



Caring About Older Carers

Providing Support for People Caring Later in Life



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Acknowledgements

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Published by Carers Trust
32–36 Loman Street
London SE1 0EH

Tel: 0844 800 4361
Fax: 0844 800 4362
Email: info@carers.org

Carers.org
matter.carers.org
babble.carers.org
<http://professionals.carers.org>



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1

Why support older carers?



The 2011 Census revealed that there over 1.8 million carers aged 60 and over in England – almost 16% of the population of this age range. This includes a huge 20% of the population in the 60–64 age group, compared with 12.6 % of the overall population. The number of carers aged 85 and over grew by 128% in the last decade (Carers UK and Age UK, 2015).

This group is often invisible, with many older carers providing long hours of vital care and support while their own health and wellbeing deteriorates, resulting in poor physical and mental health, financial strain, and breakdown in their ability to carry on caring.

With an ageing population and increasing demand on health and social care services, supporting older carers better is a key way of keeping people at home, independent and healthy. It can also help to reduce unplanned hospital admissions and avoid premature admission to residential care.

What this toolkit aims to do

This toolkit is targeted at commissioners of health and social care in England and aims to highlight the needs of carers aged over 60 and to show tried and tested ways they can be supported. It shines a spotlight on particular issues most likely to impact on older carers, influenced by factors such as their own life stage, who they are caring for, their circumstances and their own health. This can help inform commissioning to properly and most cost-effectively support them.

It will also help commissioners fulfil duties to prevent, reduce and delay needs and to support older carers under the Care Act 2014.

It is important to remember that older carers are not a homogenous group. Every carer has specific and personal circumstances. The needs and wishes of each individual carer and responses to them will be unique but there are clear recurring issues which, through listening to the needs of older carers in your community and commissioning good quality services, can help older carers stay healthy, independent, and more able to maintain choice and control over their own lives.

Although the terminology and legislation referred to in this guide applies to England the standards and rationale are applicable across the whole of the UK.

About Carers Trust

Carers Trust is a major new charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, **unpaid**, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

We do this with a UK wide network of quality assured independent partners, through our unique online services and through the provision of grants to help carers get the extra help they need to live their own lives. With locally based Network Partners we are able to support carers in their homes through the provision of replacement care, and in the community with information, advice, emotional support, hands on practical help and access to much needed breaks. We offer specialist services for carers of people of all ages and conditions and a range of individually tailored support and group activities.

Our vision is of a world where the role and contribution of **unpaid** carers is recognised and they have access to the trusted quality support and services they need to live their own lives.

The services offered by each Network Partner vary but can include:

- Emotional and practical support for carers including providing care in the home to enable carers to take a break.
- Carers emergency services, offering help in a crisis.
- Outreach work in GP surgeries, hospital wards and schools to reach carers who haven't come forward for support.
- Information and advice on issues such as benefits, grants and other help available.
- Giving carers a voice so that they are listened to by local decision makers.
- Helping carers to share experiences through group support and social activities.
- Access to education, training and employment.
- Supporting young carers through preventative, whole-family work and clubs, activities and mentoring in schools.

To find your nearest Network Partner, call 0844 800 4361 or visit **Carers.org**.

Carers Trust also supports carers through interactive services **Carers.org**, **babble.carers.org** and **matter.carers.org**.

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Older carers – the Care Act and the wider context



To understand the needs of older carers, it's first important to understand the demographics of this group, who they are caring for and how much care they are providing. 54% of carers in England aged over 60 are male, contrasting with 42% of the caring population as a whole. Three in five of carers aged over 85 are male (Carers UK and Age UK, 2015), showing that the gender balance shifts significantly in this older population of carers.

Research in 2011, in a survey of 639 older carers, found that the majority (55% of the whole sample) were caring for their spouse or partner but this increases in older age groups – in the 70 and over group, 87% are caring for a spouse or partner. Approximately a quarter of carers across the age groups were caring for an adult son or daughter.

Older carers in England (UK Census 2011)

	Age 60–64	Age 65–69	Age 70–74	Age 75–79	Age 80–84	Age 85+
Number of carers	630,195	426,510	298,741	226,249	151,674	87,346
Percentage of carers in overall population of this age group	20.0%	17.1%	14.8%	13.8%	12.7%	8.8%
Percentage of carers providing 50+ hours of care per week	20.1%	27.5%	37.5%	45.1%	50.9%	55.4%

Almost one in ten people aged over 85 provide **unpaid** care and the number of carers aged over 85 is expected to double over the next 20 years (HM Government, 2014). Most carers aged over 80 spend more than 50 hours a week caring – with this data corroborated by research in 2011 where most carers aged over 70 recorded caring for over 60 hours a week (The Princess Royal Trust for Carers, 2011). This is a huge task for people whose own health may well be deteriorating, and whose caring role goes unnoticed and unsupported.

The number of older carers is increasing at a greater rate than for carers as a whole. The total number of carers rose by 11% in the ten years between the 2001 and 2011 census, while the number of older carers has risen by 35%.

A national policy perspective

Families and communities depend on carers to provide support that would otherwise need to be met by services – and research suggests the economic value of the contribution made by the UK's carers per year is in the region of £119bn (Buckner, L. and Yeandle, S, 2011). Particularly in times of economic constraint, the support provided by **unpaid** carers is desperately needed, as the need to provide this care would otherwise fall on already overstretched services. Supporting carers themselves to ensure they can carry on caring makes economic sense, and national policy reflects this.

Significant shifts in policy framework have been spearheaded by the Care Act 2014. There is increased emphasis and resources being targeted at greater integration of health, social care and community services to streamline and meet the needs of the changing demographics of the population, with a particular focus on prevention and on reducing unplanned admissions to hospital.

The Care Act 2014

The Care Act 2014 largely came into force in April 2015, with some elements due to come into force in April 2016. It puts in place significant new rights for carers in England including:

- A focus on promoting wellbeing.
- A duty on local authorities to prevent, reduce and delay need for support, including the needs of carers.
- A right to a carer's assessment based on the appearance of need.
- A right for carers' eligible needs to be met.
- A duty on local authorities to provide information and advice to carers in relation to their caring role and their own needs.
- A duty on NHS bodies (NHS England, clinical commissioning groups, NHS trusts and NHS foundation trusts) to co-operate with local authorities in delivering the Care Act functions.

Taken together, these new rights should have a significant impact on carers and the support available for them. However, this is dependent on local authorities putting these in place in a context of financial constraint. A range of publications are available in addition to the Act and its regulations and guidance, to enable local authorities to interpret these new duties (see the Local Government Association website www.local.gov.uk).

