



# **Older men who care: understanding their support and support needs**

**Professor Christine Milligan**

**&**

**Dr Hazel Morbey**

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## Executive Summary

This two phase study was undertaken in the north west of England. In Phase 1, written narrative accounts were gathered from fifteen older men (aged 50 years and above) about their experiences of caring for their wives or partners and the forms of formal and informal support they draw on. In Phase 2 a series of semi-structured individual and small group interviews was conducted with nine care providers from the statutory and voluntary sectors. Phase 2 was designed to ascertain whether care-providers: a) viewed and/or assessed the support needs of older male care-givers differently to that of older female care-givers; and b) whether this may manifest in different forms of support being offered or developed.

**The following is a summary of the key findings arising from the analysis of this study:**

- Older male carers can often be characterised by non-awareness, reluctance or resistance to identify with a 'carer' label.
- Older male carers experience impacts from their caring role, manifest in the physical, mental health, fitness, financial and social areas of their lives.
- Sense of loss is profound; loss of futures, plans, relationships and friends.
- Gendered role assumptions influence older male carer identities, constructed through the performance of care tasks or the fulfilment of a carer role.
- Deep social isolation characterises older male carers' sense of connection to friendships or supportive networks.
- Older male carers report mixed experiences of statutory health and social care support with service assessments tending to focus on domestic roles and tasks, and areas less relevant to older male carers.
- Older male carers find practical solutions to managing the challenges of caring; harnessing their existing skills and experiences can present older male carers with supportive strategies and role affirmation.
- Gender may be an influencing determinant regarding privately purchased domestic and household services.
- Age and previous career can make a difference to what support is required and knowledge of where to access that support.
- Older male carers are less likely and less forthcoming in asking for help and support than older female carers; they tend to reach crisis point before asking for support from care services.
- Older male carers can experience limited family support especially at distance, and for rural and retirement communities.
- The cared-for's need for personal care often marks the point at which service intervention is requested by older male carers.
- Older male carers are primarily interested in practical support.
- Older male carers are less likely to get involved with carers' support groups and other group activity that is largely female dominated deepening their social isolation.
- Older male carers may experience difficulty acknowledging the emotional aspects of caring.
- Through the research process, care practitioners developed a growing awareness of significant gender features to their work.
- Gendered nuances subtly underpin care provider's experiences of older carers and their assessment of needs.

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## 1. Introduction

The UK population is rapidly ageing; and whilst many older people lead healthy and active lives – especially in early retirement - with increased age comes an increased risk of declining health and mobility (Milligan, 2009). Older people who experience a decline in their physical or cognitive health often require the help and support of a spouse or other family care-giver to undertake activities of daily life – from shopping, cooking and cleaning to the more personal care tasks such as help with dressing, bathing, medication and toileting.

Today, 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). This informal care can vary from a few hours a week undertaking fairly simple domestic tasks to over 50 hours per week for those who take on more intensive care-giving responsibilities. The extent of this informal care-giving has been estimated to save the UK economy more than £119 billion a year (Buckner, 2011). With an ageing population, and policies focused around ageing in place, this economic saving is set to increase substantially in coming decades – indeed, Pickard (2008) estimated 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, but it does rely significantly on the availability and willingness of people to undertake this unpaid work. This not only places carers at the centre of future health and social care strategies in the UK, but indicates that informal carers should be viewed as partners in the care of their family member.

Historically, informal care-giving for our older populations has been undertaken largely by women (ONS, 2013a), however, whilst *overall* women still assume a greater caring role than men, this very gendered landscape of care-giving is changing – particularly amongst older care-givers, i.e. those aged over 65 years of age. Recent analysis of the 2011 census for England and Wales, for example, reveals that 15% of all those aged over 65 are male carers compared to 13% of women; furthermore, these older male carers are likely to undertake more *hours* of care than older women (ONS, 2013b).

This shifting landscape of care is not unique to the UK - a small, but growing body of work has highlighted an increase in male care-giving across a range of countries from Europe to north America (see for example, Ducharme et al, 2007; Ribeiro and Paúl, 2007; Akpinar and Küçüküçlü, 2011). Importantly, in a review of male care-giving for people with dementia, Baker and Robertson (2008) noted that not only is the research on this topic limited, but those studies that do exist, indicate that men experience care-giving differently from women.

By and large, however, gender is not considered critical to care-giver research, and as a consequence, the gendered nature of care-giving often goes unquestioned. Even where gender *is* considered, it is often simplified to a male/female comparison, so failing to address potential variations *within* groups.

Interestingly, Baker and Robertson's review revealed methodological differences in outcome, in that studies using surveys or interviews tended to report highly stereotyped emotions, e.g. men disclosing pride whilst women disclose affection – a difference that was less evident in more observational or diary-based studies.

Deepening the sophistication of our knowledge of how older male carers cope with and experience care-giving is thus important if we are to understand the challenges they face, the coping mechanisms they employ, and the extent to which their support needs may vary.

The overall aim of this study was thus to gain a deeper understanding of the extent and nature of care-giving undertaken by older men, the support they require, their coping mechanisms and any barriers or limitations to the forms of care they were able/willing to undertake.

The objective of this work was to offer insights into how we might provide and /or develop appropriate interventions to facilitate older men's ability to successfully manage their caring role.

## 2. Overview of Methods

This was a two phase study undertaken in the north west of England. In Phase 1, written narrative accounts were gathered from fifteen older men (aged 50 years and above) about their experiences of caring for their wives or partners and the forms of formal and informal support they draw on. Where an older male caregiver wanted to participate but had difficulty writing, he was given the option of providing the same narrative orally (through a recorded telephone narrative). This occurred in two instances.

