we could argue for it to continue. But it's been such hard work to get off the ground.'*

(KUT Coordinator, November 2012)

*'The project was defined within an inch of its life ... it was hard to fulfil requirements ... but as a pilot, you learn from pilots. Shame for the [coordinators] ... it wasn't what they had hoped it would be. They were raring to go ... they gained from organising training, but it hasn't been what they thought it would be. Personal disappointment for the coordinator.'*

(KUT, Line manager, November 2012).

In each case pilot project coordinators spoke about the close working and supportive relationship they had with their managers. Some also benefited from the Age UK manager being available for data gathering and report writing, or from administrative support.

## 7. Conclusion

Death is now an event of older age, and needs for care and support have become more complex. Frailty, multiple comorbidities and reduced family size are some of the challenges that current systems will need to anticipate and accommodate. (Hanratty et al, 2013: 11)

The special needs and circumstances highlighted in the above quote are echoed by the *Supporting Older Carers of Those Nearing the End of Life* Programme evaluation findings. A key element to these findings is that *all* areas of support, be they practical, financial, social welfare or health related, are underpinned by the **provision of emotional support**. End of life support is characterised by the impending death of a family member. While it is experienced differently by each individual person, loss and bereavement occur. For many older carers this loss is experienced in the context of lifelong spousal relationships and partnerships. Grief and isolation in these circumstances can be crippling. When coupled with older carers own, sometimes multiple health issues, services require knowledgeable, skilful and aware workers and volunteers to recognise the needs of frail, vulnerable people who are caring for their dying relative or friend.

To address these needs this evaluation has shown how end of life services can provide **support at the right time, over time**. Timeliness is of central importance to ensure older carers have contact with support workers (paid or volunteer members of staff) when they need it most. For some people this is not immediately prior to death, when intensive palliative care may be provided by a number of health and social care professionals. Rather it may be over weeks or months prior to this phase, and / or after their family member or friend's death. Enabling older carers to seek support can take time, and relationships of trust may develop over several months. Being flexible enough to maintain soft contact with older carers through the end of life phase may be necessary to enable them to develop this help-seeking trust.

Specialist end of life support for older carers that is resourced through volunteer services has been highlighted by the evaluation to be a key organisational issue. Of equal importance to the substantive service provided is the means of providing the service. **Specialist services require specialist volunteers**, who are trained, supported and supervised. Volunteering in end of life care requires particular resources to establish volunteers in a sensitive area of contribution, to maintain a volunteer base, and to sustain this either as a dedicated service or as a specialist element of existing services.

Now well-rehearsed demographic projections indicate dramatic and burgeoning populations of older people needing support and care by family carers in their homes and communities (Age UK, 2010; Calanzani et al, 2013; NCPC, 2012). The above three key features of the *Supporting Older Carers* Programme evaluation are pivotal to enabling future providers of end of life support for older carers to move beyond addressing the tip of the iceberg to providing necessary, appropriate and sustainable levels of support.

## 8. Recommendations

The following recommendations are drawn together from the various data, analysis, and background work undertaken for this Programme evaluation. They highlight target areas and aim to give specific guidance for a range of key stakeholders involved in *supporting older carers of those nearing the end of life*:

### 8.1 recommendations to support older carers:

- Older carers require their health and social needs to be addressed *alongside* those of their family member to feel comfortable about accessing and accepting services. This recognises **complex, multiple needs** and the often mutual components of older carer and cared-for health and social circumstances
- Older carers may need time to accept offers of support. **Timeliness of support** and **soft contact over time** are important to allow individual carers to accept support at a time appropriate to them, and/or to allow a trusting relationship to develop with support workers that they can then call on when needed
- Befriending and friendship services should provide **meaningful support** for cared-for people to allow older carers to feel able to leave their family member to gain respite.