NHS England's Five Year Forward View

NHS England's Five Year Forward View (NHS, 2014) places emphasis on supporting carers and particularly highlights those who are aged over 85. It promotes work with GPs and the voluntary sector to identify and support carers. The voluntary sector is recognised as a vital resource, often with reach into underserved groups

and impact well beyond that which statutory services can achieve. It is recognised as providing a rich range of activities including information, advice and advocacy from expert paid staff, alongside the added value that volunteers may bring. The report encourages partnership with voluntary sector organisations that may include grant funding over multi-year periods to achieve positive outcomes.

The Better Care Fund

The Better Care Fund (NHS England, 2015) provides local authorities and clinical commissioning groups – though health and wellbeing boards – with a shared fund to invest in agreed local priorities which support health, care and support, focusing in 2015/16 on reducing unplanned admissions. It provides a key opportunity to promote integration in provision to ensure availability of a range of preventative care and support services. Plans for 2015 were required to state how much was being allocated to carer-specific support indicating that this is a clear priority. Integration is likely to remain a priority in the years ahead, and supporting carers is a key element of this.

The needs of older carers

There is general recognition that some carers can be harder to reach, or perhaps easier to overlook and less likely to access services. Very often this can be because barriers exist in the structure and accessibility of services for some groups of carers or because carers do not expect to receive or actively seek support. In addition, many carers simply do not recognise that they are a carer.

It is vital that those working in a wide range of community based services including primary care are equipped to recognise carers and proactively help them to access appropriate information, advice and support.

Research has shown a range of areas of concern. For carers as a whole, The Personal Social Services Survey of Adult Carers in England 2012–13 (Health and Social Care Information Centre, 2013) showed that particularly high levels of carer needs, expressed in terms of poor quality of life scores, were reported among carers with mental health problems of their own, among carers from Asian/British Asian communities, and among those caring for 15–20 years. This length of caring role is very common, for example, when caring for an adult son or daughter with a disability.

Specifically in relation to older carers, particular needs to consider are:

- Carers aged 60–69 often juggle caring with the demands of work and financial pressures while those aged over 70 may be more likely to find it difficult to cope with the physical demands of caring.
- Carers will be caring for people with a wide range of health conditions and disabilities, with varied emotional and physical demands and concerns for the future.
- Over 16% of older carers in research in 2011 (The Princess Royal Trust for Carers, 2011) were caring for more than one person. This is more common for the younger age group 60–75 where significant numbers care for a parent as well as an adult son or daughter, grandchild or someone else with a disability or long-term health condition.

The following sections look at each of the key concerns for older carers from some of the research above. Each of these areas has been identified for older carers in general but there may be particular groups where an area would be most likely to be a pressing issue, which is highlighted. Each section then looks at how services can be commissioned to help address each of these issues.

Measuring impact: Carers Star

All services that support older carers will need to be able to demonstrate their impact on the lives of the carers they support. The Carers Star is an outcome measurement tool which has been developed for use specifically with carers and covers seven key areas – health, the caring role, managing at home, time for yourself, how you feel, finances and work.

See www.outcomesstar.org.uk/star-guides for more information or email Carers Trust at star@carers.org.

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Identifying and involving older carers



Many carers simply do not realise they are a carer – they may simply think of themselves as someone’s wife, brother, son, partner, friend, neighbour. However, unless carers are identified, it is difficult to get support to them until they reach crisis point. Identifying carers in primary care and community pharmacies, and in other community settings, and referring carers to local carers organisations, can be the first step in helping someone to realise they are a carer and begin to get the support they need.

Particular attention may be required to recognise and involve carers who are less likely to approach services or speak out themselves.

Identifying older carers

Older people may be more reluctant than other carers to ask for or accept help and less likely to reveal their caring status or to identify themselves as a carer. This could be for a range of reasons including a sense that asking for or accepting help is a failure on their part. They may also be fearful of someone else taking over or even removing the person they care for from them, or the person with care needs may be adamant that they will not accept care from anyone else. Additionally, there is often a sense of dignity in remaining independent. It may therefore be that services need a particularly skilled and sensitive approach to older carers to address their concerns and this may be a process rather than a one-off intervention.

A caring situation may not be obvious especially if the person being cared for is not living at the same address. However, older carers are likely to be accessing primary care services such as their GP and community pharmacies with a range of health or other needs for themselves or the person they care for, so these are important places to identify older carers. Health and care staff undertaking home visits are also in a key position to identify carers.

It is important to train health and care staff in carer awareness and the importance of carer identification, and also to establish referral pathways with local carers organisations. This can help ensure that health and care staff not only identify carers but refer them to a local agency which can ensure they are offered a carer’s assessment, and are linked in with a range of local support.

Identifying older carers from diverse communities

Lesbian, gay, bisexual and transgender carers

Research shows that lesbian, gay, bisexual and transgender (LGBT) carers may be less likely to be identified by social care professionals (Musingarimi, P, 2008), than other carers and therefore less likely to receive support and be involved in

decisions. In addition, they may have concern that services or workers may not be LGBT friendly, or they may feel uncomfortable about coming out to people who can help (LGBT Foundation, 2015). With LGBT people making up 5–7% of the older population this is a significant issue.

Carers from black, Asian and minority ethnic backgrounds

Carers from black, Asian and minority ethnic backgrounds (Gregory, C, 2010) are also less likely to take up services or be recognised and involved. All organisations can and should be responsive to the specific needs of black, Asian and minority ethnic carers, but the low take up of mainstream services is often seen as the carers not taking up what is on offer, rather than thinking through institutional barriers or whether the support is culturally appropriate.

Black, Asian and minority ethnic carers are not a homogeneous group and the diversity between and within communities as well as cultural perceptions of disability and caring need to be carefully considered.

Research shows that unless specific provision is made to engage marginalised groups, user and carer involvement will continue to reflect broader social divisions and exclusion (Beresford, P, 2007).

May be most likely to affect

All carers, in particular:

- Older carers new to a caring role.
- Carers of people with long-term degenerative conditions, for example dementia.
- Older carers from black, Asian and minority ethnic backgrounds.
- Older carers from the LGBT community.
- Carers with communication difficulties or whose first language is not English.

Examples of services to identify older carers including from diverse communities

- Links between primary care and community services and local carers organisations to identify and refer carers.
- Training for staff in hospital based and community services in carer identification and referral.
- Targeted work to reach and support marginalised carers (links with duty under the Care Act for local authorities to identify carers and for the NHS to co-operate).
- Joint work with local voluntary groups supporting people from different parts of the community to reach carers from diverse backgrounds.

Positive practice example in the Carers Trust network

Reaching carers in partnership with community pharmacies – Carer-friendly Pharmacies

The Carer-friendly Pharmacy pilot, a partnership between Carers Trust, the Pharmaceutical Services Negotiating Committee and the Centre for Pharmacy Postgraduate Education, has highlighted the key role community pharmacies can play in identifying carers and helping them access other forms of support.