Narrative correspondence is a technique that solicits stories from participants, written in the absence of the researcher, around their experiences of particular events or processes in their lives and the meanings they attach to them. The absence of the researcher means that participants remain in control of the process, making this a more participatory and empowering research process for the participant. This technique allows decisions around the form of participation, the extent of the data given and the ownership of the data, to remain more firmly in the hands of the researched (Milligan, 2005). It has proven particularly useful in eliciting meaningful insights into the experiences of health and impairment amongst vulnerable and hard to reach groups (Thomas, 2010).

We were also interested in whether care providers (either consciously or unconsciously) thought differently about the sorts of support older male caregivers might need and whether this was reflected in assessment and delivery of formal care support services. With this in mind, in Phase 2 we undertook a series of semi-structured individual and small group interviews with a total of nine care providers from the statutory and voluntary sectors across the north west of England.

Ethics approval for the study was gained from Lancaster University Ethics Committee and from Lancashire County Council Ethical Review Committee.

In accordance with good ethical practice, all transcripts have been anonymised and all participants have been allocated pseudonyms to ensure confidentiality. Where a participant's spouse, partner or other family member are referred to, they too have been allocated pseudonyms.

Further detail of the research design and methods are outlined in the Appendix.



### 3. Findings and discussion: Perspectives from older male carers

#### 3.1 Older male carer and cared-for family member characteristics

The older male carers in this study ranged from 56 to 89 years of age with a median age of 69.5 year. One participant cared for his mother. All other participants cared for their wives, though four also cared for a mother (N=2), a mother-in-law and an autistic grandson. The ages of those cared for ranged from 18-99 (the grandson and mother-in-law) but of the wives cared for, the ages ranged from 55 to 90 years of age. The median age of those cared for was 67.7 years of age. This figure is slightly skewed by the ages of the grandson and mother/mother-in law, but if wives only are accounted for, the median age of those cared for was 67.2 years. The length of time participants had cared for their wives ranged from 10 months to 30 years, with the median length of time spent caring at 9.9 years.

All but one of the male carers had either retired from work or had given up working to care for their wives full-time. The one carer who continued to work was part-time taxi driver and managed to fit his work around respite care. The background of these carers was extremely varied, ranging from a retired GP and a scientist to a taxi driver and retired factory worker. Figure 1, on the next page, illustrates the ages and characteristics of the participants and those they care for.

**Figure 1: Carer and Cared-for Characteristics**

| Carer Pseudonym | Age | Previous occupation                                  | Years Caring | Cares for             | Pseudonym         | Health issue   | Age       |
|-----------------|-----|--|--------------|-----------------------|-------------------|--|-----------|
| <b>Bob</b>      | 67  | MD of own business                                   | 10           | Wife<br>Mother        | Jenny             | Mental breakdown & post-traumatic stress<br>Frail – in care home | 58        |
| <b>Henry</b>    | 84  | Retired GP   | 2            | Wife                  | Patricia          | Alzheimer's  | 85        |
| <b>Robert</b>   | 75  | 'educated professional'                              | 20           | Wife                  | Joanne            | Trigeminal Neuralgia and Dementia                                | 72        |
| <b>Jeffrey</b>  | 58  | Factory worker                                       | 30<br>10     | Wife<br>Mother-in-law | Anna<br>Geraldine | Cerebral Palsy 'frail'   | 56<br>82  |
| <b>Alan</b>     | 63  | Teacher  | 8            | Wife                  | Mary              | Multiple Sclerosis   | 59        |
| <b>Edward</b>   | 75  | Farm worker  | 5            | Wife                  | Lizzie            | Parkinson's  | 75        |
| <b>Joe</b>      | 59  | Senior chartered civil engineer                      | 15           | Wife                  | Anne              | Muscular Dystrophy   | 56        |
| <b>Harry</b>    | 56  | Taxi Driver (still works nights part-time)           | 10           | Wife<br>Grandson      | Diane<br>Ian      | Physical disability and depression<br>Autism                     | 55<br>18  |
| <b>Peter</b>    | 82  | Oversees civil servant /bursar of independent school | 10           | Wife                  | Jane              | Stroke   | 79        |
| <b>Alistair</b> | 64  | Still working P/T – no info on work                  | 4<br>7       | Wife<br>Mother        | Pam<br>Evelyn     | Bi-polar & Parkinson's 'Frail'                                   | 60<br>98  |
| <b>Andrew</b>   | 66  | Probation officer                                    | 10 mths      | Wife                  | Susan             | Brain tumour   | 66        |
| <b>Neil</b>     | 65  | No info  | 10           | Wife                  | Yvonne            | Hydrocephalus and physical disability                            | 60        |
| <b>Joseph</b>   | 89  | Scientist  | 7            | Wife                  | Annette           | Disabling neuropathic pain                                       | 90        |
| <b>Dave</b>     | 76  | Mechanical engineer                                  | 9            | Wife                  | June              | Multiple Sclerosis   | 71        |
| <b>Clive</b>    | 63  | Ex-services  | 1 year       | Mother<br>Brother     | Rosemary<br>Owen  | Limited mobility<br>Cancer                                       | 92<br>D/K |

### 3.2 Coping Strategies of older male carers

#### Key Messages

- Older male carers find **practical solutions** to managing the challenges of caring.
- **Gendered service** assessments focus on domestic roles and tasks, and areas less relevant to older male carers.
- Harnessing their **existing skills and experiences** give older male carers supportive strategies and role affirmation.

Older male carers employ varied approaches to managing and performing their caring roles. Some of these approaches are entirely new to them and have arisen out of necessity upon the advent of caring; other strategies are adapted from previous life-roles, while some carers have undertaken similar functions within their existing relationships with the cared-for person, hence little has changed for them in this respect. Neil for example suggested he was not a typical male carer because he had always been involved in ‘... *the domestic side of married life.*’ During their paid working lives, both he and his wife Yvonne worked full-time and shared domestic chores. He and Yvonne would clear their household jobs during the week to enable them to spend free weekends pursuing their interests. Neil is now caring for Yvonne who now has both physical and mental disabilities, but he has sought to maintain a similar approach to that which he and his wife adopted when working, by trying to retain a week-day routine so when the weather is good he can take Yvonne out in her powered wheelchair to enjoy their local environment.