### 8.2 recommendations for Age UK organisations supporting older carers:

- **Referral pathways** with external organisations and **volunteer recruitment** are interconnected priority tasks and should be instigated soon after project start-up to enable matching of service providers (volunteers) to service users (older carers)
- Assessment of older carers should take account of the multiple and mutual needs that co-exist between them and their cared-for relative. Individual **carer and couple / partnership needs** should be addressed because carers want to know that their family member does not lose out when they take a break from caring
- All service types that aim to meet needs at the end of life, including practical, financial and social, should include a component that **supports older carers on an emotional level**, to lesser or greater degrees
- **Interpersonal communication** in the last few months and weeks of life between the triad of patient, family carers and Age UK support staff and volunteers is crucial but poorly understood and researched. Healthcare **conversations around end of life** care topics are challenging for staff and volunteers, and they need to feel comfortable addressing emotional issues, in addition to undertaking practical support tasks
- Volunteering at the end of life should be recognised and promoted as a specialist service, whether it is a dedicated or embedded service. **End of life volunteering** should involve specialist training, contact with peer volunteers working in the same area, and robust mechanisms for supervision and support

- **Time managed support** approaches can protect volunteers from intense involvement with older carers. **Couples volunteering** may provide a successful way of supporting spousal/partner couples who both require support at the end of life
- There is a need to address the growing demands on staff and volunteers working with older people and their carers in homes, communities, and day services. End of life needs is not the domain of specific services, because patients and their carers require a range of individualised support. **Organisation-wide training and knowledge exchange in end of life** issues, needs and support should **bridge ALL service areas**

### 8.3 recommendations for Age UK at a national level

- Building sustainable older carer support requires funding programmes that allow local organisations to be flexible in how they **embed or add-on end of life services** to their existing provision
- End of life specialist services involving volunteers should be conceived of as both **service user and volunteering services**, to recognise that both **service users and volunteers have support needs**. These services should be resourced and underpinned with clear funding elements and delivery requirements for *both* components
- **Independent evaluation** of pilot services should ensure evaluation tools are the most appropriate and efficient means of data collection. Consideration should be given to the evaluation timeframe to ensure involvement of evaluators at optimum time points
- **Minimum periods of funding** for pilot volunteer services should be established. Outcomes for funding periods of less than 12 months are limited

### 8.4 recommendations for key stakeholders

- **Research: Evaluation** of service interventions should be **collaborative and cooperative** to facilitate working relationships with project coordinators and other staff members, including volunteers. Evaluation tasks compete with service delivery requirements, which place additional demands on individuals and host organisations. Where non-research staff members are involved in self-evaluation data collection, basic training should be provided. Tools and schedules should be appropriate, and require minimal interpretation
- **Health and social care organisations:** Working relationships with third sector organisations who provide specialist end of life services, enhance patient care through their carers receiving support in their own right. **Investment in supporting these services provides opportunities for integrated work and care provision** through:
  - Establishing direct and two-way referrals pathways
  - Inclusion of third sector services in appropriate planning, practitioner or information sharing meetings
  - Providing, or inclusion in, specialist training opportunities

- Offers of professional supervision and support
- ***Other end of life organisations:*** cross-over in local organisation's geographical areas and spheres of work are inevitable as ageing and informal carer populations grow. Providing services in similar areas and with similar carer populations at the end of life offer **opportunities for service planning and development**, joint working, and sharing of resources e.g. training, volunteer support and supervision