Community pharmacy teams offer a wide range of services to carers such as ordering, collecting and delivering prescriptions, and giving advice on the correct use of medicines.

Following carer awareness training and equipped with bespoke resources to facilitate quick and easy referrals, the pharmacies who took part in the pilot went on to identify 247 carers of whom 118 were aged 60 and above and 19 were aged 80 and above.

With the carer's permission, carers were referred to their local carers organisation and the pharmacy also let the carer's GP practice know that they were a carer.

For more information see <https://professionals.carers.org/carers-friendly-pharmacy-pilot>.

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Health and wellbeing



The health and wellbeing of older carers has been highlighted as an area of significant concern.

Research in 2011 (The Princess Royal Trust for Carers, 2011) found that:

- Two thirds of older carers have long-term health problems. Commonly reported conditions are arthritis and joint problems, back problems, heart disease, cancer and depression.
- One third of older carers report having cancelled treatment or an operation they needed due to their caring responsibilities.
- 50% reported that their physical health had got worse in the last year, and 70% said specifically that their caring responsibilities had a negative impact on their physical health.
- Across all of the older age groups, more than 40% said their mental health had deteriorated over the last year, with 75% of the 60–69 age-group saying that caring had a negative impact on their mental health.
- Less than 50% of carers over 70 who had to lift the person they care for, think that they do this confidently or safely.

Many older carers caring for a partner find themselves having to provide personal care alongside having to do all the household jobs that once were shared, resulting in high levels of stress and physical fatigue.

Tiredness is also a significant issue when a carer is on call for 24 hours a day and may be awake often in the night to attend to the needs of the person they care for. Dealing with challenging or unpredictable behaviour also causes particular stress and emotional strain, for example when the person being cared for has dementia.

Carers' health deteriorates incrementally with increased hours of caring (HM Government, October 2014). This is a concern as data shows that the oldest carers are more likely to spend more hours caring than those who are younger, particularly as this is compounded by the fact that age-related illness will be more likely.

There is a considerable body of evidence (Conochie, G, 2011), to show that carer wellbeing is a key factor in hospital admissions, readmission and delays in the transfer of care. For example, a whole systems study tracking a sample of people over 75 years old who had entered the health and social care system found that 20% of those needing care were admitted to hospital because of the breakdown of a single carer on whom the person was mainly dependent (Castleton, B, 1998).

Supporting Carers: The Case for Change (Conochie, G, 2011) also highlights that carer-related reasons for admission to nursing or residential care are common,

with carer stress the reason for admission in 38% of cases (Bebbington, A et al, 2001). This suggests that giving carers extra support to manage their caring role more effectively and maintain good health could reduce unwanted residential care admissions.

Deterioration in carer health and wellbeing therefore is likely to increase demand on health and social care services for both the carer and the person with care needs. Preventative interventions to support the carer may therefore reduce the likelihood of increased future health, social care or residential care needs of both parties.

May be most likely to affect

Mental health and wellbeing:

- Carers caring for more than one person.
- Older carers working and caring.

Physical health and wellbeing:

- Carers aged over 75.

Both physical and mental health:

- Older carers who need to do physically demanding caring tasks.
- Older carers who often need to be up in the night.
- Older carers of people with dementia or people with challenging behaviour.
- Older carers who have little back-up from other friends or family.
- Older carers who feel strongly about coping without outside support or where the person with care needs is reluctant to accept help from anyone other than the carer.

Examples of services to support carers' physical health

- Health checks for carers aged 60 or over (focusing on both physical and mental health), followed by action to address identified concerns and access to flu immunisation.
- Initiatives to identify and support both the carer and the person with care needs around trigger factors for hospital admission, for example falls and incontinence.
- Opportunities for carers to pursue own interests and activities away from caring.
- Moving and lifting training for carers who need to lift the person they care for.
- Prompt access to appropriate aids, adaptations and equipment.

Examples of services to support mental health and emotional wellbeing

- Access to breaks from caring.
- Opportunities to talk to someone who understands in a non-judgemental way. This includes culturally-specific support for black, Asian and minority ethnic groups and LGBT aware support.
- Opportunities to share experiences and swap information with other carers including those in similar situations, through training courses, workshops and peer-support mechanisms.
- Access to talking therapies specifically targeted at carers.
- Training and support in dealing with difficult behaviour.

What can good support look like?

Case study: Malcolm

Malcolm is 86 years old and living in a rural market town. He has cared for his 83-year-old wife, Linda for the last ten years. Linda has Parkinson's disease, which has led to a dramatic deterioration in her health over the last decade. Her mobility is limited and she now needs two people to help her move from her bed to a chair. In addition, she is doubly incontinent.

With Malcolm's support, Linda has been able to remain in the comfort and familiar surroundings of her own home. Despite very little communicative ability and her limited mobility, Linda's quality of life is supported by the care Malcolm provides.

Malcolm has developed his own health needs and relies heavily on the regular support that the local Carers Trust Network Partner has provided for him over the last ten years. When his dedicated Carer Support Worker visits his home twice a week Malcolm is able to step back from his 24/7 caring role and take some time out for his own wellbeing. He particularly loves to visit his local church and help with church business while the worker is taking care of Linda.

Malcolm has described the service as his lifeline. He knows that the Carer Support Worker is able to take care of his wife's care needs (including hands-on intimate personal care) and this gives him the peace of mind to leave Linda in their safe hands and take some time out to enjoy a life outside his caring role. This dedicated support has given him the help that he needs to maintain his caring role throughout the last ten years, despite his own and Linda's health needs.

Positive practice in the Carers Trust network

Giving older carers a break: Crossroads Care Harrogate, Craven, Selby and York – breaks service

Crossroads Care Harrogate, Craven, Selby and York, supports a high proportion of older carers, particularly those aged 80 plus living in a large, mainly rural area. The oldest carer that they support at present is 96 years old.

The breaks service offers paid Carer Support Workers who visit the home and take over the care of the person with care needs. This allows the carer an opportunity to step back and take a break, so supporting their physical and mental wellbeing.

Staff assess the needs of each client individually, enabling the Carer Support Workers to undertake the tasks normally carried out by the **unpaid** carer so that they can use the time to do whatever they want – housework, shopping, leisure pursuits or simply taking a relaxing break.

Promoting wellbeing through access to counselling: Carers Support Merton – counselling service

Carers Support Merton's carers counselling service attracts many older carers. The service offers 16 sessions with a counsellor, for a donation of up to £3 per session. As part of the wider work of the organisation it seeks to increase the resilience of carers by providing support for their mental and emotional wellbeing.