Some older male carers however, found taking on a caring role meant they were faced with entirely new situations. Edward had found it had been unnecessary for him to undertake household duties during his married life because his wife Lizzie ‘... *did all the bookkeeping plus the everyday running of the farmhouse ... she was up to the task and very good at it which made it unnecessary for me to do anything in the house.*’ Edward takes the ‘pressure off’ now that this is his domain by buying in frozen meals. Henry, however, took local classes to learn basic cooking skills and now finds the creativity of cooking satisfying. Other older male spousal carers developed new personal interests that could fit with their new caring roles, for example, running (on a machine in garden shed), gardening, and writing articles, all of which could be undertaken at home where carers felt they had to be, or could not leave.

In the main however, it seems that older male carers draw on previous experiences or skills to provide coping strategies in their caring roles. A particular theme emerging from the carer narratives focused around **practical solutions** to managing the challenges of caring. Participants wrote of adapting, building and reconfiguring their homes and environment to assist their cared-for family member, or to make care tasks less difficult. Jeffrey, caring for his wife Anna, undertook a wide range of housing adaptations to enable her to be as

independent as possible within the domestic setting. As a trained joiner he was able to make changes to their home, but he also completed needlework classes to learn how to adapt Anna's clothing to enable her to manage dressing herself (for example, replacing difficult to manage hooks and buttons with Velcro). Jeffrey also embarked on challenging local services (the library, supermarket and church) to ensure access for his wife in their community. This type of practical approach by older men to their caring role was recognised by a number of the care providers interviewed for the study, with one commenting:

*'... how I experience male carers - it's very visual it's very practical, it's very matter of fact ...' CP:4b, Carers' organisation, care worker)*

Jeffrey in particular noted how assessment of needs by statutory services is more often focused on cooking, cleaning and shopping care tasks, taking less account for things like housing adaptations, support with paperwork or those practical jobs that '*men usually do*'. In this sense Jeffrey highlights what may be described as an **institutionalisation of gendered services** - one that is constructed around women undertaking the caring role - as needs assessment largely relates to 'traditional' (as Jeffrey describes them) roles that daughters or other female family members usually fulfil. Yet by adapting Anna's physical environment and attending to a whole range of individualised adaptation needs, this carer had enabled his wife to optimise her independence while living with the significantly life-long debilitating condition of cerebral palsy.

Just as Jeffrey had done, Andrew also drew on **previous work skills and experiences** to help him to support his wife Susan, who suffered a rapid and dramatic decline in her health following the development of a brain tumour. He found writing a daily log about Susan's condition gave him distance and perspective by allowing him to '*... stand back and observe*', a skill he employed during his working life as a probation officer and social worker.

While inventive, adaptive and multiple coping strategies were evident within the older male carer narratives, their descriptive stories also conveyed a sense of the need to 'just keep going'. The highly individualised strategies recounted in these narratives are clearly helpful, but ultimately it was apparent that no amount of coping strategies can protect against the 'massive' impact of caring for and about a family member through the months and years of taking on the responsibility for providing critical, intimate, and un-ceasing care and support.

### 3.3 The impact of caring on older male carers

#### Key Messages

- Older male carers experience **impacts from their caring role**, manifest in the physical, mental health, fitness, financial and social areas of their lives.
- **Sense of loss is profound**; loss of futures, plans, relationships and friends.
- Gendered role assumptions influence **older male carer identities**, constructed through the performance of care tasks or the fulfilment of a carer role.

As might be expected, older male carers report a range of **impacts and consequences of caring** across different areas of their lives. These are similar to those well-reported impacts often associated with the rigors and demands of fulfilling care-giving tasks at all ages, but particularly in older age, and having to adapt lives to manage changing circumstances (e.g. Milligan, 2009; The Princess Royal Trust for Carers, 2011). The impact on health was widely recognised with physical effects (back problems, sleep disturbance, worsening of carers' own long-term health conditions), mental health issues (from stress, anxiety, fatigue and fear), decline in fitness levels (through giving up sports, being unable to leave the house, confined to a slow pace of life), financial implications (from giving up paid employment, care cost impositions), and impact on social activity (stopping educational courses, volunteering, interests and travel).

Of particular pertinence in the older male carer narratives were expressions of loss; **loss of futures, plans, relationships and friends**. From the mundane to the singular, these carers felt loss in many areas of their lives and experiences; in no longer being able to enjoy joint pleasurable interests, sexual intimacy, 'normal' conversations, family worries or traumas, or the grounding perspective arguments brought to mutual engagement in a relationship.

In writing of caring for his wife Jenny, once a full-time senior teacher who now has a serious mental health condition, Bob highlights the slow degeneration of their marital relationship with the loss of the person his wife used to be, loss of the future they had planned together, of the intimate relationship he can no longer expect, and the loss of friends, which he clearly feels profoundly:

*'... the loss of people who you can say 'well they're friends' ... for some reason is almost worse than losing all the other gubbins, like being able to get on a plane and go somewhere. ... if you said to me, 'who is your friend, no connections to anything?' I would really struggle.'* (Bob career for Jenny)

Of particular interest and relevance to this report is the **impact felt by older male carers on their gender identities** - both on their individual identities and on relational identities with the cared-for person. These identities can be viewed as being constructed through the care tasks they perform, or through the social perceptions and status conferred on male carers, thought their engagement with what are perceived of as female roles. This can occur within their own personal relationships, or more widely in society. Thus, the very acts of care can be sharply experienced by older men as challenging their gender identities. Robert, for example, relates this to how he felt about the personal care he undertook for his wife Joanne who was diagnosed with dementia. His narrative reveals how the emotional impact on a husband of seeing a wife decline cannot be underestimated. He struggled to perform all the bathing and personal hygiene tasks noting that *'... as a man this presents a particular challenge as one felt so intrusive, especially as my wife had always been a private person'* (Robert, carer for Joanne).