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## 10. References

- Age UK (2009). *A Call in Time: Low-level support for socially isolated older people: An evaluation of telephone befriending*. London: Age UK.
- Age UK (2010). *Invisible but Invaluable*. London, Age UK.
- ASCOT: Adult Social Care Outcomes Toolkit. <http://www.pssru.ac.uk/ascot/> (accessed 23.09.13).
- Calanzani, N., Higginson, I., Gommers, B. (2013). *Current and future needs for hospice care: an evidence-based report*. London, Help the Hospices.
- Carers UK (2013). *The State of Caring*. London: Carers UK.
- DOH (2008). *Carers at the heart of 21st-century families and communities: A caring system on your side. A life of your own*. London: Department of Health.
- DOH (2010). *Recognised, valued and supported: Next steps for the Carers Strategy*. Policy paper. London: Department of Health.
- Neuberger, J. Baroness (2013). *More Care, Less Pathway: A Review of the Liverpool Care Pathway*. London: Department of Health.
- Hanratty, B. (2013). *Transitions at the end of life for older adults: Patient, carer and professional perspectives*. Final Report to NIHR SDO.
- Hudson, P and Payne, S. (2011). 'Family Caregivers and Palliative Care: Current Status and Agenda for the Future.' *Journal of Palliative Medicine* 14(7): 864-869.
- Hudson, P and Payne, S. (2008). (eds). *Family Carers in Palliative Care: A guide for health and social care professionals*. Oxford: Oxford University Press.
- Ingleton, C., Field, D., Clark, D. (1998) 'Formative evaluation and its relevance to palliative care.' *Palliative Medicine* 12: 197-203.
- Grande G., Stajduhar, K., Aoun S., Toye C., Funk L., Addington-Hall J., Payne, S., Todd C. (2009). 'Supporting lay carers in end of life care: current gaps and future priorities.' *Palliative Medicine*. 23 (4): 339-344.
- Marie Curie Cancer Care, End of Life Care Atlas.  
<http://apps.mariecurie.org.uk/atlas/flash/atlas.html> (accessed 23.09.13)
- Milligan, C. (2009). *There's No Place Like Home: place and care in an ageing society*, Ashgate: Aldershot.
- National Institute for Clinical Excellence (2011). *QS13 Quality standard for end of life care for adults*. <http://publications.nice.org.uk/quality-standard-for-end-of-life-care-for-adults-qs13> (accessed 23.09.13)
- NCPC: The National Council for Palliative Care and The National Care Forum (2012). *A 2030 Vision: Building communities and environments to support people to live and die well*. London: The National Council for Palliative Care.

O'Brien, T., Payne, S., Nolan, M., Ingleton, C. (2010). 'Unpacking the Politics of Evaluation: A Dramaturgical Analysis.' *Evaluation* 16(4): 431-444.

ONS (2013). *2011 Census Analysis: Unpaid care in England and Wales, 2011 and comparison with 2001*, [http://www.ons.gov.uk/ons/dcp171766\\_300039.pdf](http://www.ons.gov.uk/ons/dcp171766_300039.pdf) [accessed 23.08.13].

Payne S., Brearley S., Milligan C., Seamark D., Thomas C., Wang., X & Turner M. (2013). *Unpacking the home': family carers' reflections on dying at home*. Marie Curie Cancer Care funded study 2011 – 1213.

Payne, S and Grande, G. (2013) 'Towards better support for family carers: A richer understanding.' *Palliative Medicine* 27(7): 579-580.

Payne, S. (2010). 'White Paper on improving support for family carers in palliative care: part 1 and 2: Recommendations from the European Association for Palliative Care (EAPC) Task Force on Family Carers.' *European Journal of Palliative Care*. 17(5): 238-290.

Carers UK (2013). *Campaigning for a Better Care Bill*. Policy briefing document: <http://www.carersuk.org/professionals/resources>. (accessed 23.09.13)

Pickard, L. (2008). *Informal Care for Older People Provided by Their Adult Children: Projections of Supply and Demand to 2041 in England*, PSSRU Discussion Paper 2515, London: London School of Economics.

## 11. Appendices

1. Appendix 1: Carer questionnaire

Are you currently able to					Has Age UK's Support helped you?			Without Age UK Support?			
	Most of the time	Some of the time	Seldom	Never	Yes	No	Don't Know	Most of the time	Some of the time	Seldom	Never
Look after yourself - get enough sleep, exercise, eat well & attend to own health											
Spend time doing what you choose											
Take a break from caring responsibilities											
Have control over your daily life											
Feel safe											
Have social contact with people you want to											
Have encouragement & support in your caring role											
Age UK has helped me feel better about myself								Yes		No	
If Yes please explain how you are feeling better about yourself.											
Add any other comments you would like to make. For example, how could we improve this service to help you/other people in your situation?											