Many older carers find that the service provides them with a reflective space to share concerns and experiences and make sense of them. Some carers want to talk about and come to terms with fears for the future. The service is often used by carers who are caring for someone at the end of life or following bereavement and provides support through this challenging time of grief and transition.

The organisation recruits volunteer counsellors who are qualified or on recognised training courses that comply with the British Association of Counselling and Psychotherapy Code of Ethics and Practice. All counsellors must evidence being in regular, professional supervision.

Providing breaks and preventing escalation of needs: Carers Association in South Tyneside – Befriending Sitting Service

The Befriending Sitting Service provides an opportunity for carers to have time out from their caring role. It offers a befriender or volunteer who will sit with the person with care needs or assist them to go on outings. The majority of carers using the service are aged over 70 and around 70% of those are caring for someone with dementia.

Carers and the people they care for are matched with a paid befriender or volunteer. Paid befrienders offer a regular weekly visit of around 2–3 hours to spend time with the person with care needs, share news and memories or accompany them on an outing. Carers with the highest needs on the waiting list are given priority for receiving the service. Volunteers offer similar support on a less structured basis. The service allows the carer to have a break, safe in the knowledge that they know the person they care for is being looked after.

Befrienders and volunteers are also able to recognise emerging needs and concerns, and intervene early to offer support. The service is particularly helpful for carers after the person they care for is discharged from hospital, helping both the carer and the person they care for to stay active and preventing readmission.

This service has a strong partnership link with the local Alzheimer's Society which offers free training for volunteers and makes regular referrals to the project.

The service is supported with a mix of funding from the clinical commissioning group and South Tyneside Council.

5

Financial concerns



For many older carers, financial concerns can have a particular impact on their wellbeing. Older carers can feel significant anxiety about financial matters and may be reluctant to access services that would support them or the person with care needs due to limited financial means.

Research findings show that:

- Carers aged 60–64 may experience some of the greatest financial difficulty (The Princess Royal Trust for Carers, 2011).
- Many carers give up work to care and find it hard to return to the workplace after a period of absence (HM Government, October 2014). It should be remembered that many people work well into their 70s and even older.
- Many thousands of older carers are missing out on benefits to which they are entitled because they do not know what is available, they are reluctant to claim benefits, they assume that they would not be eligible or because the process for applying is too complicated (Age UK, 2014).
- Carers of adult sons or daughters with learning or other disabilities have concerns about their future which include financial concerns (Mencap, 2012).

Carers approaching retirement will be at a key point in life where changes in income may be a particular concern. Welfare benefit entitlement may alter over time, reflecting increasing age or changing health needs of the carer or person with care needs. Carers may need specialist advice in order to understand these changes and to make benefit applications accordingly.

The Care Act specifically takes account of someone's economic wellbeing as part of a definition of what issues need to be considered with regards to wellbeing overall. Additionally, local authorities are required under the Care Act to identify adults (including carers) who would be likely to benefit from independent financial advice and help them to access it, so that they can get support to plan and prepare for the future costs of care or to consider how they meet current care costs.

May be most likely to affect

- Carers aged 60–70.
- Older carers who have given up work to care.
- Older carers who have not accessed appropriate information and advice.
- Older carers of an adult son or daughter with a disability.

Examples of services to support carers' financial circumstances

- Information and advice about welfare benefits.
- Support to claim benefit entitlement.
- Carers discount card schemes.
- Support for working carers to remain in work.
- Small grants for carers.

Support for carers to improve their financial circumstances are often provided as part of a holistic package of support by carers services.

What can good support look like?

Case study: Norman

Norman is 90 years old and cares for his wife, Joyce, who is 89 and has become very frail with osteoporosis and arthritis. Norman takes care of most of the day-to-day tasks around the home including cleaning, shopping and cooking and had managed for the last three years without any outside help. He helps Joyce with getting dressed and washed.

However, recently Norman's own health has deteriorated and he is finding that he is becoming very tired. He was concerned about asking for help as he feared that he and Joyce might be separated and that she may need to go into residential care. A relative who was concerned about him persuaded him to speak to his local Carers Trust Network Partner who arranged a home visit.

The Support Worker from the Network Partner offered help in a variety of ways. She understood Norman's concerns about asking for help and supported him and Joyce to access social services and receive an assessment of their needs. As a result, a care package was put in place to help Joyce remain at home and to take the strain from Norman. The worker also helped Norman to claim Attendance Allowance and this allowed him to pay for some help to do some of the household tasks. Norman was linked up with a local male carers support group and now enjoys getting out from time to time and meeting other carers.

The support that has been put in place has enabled Norman and Joyce to remain together in their own home and has helped Norman to be able to continue caring for his wife and to have enough rest so that his own health has improved.

Positive practice in the Carers Trust network

Meeting older carers' financial and other needs: Redbridge Carers Support Service – older carers project

Currently 500 older carers are registered with the service. Many older carers find it difficult to leave the person they care for in order to access drop in based services and prefer a face-to-face service rather than internet or telephone based options. This service was designed to meet their needs.

Within two weeks of an older carer contacting the project, an assessment visit is made to the carer's home by their allocated Support Worker. The carer and the Support Worker develop a personalised support plan which identifies the immediate information and advocacy needs of the carer as well as longer-term needs to address isolation and wellbeing. Where the carer is looking after a spouse or partner, one of the goals is often around how they can do activities together as partners.

Carers are supported to make claims for welfare benefits they may be entitled to, and referrals made to statutory and other voluntary sector agencies. Some carers need time and support to accept help from other agencies and the service often finds itself helping support statutory services by being the hub and knitting services together by being able to take the time to explain what the various services do and support carers to accept help.

Volunteer befriending is one of the services provided as part of the support plan. Befrienders can visit a carer once or twice a week in order alleviate isolation. They will also make phone calls to check in with the carer.

The support plan will also highlight the core Redbridge Carers Support Service activities available to all older carers. These may include:

- Basic computer training so shopping can be done online and Skype can be used to keep in contact with family members. 60 older carers have accessed these classes in the last two years.
- The Carers Emergency Alert Card which provides reassurance when the carer is outside the home.
- Social and creative activities such as card-making workshops.

6

Social isolation



Older carers are often concerned about their own social isolation caused by the demands of caring and by the gradual weakening of friendships as caring continues. Older carers of a partner may have lost a joint social life and interests. After the caring role comes to an end, particularly after the death of the person with care needs, time spent caring may have eroded friendships and interests outside the home, leaving the former carer in an extremely socially isolated situation.

Social isolation is compounded by a lack of respite and breaks from caring. More than two thirds of older carers in the Always on Call, Always Concerned research (The Princess Royal Trust for Carers, 2011) reported not getting breaks away from caring at all with a further third only getting a break once every 2–3 months or less.