Some male carers described perceptions of others, be they relatives, friends, acquaintances or health professionals, as conferring a low status and value upon caring as a valid and valued role that the male carer had taken on for their family member. Jeffrey felt especially strongly and explicitly sited gendered assumptions and opinions in relation to his role and support of Anna:

*'I'd like some respect for what I do and parity with other jobs that males do ... it's a bit like being a housewife, I don't know if you've been a housewife ....but you don't count quite as much do you? ... they think it's all tea, talk, and toileting. But it's nothing like it, you know, it's the entire environment, and educating people how to take care of people with disability. ... My family say to me "you're on permanent holiday, you just sit at home and do this and, you don't work do you?".'*  
(Jeffrey, carer for Anna)

Similar lack of respect and acknowledgement was felt by Alan, carer for his wife Mary and their young daughter, when they planned to take a family holiday. In his narrative he relays a response to this from their family social worker who suggested his carer allowance should be suspended during the holiday period. He conveyed his disbelief at the time: *'She could not comprehend we were going away as a family and I would still be caring for my wife!'* Bob found he was judged in his approach to caring for his wife Jenny, who experienced a serious mental health condition. His relationship and role are conflated in gendered expectations expressed by his relatives about how he should manage Jenny's challenging and disturbed behaviour, *'I got comments like "you just need to assert control over your wife and just keep her in order."'* (Bob, carer for Jenny)

Changes to role and identity fundamentally impacted on Alistair who eventually left paid employment to care for his wife, Pam, who suffered a life-long limiting mental health condition, and later Parkinson's disease. In finally accepting counselling support he describes how he would be reticent in disclosing this form of emotional support to his male friends and colleagues, saying *'I guess it's a man's thing'*. Following many years of caring for Pam, Alistair comments on only recently coming to have some partial acceptance of the

term 'carer', while also relaying '*This is the first time in my life when I doubt my ability to cope at times*' (Alistair, carer for Pam).

These difficult caring experiences were tempered to some extent by reflections of the more positive impacts of caring expressed in the narratives of some of the older male carers in this study. These included: being more involved in a child's upbringing through spending more time at home; being able to get jobs done in the house; spending time more time with a spouse than would otherwise been possible; having a closer relationship through time spent together; satisfaction and reward from having been able to keep a spouse well and strong; and finally, one carer wrote of having contributed to staff training through being an experienced carer.

### 3.4 External support accessed by older male carers

#### Key Messages

- Older male carers report **mixed experiences of statutory health and social care support**.
- **Limitations to family support** especially at distance, and for rural and retirement communities.
- Gender may be an influencing determinant regarding **privately purchased domestic and household services**.

Male carer narratives report **mixed experiences of support** they received from health and social care services. Two contrasting experiences illustrate 'at best' and 'at worst' the provision that older male carers in this study received. As noted above, Andrew cared for his wife through a rapid onset illness following her diagnosis of a brain tumour. In his written narrative he related a collaborative approach to the care his wife received developed by his GP and inpatient hospital care providers. He detailed the 'massive' care plan put in place when Susan was discharged from hospital in order to support her home death. Within 24 hours Andrew describes being supplied with special tables, raised toilet seats, special cushions, a wheel chair, an extra stair banister, grab rail at both the front and back doors, and an electric recliner chair. In addition to these practical aids, homecare visits were arranged 2-3 times per day, night cover organised as well as regular visits from the GP and McMillan nurse. Andrew also received an assessment visit from the local carer support service, resulting in: the provision of a fortnightly cleaner; referral for massage therapy for himself; identification of emergency arrangements should he be incapacitated and unable to care; and continuing care and visits from the carers' care worker, which included physical, emotional and spiritual support. Andrew and Susan also belonged to a Friendly Society that paid all their petrol bills for hospital visits. Andrew's care package included some means-tested contributions to care, although 100% of the costs for night cover were paid by social services. While he found some difficulties following the financial arrangements of this complex care package, overall, Andrew was very satisfied with it. Bob's experience however, was entirely different. While he believed their family GP's care of his wife had been excellent, he commented in his narrative that: *'From my point of view he's been brutal ... he's not the slightest bit interested in my needs.'* (Bob, carer for Jenny). Despite caring for a wife who self harms and has suicidal tendencies for over 10 years and a 92 year old mother (now in a care home), Bob noted that his GP failed completely to recognise his own need for support as a carer, expressing what he referred to as a 'just get on with it' attitude.

Andrew's account of relatively short-term service provision for end-of-life and palliative care is one of responsive, clearly coordinated and integrated working across both services and professionals involved in supporting him and his wife. Jeffrey recounts a different story of having to make persistent challenges to establish appropriate services to enable his wife



Anna to remain as independent as possible in a long-term caring scenario. His narrative describes many attempts to get practical help and support, with an eventual visit to his MP appearing to influence this. Some services were withdrawn (chiropody) which he now does for Anna, some were too problematic ‘... *they don’t solve a problem, they change a problem*’, some unworkable (vouchers that did not cover the support that they needed), and too complex (personal care budgets). Alan also wrote about personal care budgets and how he felt the local authority consistently tried to persuade him and his wife to move to this form of care funding. However, his view was that he already managed his own, his wife’s and his adult daughter’s (who he also cared for) finances and having to manage a further budget would have been an additional burden.

Interestingly, in contrast to the resistance expressed by older male carers to personal care budgets and voucher systems, care providers from both social services and third sector organisations participating in this study viewed personal care budgets entirely positively. In their view, they offered flexible and individual solutions to carer needs, and with the exception of one social worker, who pointed out the support that could be provided to manage the budget, none of the other service-provider interviewees highlighted the potential difficulties this kind of funding for care services can raise for older carers.

It was evident that **external family support** (i.e. not immediate family) was not necessarily something that older male carers could rely on. While a number of carers reported contact **with family members at a distance**, there were comments that suggested, while it was appreciated, family could not give anything other than ‘arm’s length’ emotional support. This was received through email, sometimes with extended family abroad, or by telephone when, for example, advice could be sought. Friends were described as ‘well meaning’ but too far away to be of practical support. Similarly neighbours might keep a ‘watchful eye’ but as one older male carer said, he could only call on them in a ‘real emergency’. For other older male carers their relatives were deceased. One carer was thus led to describe what he referred to ‘the myth’ of support from family and friends.

Children were referred to by older male carers as forming part of their support systems. Nevertheless, these carers also understood that their [adult] children had families and demands of their own and expectations of what help they could reasonably give was limited. While Bob’s daughter had been a tremendous support, at the relatively young age of 16 years he felt she was limited in what she could understand about her mother’s condition. Peter’s daughter had been able to ‘get him started’ with cooking to the extent that it developed into a hobby. Limitations on close or extended family support may be particularly relevant to this study sample, which included a number of older male carers living in rural localities to which they had moved to following retirement, and therefore they may no longer be in close proximity to family networks.

Some older male carers described the **private services and support they had purchased**. This included household/domestic cleaners for a number of carers, ‘companions’ for their cared-for family member, and a music teacher. As noted above, one older male carer also purchased frozen meals to alleviate pressure on cooking. It may be the case, as suggested by this fairly small study, that some older male carers need specific support to meet their and their family member’s domestic needs. As such there may be a gendered dimension to the private purchase and payment for services to assist them in these areas. Further research

would be needed to determine to what extent gender influences the support older male carers seek out and may need to pay for out of their own pockets, and if diminishing welfare payments and/or personal care budgets have a specific impact on this group of carers.

### 3.5 Older male carers' friendship and social networks

#### Key Messages

- **Deep social isolation** characterises older male carers sense of connection to friendships or supportive networks.
- **Gendered friendships and ways of relating** inhibit connections with other men to gain support.

A range of quotes in this section portray the deep **social isolation and absence of supportive networks** that were felt by many of the older male carers involved in this study:

*'I feel trapped, I don't have a social life and I just feel I am in a situation that does not have any way out.'* (Harry, carer for Diane and Adam)

*'... our true friends live too far away to be of any particular help ...'* (Joe, carer for Anne)

*'I have had to withdraw from most of my community work and activities.'* (Peter, carer for Jane)

*'... my wife is very limited in what she can cope with socially so we rarely operate as a married couple. This I find isolating and the inevitability that we are beginning to live separate social lives.'* (Alistair, carer for Pam)

One older male carer suggested that friends no longer stayed in contact because they wanted to remember his wife as she once had been. Another spoke of his son's trauma at seeing his mother decline, and so stayed away. A further carer said that all of his friendships had declined and his only social contacts were those remaining through his business, and these he found difficult to maintain. While Bob recognised the value and potential for support of friendships he was unable to foster these because of the demands of caring:

*'... one of my numerous jobs is to ring up one or two people and go and have a coffee or a half with them sometime, but there's always something to do, that's the problem.'* (Bob, carer for Jenny)

Conversely Neil found that a lot of people from their neighbourhood spoke to them when they were out, indeed that they had made new friends. However, on the whole older male carers found it difficult to develop new social networks. Gender influenced this in specific ways. Jeffrey found it difficult to identify with other men in non-carer interest groups he

joined because of the lack of identification with his role and what he described as his inability to keep up with more 'male oriented interests' such as going to football matches and cars, due to his caring role. Conversely, he felt the domination of carers' groups by women meant there was more scope for them to meet up and talk together about common interests. Essentially he experienced exclusion from both of these potential social groups, noting:

*What's hard about it [caring] is the isolation, and the things people say to me.... I've been to classes to learn to do sewing and things like that. Well a fella' doing that, either you're sexual orientation's slightly different or you're a weirdo, you know?..... you're a man out of water, because women will go for a coffee and talk about girlie things and I'm not invited, I just get the jobs, you know the domestic jobs and none of the fun bits.*

and

*I've a joiner friend that I do manage to go out with occasionally and that's it. It can be difficult if you've no family and you've no job, you know, and you don't do football and you don't do cars ... you're struggling, for something in common with people.*  
(Jeffrey, carer for Anna)

Finally, this concluding quote explicitly addresses **gendered friendships and ways of relating** that one carer felt hampered his ability to gain support from other men. He found that his seriously ill wife had friends who wanted to support her and spend time with her, but he had no-one who did this for him:

*'you don't get this ... you know, some bloke ringing me up saying 'how are you doing? Haven't spoken to you for ages' you just don't do it, you know. ... 'let's have a natter, it must be tough for you,' you know, 'we'll get together.' No, nobody, nobody (chuckles) at all ... 'and you start to think is it me? I think it's men.'* (Bob, carer for Jenny)

### 3.6 Gender specific issues and characteristics of older male caring

#### *Key Messages*

- Non awareness, reluctance or resistance to **identify with a 'carer' label**.
- Older male carer's provision of **personal care for family members often prompts** service intervention
- Older male carers may experience **difficulty acknowledging emotional aspects of caring**
- care practitioners developed a **growing awareness of significant gender features** to their work

Interviews conducted for this study with care providers give insights into issues relevant to understanding gendered relations of care as these relate to older male carers, and they further illuminate some of the areas related to gender that emerged from the carer narratives reported in the earlier sections of this report.