Studies have shown how supporting carers or providing them with a break can improve their health. One study found that 35% of carers without good social support experienced ill health compared with 15% of those with good support and that fewer carers experienced mental health problems if they had taken a break since beginning their caring role (Singleton, N, et al, 2002). Additionally, it is acknowledged that male carers tend to be less likely than female carers to access carers services and breaks and this can compound issues of isolation. Research in 2014 found that older male carers often felt local support services did not meet their needs (Slack, K and Fraser, M, 2014).

A key principle in the Care Act is that of prevention of the escalation of need. Local authorities have a duty to prevent, reduce or delay the need for support and this specifically includes provision for carers. Services that help to reduce loneliness and isolation are specifically highlighted in the guidance as an important factor to address this duty.

May be most likely to affect

- Older carers providing 50 hours or more a week of care or where the person with care needs is housebound or has mental health problems including dementia.
- Older carers who do not receive respite support or breaks.
- Older carers who feel strongly about coping without outside support or where the person with care needs is reluctant to accept help from anyone other than the carer.
- Less mobile carers.
- Carers for people at the end of life and bereaved carers.
- Older male carers.

Examples of services to support carers' social inclusion

- Peer support groups.
- Befriending schemes (face-to-face and telephone).
- Respite care services.
- Carers social groups.
- Outings, short breaks and activities for carers.
- Training and support to use IT.
- Activities which can involve the carer and person they care for together.

What can good support look like?

Case study: Barbara

Barbara is 72 and has been caring for her partner, Rowena, 68, for the past six years due to her chronic obstructive pulmonary disease. Rowena is on a continuous supply of oxygen and had been experiencing depression for a number of years. She had also been extremely anxious and withdrawn. Barbara had found it increasingly difficult to cope with her caring role as Rowena was very nervous about having other company other than her partner and daughter and so Barbara was becoming less and less able to leave her.

The Carers Trust Network Partner introduced a volunteer befriender to Barbara and Rowena four years ago. The befriender built up a good relationship with the couple and Rowena now confides in her. The befriender started to engage Rowena in craft activities at home and Barbara was able to leave them together and enjoy some time to herself. Over time, Rowena started to go on outings with the befriender, which she had not felt able to manage for a number of years. They now go on trips to the garden centre and local park.

Barbara is astonished at the change in Rowena's outlook. She can see that with the support of a befriender Rowena feels more independent, capable and valued. Barbara is able to have some time to herself, see friends and link in to activities, and feels more able to cope with her caring role.

Positive practice in the Carers Trust network

Building an inclusive older carers community: York Carers Centre – addressing loneliness and isolation

York Carers Centre has worked closely with the Joseph Rowntree Housing Trust in New Earswick to identify older carers to address issues of loneliness and isolation. It uses the local hall to provide a place for older carers to meet and have a meal together. This ensures that carers are never far from home or the person they care for so they are more likely to attend meetings.

The meetings provide an opportunity for participants to take part in social activities, get information and advice and have respite from their caring role. The group sometimes has visiting speakers, such as a local solicitor to talk about will-writing. The group is involved in having a say about the developments that are happening on the housing estate and links in with other activities at the hall. The carers centre support staff are also able to help carers to consider their own health and wellbeing and ensure that they are receiving the support that they need.

The group is funded with local authority funding and a grant from a York-based charitable foundation. This has enabled the group to buy tablets – responding to an expressed interest in the use of new technology by carers. This has led to inter-generational work with younger carers showing older carers how to use the tablets. The focus is on the use of tablets to aid socialisation, increase engagement in community links and take advantage of technology, for example by learning how to use health apps.

This gives carers increased patient access to their own medical health records and allows them to be more involved in managing their health through access to new technology. It has also opened up opportunities to use the tablets for reminiscence activities, which are especially valuable for carers of people with dementia.

The older carers group provides a local solution for about 20 carers each week where they can receive a range of help and build friendships. Some carers have gone on to socialise outside the meetings and access other local community activities together.

Combating isolation for carers of people with dementia: Swindon Carers Centre – Open Minds group

Swindon Carers Centre started a group in 2013 for carers over the age of 65 who care for someone who is over 65 or has some form of dementia. This was in response to a specific request from carers as they found it difficult to attend events if they could not go along with the person they were caring for.

The group was named Open Minds by the carers themselves. They meet monthly with a different type of activity each time – including craft, singing, dancing and outside entertainment. The group is facilitated by two members of staff and a couple of volunteers who help with refreshments and other tasks. As a result of a very well attended tea dance this has also now become a regular bi-monthly event with around 52 carers and the people they care for attending.

Taxis are provided for people who have mobility issues or could not otherwise attend the events. This service is supported by volunteers from the church who host the dance and is an excellent example of community partnership working.

Carers have stated that they find the group a safe and welcoming environment where difficult behaviours are not frowned upon. The group has become extremely popular and has a regular attendance of around 46 people. It has now become widely known throughout Swindon.

The group has been funded by a local charitable fund and is now looking to develop and expand due to the overwhelming popularity and success of the project.

7

Concerns for the future



More than 80% of older carers responding to research (The Princess Royal Trust for Carers, 2011) had worries about the future including what will happen to the person they care for if they can no longer care for them. There is also considerable concern among older carers about how they will cope if the needs of the person that they care for become more severe.

The Care Act requires that a carer's assessment considers the carer's potential future needs for support as well as those currently present. Carers play a significant role in preventing increased needs for care and support for the people they care for. It is important that local authorities also put in place support to prevent carers from developing needs for care and support themselves. This could include emergency planning, as well as planning for what help may be required if and when the health of the carer or person with care needs deteriorates.

In some areas an emergency care scheme exists, where arrangements are in place to deal with situations where a carer, for example is taken unwell. Research suggests that the peace of mind this brings for carers enables them to continue to provide day-to-day care and promotes their own resilience, knowing that if anything untoward happens, there are arrangements in place (Elwick, H and Becker, S, 2011).

The Care Act guidance also highlights that services which encourage early discussions in families about potential changes in the future are important in addressing a local authority duty to prevent escalation of need. It specifically mentions conversations about potential care arrangements or suitable accommodation should a family member become ill or disabled.

Lasting power of attorney

If there is concern that the person with care needs will lose their capacity to make decisions for themselves, it is important that lasting power of attorney is put in place while they still have capacity to express their wishes.

It is often assumed that lasting power of attorney relates only to finance and property, when in fact it can also relate to health and welfare, meaning that a person can let their wishes for their future care be known. Often, due to the sensitivity of the subject, people wait too long to put lasting power of attorney in place, resulting in a much longer and more complex process later. Further information on making a lasting power of attorney is available at www.gov.uk/power-of-attorney/overview.

Older carers of adult disabled sons and daughters

Older carers of adult disabled children will often have been caring for their son or daughter (sometimes more than one) since they were born, as well as possibly caring for their own parents or partner. Research (Mencap, 2012) indicate that key concerns and needs for this group of carers are:

- The need for help with emergency planning in case the carer is admitted to hospital.
- The need for help with planning for the future financial, housing and care needs of the person being cared for. This includes legal information about leaving money or property by will or trusts.
- The need for assessments and care packages that recognise the changing needs of both the parent carer and the person being cared for as the parent becomes less active and needs more help with domestic and personal care tasks. Parents in this situation, as well as their son or daughter, may express fears that they may be separated. This mutual caring needs to be recognised and receive an appropriate response through sensitive use of personal budgets and practical help (Foundation for People with Learning Disabilities, 2015).

Carers of people with dementia

Carers of people with dementia also have particular needs in terms of planning. With nearly half of carers aged over 75 caring for someone with dementia (Carers UK and Age UK, 2015), this is a crucial group whose needs should be addressed. Research commissioned by Carers Trust (Newbronner, L, et al, 2013), identified the caring journey undertaken by carers of people with dementia and the different needs of carers at various points of this caring journey.

Ten stages of caring were identified and associated needs described including timely diagnosis, information about dementia and its progression, when the capacity of the person with dementia declines, when the person loses mobility or develops behaviour problems, and when incontinence becomes an issue. These form a framework for how support for this group can be developed. Planning for these can be a vital element in helping carers cope.

May be most likely to affect

- Older carers of adult disabled children.
- Older carers of people with deteriorating health conditions.
- Carers aged over 75.
- Older carers with poor or deteriorating health.
- Older carers who feel strongly about coping without outside support or where the person with care needs is reluctant to accept help from anyone other than the carer.

Examples of services to support older carers to plan for the future

- Emergency planning support.
- Emergency care schemes.
- Long-term planning support.
- Counselling and mentoring support.

Positive practice in the Carers Trust network

Helping older carers plan for the future:

Wandsworth Carers Centre – Emergency Planning Service

Wandsworth Carers Centre offers a framework and support for carers to plan for the future and for emergencies. Many of those using this service are older carers. The centre uses the Carers Star outcomes measurement tool and often during discussions around this with carers they will identify the need for a carer to plan for the future and for emergencies.

The Emergency Planning Service primarily receives referrals from social services as well as self-referrals and works with carers to identify the services that would be required in the event of an emergency if they were unable to care. The carer is then provided with a card with a unique identifier. The information from the plan is logged on social services' records so that in the event of an emergency a record of the needs of the person being cared for can be easily retrieved and emergency support can be put in place.

The Future Planning Service allows carers to consider options for the future as, perhaps, their caring ability gradually decreases or the needs of the person they care for increase. These conversations are sensitive as carers may find these issues particularly hard to face. Skilled staff are therefore needed to help carers with this. The centre is also trialing short courses specifically designed to help carers begin to have these difficult conversations and to understand the variety of options that may be available for the future.

Emergency support and longer-term planning:

Carers Trust in Greater Manchester Crossroads care service – Bolton Older Carers Project

The Bolton Older Carers Project provides:

- Short-term emergency support to older carers in crisis (for example if they are unwell or have an accident that prevents them providing care).
- Help with future planning for older carers and the people they care for.

Carers Trust in Greater Manchester had identified that the capacity of older carers to continue caring can diminish over time as a result of failing health, reduced

energy and exhaustion and that older carers had serious concerns about what would happen to the person they care for when they were no longer able to care or had reduced capacity for caring.

The Bolton Older Carers Project takes a strategic approach to the provision of services to older carers by not only providing short-term emergency support when there is a crisis, but also supporting and advising older carers with long-term planning options. Workers make a visit to each older carer to carry out an initial assessment which will be used in an emergency situation, provide them with information so they can make informed choices about future emergency situations, and help put together a plan for the longer term. The service also:

- Provides information and signposting to other services.
- Helps the family to make a referral to appropriate services to help them continue in their caring role.
- Supports families to think about the future and consider options for the longer term.
- Assists older carers to plan, prepare and consider options for the time when they are no longer able to care.
- Supports older carers to put in place an emergency plan.

The project has two dedicated part-time Support Workers who provide emergency support when required, engage with older carers to build up relationships and put in place long-term plans, and support carers to deal with problems before they turn into crisis.

Having support available in an emergency and future planning in place gives great peace of mind and comfort to older carers living in Bolton.

The project takes referrals from Bolton Council's Adult Care Team and Bolton Carers Support.

8

Information and advice



Information and advice is crucial to carers, both to help them in their caring role and also for aspects of their own lives. However, carers often say that access to information is patchy, or comes too late to be of most use.

The Care Act 2014 now places a clear duty upon local authorities to provide an information and advice service for those with care needs, and carers. In particular, the Care Act guidelines are clear that such information and advice is likely to include a range of approaches and channels including face-to-face, telephone, peer support, online and media information.

It is important that carers and families have time to think through their options and make informed decisions about their own lives alongside caring, including decisions about remaining in education or paid employment, claiming benefits and contributing to pensions. Early access to information and advice and, where appropriate, early intervention (rather than waiting until a crisis occurs), are key elements in supporting people to undertake caring roles effectively.

A number of 'trigger points' for the provision of information and advice are also suggested in the Care Act:

- Hospital entry or discharge.
- Diagnosis of health conditions.
- Application for Attendance Allowance, Carer's Allowance, Personal Independence Payment.
- Contact with local support groups and charities.
- Contact with or use of private care and support services.

Many older carers are more likely to approach services to get support for the person with care needs than themselves and may never self-identify as a carer. It is therefore vital for staff and volunteers in other health, social care and community settings to be carer aware and to recognise that someone may be a carer and in need of information and advice. They should also know where to signpost people and what information and advice services are available.

Older carers may particularly struggle to access standard information and advice services due to being unable to leave the person with care needs at home for long enough periods of time or due to their own mobility. They are also less likely to have access to online information. Therefore, provision that takes into account these limitations is key to supporting older carers.

Examples of services providing information and advice for older carers

- Services providing access to timely information and advice as these underpin every area of carers' needs and concerns, including those listed above. For example, a carer may need information and advice about the medical condition of the person with care needs, especially at critical points such as at diagnosis or while in hospital following a trauma (for example, a stroke or fall).
- Services available to support carers' needs or the needs of the person they care for. Information may be needed about:
 - Power of attorney, wills and trusts.
 - Welfare benefits.
 - Health and social care services, pathways and assessments.
 - Access to breaks from caring.
- Services to help carers maintain their own health and wellbeing.