Across the care practitioners all noted the low number of older male carers they supported, or the few numbers of referrals they received. Partially responsible for this they suggested was a resistance by older male carers to **identify with, or recognise, their 'carer' label**. The care providers largely attributed this, especially when older men were undertaking care over many years, to an understandable self-identity with lifelong roles and relationships with their cared-for family member, i.e. they are husbands or sons not 'carers'. Further to this, care providers saw the non-association with a carer title as resulting in unawareness of sources of support, or reluctance to access help and support. Further exacerbating this issue they suggest is the observation that older male carers rarely attend carer support groups. Ultimately these factors render them invisible and a particularly difficult to reach group of carers.

We heard earlier from Jeffery that he felt excluded from female carer relationships when women predominate in numbers and can join together to talk about common experiences. One care provider spoke about an older male carer who would attend a day centre with his wife, but he would sit alone and read his newspaper. It might be speculated about the failure of older male carers to access this form of group support, and whether this is a reluctance to access support, or a failure to engage, or the result of a lack of gender appropriate support group opportunities for older men.

Service uptake is complex with the intersection of gender and age appearing to influence which older men accept support. While there was an overall sense from the care providers that older men were more reluctant to accept help, this seems to differ according to age. Broadly speaking there appears to be lower and/or later uptake of services by older age cohorts. Thus, younger male carers (50-65yrs) were viewed as more likely to actively seek support, mid-range carers (65-80yrs) when offered support may more readily accept it,

while older aged carers (80yrs and above), may be the most reluctant group to accept support, with this latter group reported by care providers as often attempting to stoically keep going in the face of what can be extreme circumstances.

Care practitioners commonly reported that the **provision of personal care for family members often prompted service intervention**. Personal care needs were described as the tipping point of care that older male carers could comfortably provide. A care practitioner described the circumstances of an older woman of 103 years cared for by her son of 70 years, who provided all her care until she needed personal care. The social worker observed that: *'...sons don't tend to want to provide personal care to their Mums. So that's... I suppose that is a gender thing'* (CP1: Social services social worker). In this sense the care practitioner suggested a generational gender influence to providing care as she believed male spouses would more readily provide personal care for their wives. In other examples it appeared to be the case that personal care needs would be met by female members of the household (daughters and daughters-in-law), where a husband undertook other aspects of care. In a similar way a different social worker noted that male carers expressed a preference for female care workers if personal care was to be provided for their family member, while this appeared not to be the case for other forms of service e.g. assistance with cooking or household support. We would argue, therefore, that gender can be considered a defining feature of family caring, where intimate care of the body and bodily functions prompts explicit attention to what might be considered acceptable gendered norms, values and social roles.

Care providers support the earlier observation in section 3.2 of older male carers seeking practical solutions to care needs. One care provider commented that she thought older male carers wanted to fix something and that they were **less likely to engage in conversations with more emotion content**. Two further care providers noticed a similar feature to older male carer communication:

*'I think they are very focused on the 'this is what we do, and this is how we do it and this is when we do it', but to talk about their sense of loss on that emotional level: that sense of intimacy, that sense of friendship, you know, all of those things, so men don't often express that very easily ... They find it really hard to engage with that.'* (Annette: carers' organisation, social worker)

*'... if [they] don't want to look at that, [they] won't. ... I could come out of seeing a male carer and not really know who he was or who he is.'* (Marianne: carers' organisation, care worker)

This self-conceptualisation and means of communicating about their caring role, indicate the need for gender sensitive assessment of carer needs, that accommodate how older male carers talk about caring and that facilitate their own understanding of their needs as carers.

These interesting gender issues emerged through analysis of recorded data in which the majority of care practitioners early on in their interviews acknowledged few gender relevant

issues related to their assessment, support or work with older male carers. Other than the fewer numbers of older male carers referred to them, or that they had in their case loads, care providers suggested an individualised approach to each carer in their own right, enabled them to identify and address carer needs. As such, other individual carer characteristics were viewed as of equal importance to gender in determining carer needs and the ability of older men to perform this role, e.g. age, employment, and locality. However, on reviewing their case loads and through further discussion in interviews some **care practitioners developed a growing awareness of significant gender features to their work**. One voluntary sector dementia care provider noted with surprise the number of older male carers referred but who had refused a service. She only noticed this when she was gathering information prior to being interviewed. When considering her approach to assessment of carers one social worker outlined her approach as generally the same for both men and women. However, when considering this further she reflected that differences were in fact apparent in how men and women choose to draw on support offered to them. Finally, following gender focused discussion a care provider stated:

*‘ ... we’re sort of kind of saying we perhaps need something that’s more male orientated.’ (Ellen, carers’ organisation, care worker)*

#### 4. Findings and Discussion: Care providers' perspectives

A second element of this study aimed to gain an understanding of older male care-giving from the perspective of care providers. The objective here, was to ascertain whether care-providers: a) viewed and/or assessed the support needs of older male care-givers differently to that of older female care-givers; and b) whether this may manifest in different forms of support being offered or developed. As detailed in the appendix, nine care-providers were interviewed in total from both the statutory and third sector.

**Figure 2: Care Provider Participants**

|   | Pseudonym | Role   | Sector           |
|---|-----------|--|------------------|
| 1 | Jennifer  | Social Worker                                    | Statutory sector |
| 2 | Jo        | Dementia Advisor                                 | Statutory sector |
| 3 | Susanna   | Social Worker                                    | Statutory sector |
| 4 | Ellen     | Adult carer support worker                       | Third Sector     |
| 5 | Marianne  | Adult carer support worker                       | Third Sector     |
| 6 | Elaine    | Adult carer support worker                       | Third Sector     |
| 7 | Annette   | Social worker (adult carer support)              | Third Sector     |
| 8 | Brenda    | Carers' Health Worker (GP practices & hospitals) | Third Sector     |
| 9 | Belinda   | Carer support worker                             | Third Sector     |



## 4.1 Care providers' perspectives on older male care-giving

### Key Messages

- Older male carers are **less likely and less forthcoming in asking for help and support** than older female carers;
- Older male carers **tend to reach crisis point before asking for support** from care services;
- **Previous career can make a difference** to what support is required and knowledge of where to access that support

In general care providers viewed older carers as having a mind-set of 'just getting on with it' whether male or female. As Jo (Dementia Advisor) commented, 'we're dealing with quite a stoical older generation who sometimes feel that they don't want or need support. People feel often that they're coping fine and don't understand why they'd need an assessment.