Carers may also need:

- Options about how they access information, for example online; leaflets; phone helplines and face-to-face.
- Active assistance to claim welfare benefits or social care assessments.
- A range of information options and assistance available for carers whose first language is not English.
- Proactive initiatives to check-in by phone with older carers identified as caring intensively and/or caring for people with degenerative conditions, for example dementia or cancer, to identify deteriorating situations.
- Home visits for older carers who are caring intensively and/or caring for people with deteriorating conditions.

Positive practice in the Carers Trust network

Ensuring older carers get the range of information and advice they need: Camden Carers Centre – Older Carers Outreach Project

This project works with carers who are aged 70 and over to reduce isolation and improve the health and wellbeing of older carers. A key part of the service is a targeted telephone outreach service which works with isolated or housebound carers to encourage them to re-engage with their local communities and support services, where appropriate.

The service can offer support based on the needs identified and examples of outcomes achieved include:

- Identifying risk where carers are lifting the person they care for and likely to cause themselves harm, and referring for appropriate support.

- Carers feeling happy that they have a connection with the carers centre and able to turn to them if their situation deteriorates.
- Information and referral to other relevant organisations to offer carers support.
- Identifying safeguarding concerns and taking appropriate action.
- Providing access to a programme of events and activities. These include joint events for carers with the people they care for, especially in situations where the person they care for has dementia.
- Specific outreach work to very isolated or housebound carers, to encourage them to re-engage with their local communities and support services, where appropriate.

Public health is funding an expansion of this service to include the recruitment of volunteers to offer outreach support to carers in their own homes and help carers with identified concerns. This includes linking with specialist support, supporting the carer and person with care needs to accept and access help with the caring role, linking carers to each other to create new networks and accompanying carers to community activities when they are lacking in confidence to go alone. This service will also help carers to consider the sustainability of caring relationships and to support people through difficult decisions.

Carers access the service through referral from health and social care, supported housing, local day centres and community centres or can self-refer.

9

Assessment, support planning and involvement



Assessment

Carers are often unaware of their rights to a carer's assessment, or are unclear of its purpose, or are fearful of intrusion from social care professionals. Sometimes they are anxious that they are being assessed to see if they are a "good enough" carer. A great deal can be done to improve these perceptions including providing information in advance to help understand the purpose of an assessment and plan for it, and ensuring follow up, as found by research by Skills for Care and Carers Trust (Carers Trust and Skills for Care, 2013).

The Care Act opens up the right to a carer's assessment to all carers in England with the appearance of need, regardless of their financial resources or those of the person they care for. This must establish the carer's need for support and how practical it is for them to carry on caring. It is vital that the assessment is a meaningful experience for carers, and that they have the chance to fully engage with this.

Assessments may be combined, for example the carer can be assessed along with the person with care needs but this must be the wish of everyone being assessed. However, this can lead to a situation where one party is reluctant to state their feelings for fear of upsetting the other, and may result in their needs not being expressed or addressed.

Carers can also be offered self-assessments. However, self-assessments are not appropriate for all. Many carers are not aware of support available or are reluctant to ask for it. A face-to-face assessment is often needed to build trust and open up possibilities for support.

If carers have difficulty in engaging with the process of assessment then local authorities have a duty to provide independent advocacy to represent and support carer involvement in assessments and preparing support plans.

Support planning

Carers themselves have the right to a support plan following an assessment and to be involved in the preparation of a care and support plan for the person they care for and to receive a copy of that plan. Processes need, therefore, to be in place both to recognise and involve the carer when the person with care needs is in contact with health and social care settings and to appropriately assess the support needs of the carer themselves. They also need to ensure assessment and care and support plans link together appropriately and use a whole family approach.

Some carers value the flexibility of a direct payment for the person with care needs so that they can buy in appropriate help, for example help getting the person with care needs to bed – others feel overwhelmed by the burden of employing and

managing someone, and processing the direct payments. Support therefore is often needed to ensure that managing direct payments does not become another job for an already overstretched carer.

Carers who are eligible will, under the Care Act, have a personal budget for their own support. Carers should be encouraged to think about what would help them improve their own wellbeing, and a very broad approach taken to what a carer's own direct payment can be used for, providing it supports them to meet this objective.

Involving carers as experts and partners in care

The NHS Five Year Forward View (NHS England, 2014) acknowledges the need to recognise that patients, their family and carers are often 'experts by experience'. Many older carers have very long experience of caring and yet this may be easily overlooked. The Triangle of Care (Carers Trust, 2013) model for carers of people with mental health problems, including a specific adaptation with the Royal College of Nursing around carers of people with dementia, is a clear and comprehensive model that demonstrates good practice in partnership working between service users, carers and professionals. It shows the benefit of involving carers as partners in the care of the person they support, both for the carer themselves and the person they care for.

May be most likely to affect

- Older carers interacting with statutory and other services about the needs of the person they care for.
- Older carers who feel strongly about coping without outside support.
- Older carers from diverse groups less likely to access assessment.

Examples of services to support assessment, support planning, and involvement

- Assessment and planning processes which are flexible to meet the needs of carers.
- Advocacy services to represent and support carers if needed.
- Involvement of carers as partners in care, especially at key points in the life of the person being cared for, for example admission and discharge from hospital, during care planning, and at points where the care needs change.
- Information, advice and training that addresses different aspects of caring at different points in a caring journey.
- Creative carer involvement in local strategic planning in health and social care.
- Training for professionals to raise carer awareness.

What can good support look like?

Case study: Yusuf

Yusuf, who is 86, cares for his wife Fatima who is 89. Yusuf has been caring for her for around four years.

Yusuf provides Fatima with physical support with moving around indoors, getting out of a chair and in and out of bed. He also supports her with getting in and out of the shower and helps her with getting dressed, particularly helping her to put on her shoes and socks. He accompanies her outdoors, providing reassurance and physical support. He also offers emotional support, making sure that she takes her medication and accompanying her to her appointments.

Fatima does the cooking but needs help with tasks such as reaching, lifting and carrying.

Yusuf feels that their relationship is very good but that caring has limited his social life as the difficulty of going out with Fatima means that he often has to leave her at home. He cannot go out for long and when out he is constantly checking to see if Fatima has phoned. He doesn't get to see his sons and their families as often as he would like to.

The Carers Trust Network Partner supported the couple with:

- A successful claim for Attendance Allowance.
- Obtaining equipment including a pendant alarm, chair, shower chair, shower rail and frame.
- Accessing a carer's assessment.
- A Carers Emergency Card.
- A £400 Carers Break grant towards a holiday break.
- Information and advice about the Mental Capacity Act and lasting power of attorney.
- Obtaining a cinema discount card to help them get out more.

Yusuf felt that the services provided gave him peace of mind, stress relief and helped to prevent injury from lifting.

Positive practice from Carers Trust

The Triangle of Care: Carers Included: A Guide to Best Practice for Dementia Care (Carers Trust and Royal College of Nursing, 2013) was developed in partnership with carers, people with dementia and professionals to help acute hospitals identify and support carers when the person they care for is admitted to hospital. The Triangle of Care is based on six principles which if implemented by a hospital ward (and wider acute services) means the carer is identified earlier, involved equally in care and provided with support. It provides an opportunity to ensure the best care for the patient by engaging fully with the carer and ensuring the carer has support

for their own health and wellbeing as well as addressing any support needs for the person they care for. The guide, developed by Carers Trust and the Royal College of Nursing, includes good practice examples as well as a self-assessment tool to enable services to measure where they are and how they can improve.

The Triangle of Care – six standards

- 1** Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
- 2** Staff are 'carer aware' and trained in carer engagement strategies.
- 3** Policy and practice protocols regarding confidentiality and sharing information are in place.
- 4** Defined post(s) responsible for carers are in place.
- 5** A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.
- 6** A range of carer support services is available.

(Carers Trust and Royal College of Nursing, 2013)

10 Bereavement and life after caring



Many older carers will have been caring for many years. Some will have given up work to care for a parent or partner and others will have been caring for an adult son or daughter for most of their adult life.

The period when the caring role comes to an end because of the death of the person they care for is a particularly vulnerable time for the carer, who has to deal with both bereavement and the loss of a key role in their life. Research (Larkin, M, 2009) shows that carers report feeling a 'void' after the death that is linked, of course, to the bereavement but also quite clearly to the loss of their caring role. It takes time, effort and often external support to help rebuild a different life after caring.

Often much of the contact that the carer has had with others has been related to their caring role (for example social care staff, medical appointments and paid Carer Support Workers) and so the former carer can easily become very isolated and struggle to re-engage socially. There is often a limited time post-bereavement when carers can access carers services and the full emotional effect of the loss can take some time to emerge.

Carers can also experience challenges with the change in their day-to-day caring role when the person they care for moves into permanent residential care. The carer still has a significant caring role but this will change considerably and carers will need to cope with a considerable period of readjustment.

Examples of services providing support after caring:

- Counselling services.
- Life after caring peer support or training groups.
- Information and advice services and signposting.
- Befriending schemes.
- Advocacy and mentoring services.

What can good support look like?

Case study: Patience

Patience is 66 years old and cared for her mother, Angela, who was diagnosed with dementia seven years ago. Patience gave up work at the age of 59 to care for her mother as her condition had deteriorated. Angela moved in with Patience at that time and Patience had managed to continue to care at home right up till the point when Angela was taken into hospital with a chest infection just before her death six months ago. During the past seven years Patience has lost contact with most of her friends and her only other relatives live abroad. The last two years in particular had allowed her little time to have a life outside her caring role.

Since Angela's death Patience had really struggled to find purpose in her life and had become depressed and anxious about going out. She had seen her GP and been prescribed anti-depressants.

Patience was invited along to a facilitated group for bereaved carers at her local Carers Trust Network Partner over eight sessions. At this group she met other bereaved carers who understood what she was going through and she felt able to discuss her grief and loss for the first time. She gradually began to be able to think about how to rebuild her life and feel more positive about her future. By the end of the group sessions she was looking into undertaking voluntary work, had made new friends and was feeling more confident.

Positive practice in the Carers Trust network

Supporting carers looking after someone at the end of their life: Carers Network, Westminster, Hammersmith and Fulham – End of Life Carers Project

The End of Life Carers Project is a specialist project for carers aged 65 and over looking after someone approaching the end of their lives. It is funded for three years by City Bridge Trust, was set up in autumn 2014 and is being delivered by Carers Network across Westminster, Hammersmith and Fulham. Eligible carers are those looking after someone:

- who has a terminal diagnosis and is likely to die within a year, or
- who is aged 80 and over with complex conditions, or
- who is in residential care.

Through home visits and over the phone, the project helps carers have a better quality of life by ensuring they access all the financial, legal and practical help and information available from both statutory and voluntary services. Through the provision of services, equipment and breaks, it helps carers to have some life of their own alongside caring. It also helps the person they are caring for to choose to die at home if they wish. Both the carer and the person being cared for therefore have more choice and control at this stage in their lives.

Through one-to-one sessions and in workshops, carers are able to talk about the following kinds of issues:

- How to start talking about dying to the person being cared for, to family members, friends and others.
- Condition-specific information and end of life choices around the person's wishes about where they die and treatment options.
- Funeral arrangements and practical matters following a death.
- End of life and spirituality and culture.
- Carers' transition planning at the end of their caring role.

Key to the success of the project are the close working relationships developed with a range of health and social care agencies. Strong links have been made with the local GP's End of Life Register, with the broader primary care providers, hospices, Macmillan Nurses, Admiral Nurses, hospitals and Community Matrons.

11 A checklist for local support



1 Identification

- Is training in place to raise awareness of older carers in order to enable health and care staff to proactively identify them and know what to do?
- Do we have clear referral pathways in place for those agencies identifying older carers, including referrals to local carers organisations?
- Do we ensure we identify carers from diverse communities?

2 Prevention

- What services do we have in place that prevent, reduce or delay the need for support for older carers?
- Do these services specifically address the following needs:
 - Health and wellbeing (physical, mental and emotional).
 - Financial concerns.
 - Social isolation.
 - Concerns for the future.
 - Life after caring/bereavement.

3 Information and advice

- Are information and advice services easily accessible for older carers who may have difficulty in visiting a central point in restricted times or do not have internet access?
- Do staff and volunteers in information and advice services understand and recognise key trigger points in the caring journey?

4 Assessment and support planning

- Are there clear accessible pathways for older carers to receive a carers assessment?
- How is this information shared?
- Are face-to-face and individual assessments offered as well as combined assessments and self-assessments?
- Are there agreed ways of support planning for carers, and involving older carers in developing care and support plans for the people they care for?

- Are older carers supported to use direct payments for themselves and others?
- Is assessment and support planning for carers and people with care needs joined up so that a whole family approach is used?

5 Recognition and involvement

- How do we involve older carers in local policy and service development?

6 Monitoring and evaluation

- How do services measure the impact of their work on older carers' health and wellbeing, financial situation and social isolation?

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Carers Trust

32–36 Loman Street
London SE1 0EH

Tel: 0844 800 4361

Fax: 0844 800 4362

Email: info@carers.org

Carers.org

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