However, care providers also noted that, in their experience, **older male carers were less likely to ask for help and support than older female carers**, in part this may be because older men [particularly the older generations] feel it is their role to support and provide for their wives. As Susanna (social worker) commented:

'the difficulty I've found in my experience with older male carers is to have them agree to any form of carers' assessment at all. Quite often I find they don't identify themselves as a carer. It's, you know, "I'm their **husband**" this is my wife, this is what our vows were about, looking after each other. They don't... quite often they don't like the label of a carer and therefore see accessing carers' services as something that isn't appropriate to them'

Hence, in contrast to older women, care providers perceived older men to be far more resistant to accepting support, citing numerous occasions where referral visits to older male carers have resulted in refusal of services or equipment. Drawing on her notes on one older male carer Jo goes on to comment:

*'and he agreed I could go and see him, and when I went to see him he just said 'it's fine, everything's fine,' he said 'my wife's struggling in the shower' and I said well maybe... offered to refer him to an OT [occupational*

therapist] to get some kind of equipment, which was refused, and everything I kind of offered was refused.'

Indeed, care providers in this study noted that [older men often reach crisis point before approaching care services for support](#). The need for what was described as 'heavy end' personal care was often referred to as 'the line that was drawn' between coping alone and seeking care support.

*I know one male carer that I still work with, you know, well the reason I met him, I was on duty and he came to the office because his wife had said she was going to kill him, and this is a woman who hadn't been on any - who hadn't been on our radar at all, and it was only when things were completely desperate, and I think he just felt that he ought to be... as her husband, he ought to be handling this. And that made him reluctant to access support. (Jennifer, social worker)*

Most care providers noted particular resistance to undertaking personal care in cases where the older male carer was a son providing care support for his mother:

*'as an example of personal care perhaps assisting in the way of supervising a shower (sic). Whereas the more intimate would be the more physical with washing the genitals and the breasts and that area that I've found that sons particularly have felt very unable to provide that level of support. But they would be able to supervise a shower if it meant that they were just checking on that individual, not having to provide hands-on help. '* (Susanna, social worker)

and

*'I have one gentleman who has recently just had to place Mum in a care home because he just, he just couldn't go down the personal care route.'* (Marianne, adult carer support worker)

Interestingly, care providers noted that whilst older men were unlikely to provide personal care for a mother, they nevertheless were more likely to provide other forms of support for their older mother than to their older father. This may be because sons see their mothers as being more vulnerable than their fathers whom they may have perceived to have been the head of the household, whilst the mother has taken more of a nurturing role, and now needs help herself. Others, however, commented that, in their experience, older male carers were likely to receive *more* support with caring from close family members than older women, particularly from adult daughters who may help with domestic and personal care tasks. Clearly, however, [views on whether older men or women are more likely to receive support](#)

from adult children are mixed and given the relatively small sample size this is an issue that warrants further investigation.

This issue aside, care providers also noted that one possible reason older female carers are more forthcoming in asking for support is that they and their female siblings are more likely to have looked after ageing parents than their male counterparts, and as a consequence will have a greater awareness of what services are available.

*'particularly maybe the 80 plus, that wasn't something that they [men] did, they didn't look after their parents, that was the sisters and suchlike, that was the females of the family, so perhaps they haven't got the same knowledge, informal knowledge of what could potentially help them.'* (Susanna, social worker)

Others noted how previous career can also make a difference, with those who have been part of social work and medical professions having more awareness of what support is out there and how it can be accessed.

## 4.2 Assessing and addressing support needs

### Key Messages

- Older male carers are less likely to get involved with carers' support groups and other group activity that is largely female dominated and deepening their social isolation.
- Older male carers are primarily interested in practical support.
- Gendered nuances subtly underpin care provider's experiences of older carers and their assessment of needs.

Almost all care providers stressed that assessment was based on need and people's individual characteristics rather than gender, hence little account was taken of potential differences between older male and female care givers. However, in looking through her list of referrals, Jo (a Dementia Advisor) noted that of the 101 referrals she currently has on her books, only nine are older male carers leading her to comment 'Yes, it's made me think':

*I kind of approach it similarly for male and female, which might be quite wrong now I've spent the morning looking through my statistics (little chuckle) and seeing just how many chaps have refused..... I hadn't done this till this morning and I'm quite shocked at how few male carers we've picked up and I kind of think I need to possibly change in approach because a lot of these people who've been referred to me, who are male carers, have said no to the service.*

Nearly all care providers acknowledged that male carers are less likely and less inclined to get involved with carers' support groups and other forms of group activity that are largely female dominated. The tendency not to differentiate between the genders in terms of service provision means older male carers can find themselves more socially isolated than older female carers.

'traditionally, I suppose we think of women as much more likely to sort of come in to, like, support groups and things like that. Men tend to not want to as often, and probably knowing it's full of women it's a ... they're the odd one out.' (Ellen, adult carer support worker)

and

'occasionally, a few men that will come through to different groups. It's not that there's no men there, there are but it tends to be... you'd have to work at getting

them there a bit more than you would... the ladies you could just say 'there's this group' and they're like 'lovely we'll come'; whereas with the men, you maybe have to nudge them a bit more to come, to access something. They do tend to isolate themselves much more' (Belinda, carers' support worker)

Brenda (carers' health worker), however recounts an example of a carers support group in her previous place of employment that had been successful in attracting and maintaining an equal mix of older male and female carers from a diverse range of backgrounds. Echoing a growing recognition that there may be an important role for gendered activity interventions for older people, the key to its success, she felt, was in recognising the [importance of providing some separate space for men to meet and talk with other men within a group setting](#).

'the men that were going were long-term regular people that attended, they were quite a mix in their sort of social set, you know, people that maybe weren't... didn't have high-powered jobs, you know, more manual labour, farm workers, coming up to someone that was more of a professor-type post, you know, a real range of males there. But the group actually did split off in the afternoon, they did something's together in the morning as a group, had lunch, and then the men went over to a man's corner so to speak, and they did the man things, not that they were doing anything 'rufty and tufty' but they were doing quizzes, they were chatting about sports, they were chatting about politics, they were just... it seemed like, you know, it's almost like the old after dinner where the men went off to have a cigar and the ladies went off to... what... a cup of tea. It was kind of that division, and maybe that's what worked well. They had other males to talk to, but again, a range of males with a range of experiences and it really mixed in well I think. And I was really confident to take men there because it would work well.'

This echoes observations made by participants that [care services tend focus on the provision of services that are more female in orientation](#), because overall there are more female than male carers, hence this is where overall demand is greatest. But as Belinda comments when discussing this issue: *'maybe we do miss, you know, we miss the men but ...the men do make themselves more invisible I think'*.

Overall, care providers took the view that [older male carers are primarily interested in more practical support](#) that provided them with emergency backup, periods of respite from caring to allow them to undertake shopping or undertake some form of social activity, or relieved them of their discomfort in undertaking personal care. As Ellen notes:

*'I think one of the main things that the male carers tend to be more keen on from the range of the services [is the] carers' emergency card. So that the carer would carry the card in their wallet so if something was to happen to them and they had to go into hospital, weren't able to communicate, it would say on there that they look after such and such, please contact the carers' association and the adult social care department who activate the contingency plan which hopefully they will have done at the same time as setting up that carer's card. I think in terms of support within the household the main areas have been around physical assistance with washing of the cared-for, and also night-time support.'*

Re-ablement services (short-term services designed to support the maintenance of care at home and prevent a move to institutional care settings) were also deemed useful allowing older male carers short periods of support to facilitate their ability to manage tasks they may feel less confident in undertaking. Support to help them manage with cooking meals (particularly in relation to special dietary needs), domestic tasks and medical tasks were seen as being particularly valued. As Susanna commented:

*'there's a chap I worked with recently that's wife had dementia and was progressing further down the line, and he didn't know how to turn the washing machine on to do the washing when she had been... sadly been incontinent, he couldn't do... he didn't know how to. So it [re-ablement] was about helping him to learn how to do that and he embraced that and wanted to do that.'*

However, care providers were keen to emphasise that the need for this sort of support could equally apply to some women and that this varies across age cohorts, with the oldest old male carers requiring more support with learning domestic tasks and undertaking personal care than younger old.

What older male carers were less likely to take up were those services that provided emotional support. As Brenda and Belinda observed:

Brenda: I think women generally will talk to someone, whereas quite often men don't talk about those things as much particularly in that kind of relationship and those circumstances.

Belinda: With a female there's a sense of 'I'll sit and I'll talk and I'll cry and I'll touch on those places that are really painful'. It's like the females will engage more on the emotional level of it, whereas the males are kind of a bit more, gosh that's a bit...

Brenda: yes, definitely

As discussed in section 3.4 above, there were clear [differences in the views of carers and care providers on the usefulness of personal care allowance and voucher schemes](#), with care providers seeing these services as providing far greater flexibility for the carer and cared for than traditional service options. Though not a specifically gendered issue, as we have already discussed, by and large for older carers, this approach to care is viewed as far more problematic (although clearly individual views will differ).

Some care providers however also acknowledged difficulties with these approaches, in particular noting the lack of flexibility in voucher schemes that presented particular problems for older carers living in rural areas:

They're [vouchers] being re-shaped at the minute, that would be for sort of relaxation therapies, and sit-in services and things like that. But it was quite prescriptive and the feedback we gave and the feedback we got from families was that with it particularly being a rural area there needs to be more flexibility around the... what these vouchers can be used for because, you know, the practicalities of a carer in Grasmere going to Kendal for some relaxation therapy, leaving their vulnerable family member... it's sort of defeating the whole object really. Quite a stressful thing to do ....' (Jennifer, Social Worker)

Finally, on approaching all our care provider participants for interview on this topic, all took the initial stance that there was no difference in how they understood and approached the care needs of older male and female carers. What was of most interest, we feel, was that in the course of the interview, they began to reassess this view. Whilst it was still clear that providers approached the assessment on the basis of individual requirements not gender, it also became evident to both interviewer and interviewee during the interview process that [there were gendered nuances that subtly underpinned care provider's experiences of older carers and their subsequent assessment of needs](#). This is summed up below by Susanna (social worker) who commented near the end of her interview:

'I guess originally when I came I thought, you know, there isn't really much of a difference between how we work with men and women. But I think, talking to you, there are some fine differences that perhaps on face value you don't notice. But as we've been talking, you know, about what type of tasks the men would accept help for, there are some differences there between the men and the women as to what a female carer might accept the support for, and what the male might.'

## 5. Conclusion

In this report we have drawn on older male care-givers own narratives and interviews with care providers to firstly, identify the complex interplay of carer characteristics that can influence both how older men perceive and execute their caring roles; and secondly, how care providers interpret this in terms of care needs and support. Whilst some experiences of care-giving and attendant health-related issues echo those of their female carer counterparts, this is not the whole story. Rather, gender appears to be a key determinant of what support older male carers need and access. Yet age and previous life/work experiences also intersect with gender making it important to recognise that that older male care-givers' experiences differ across age cohorts and socio-economic circumstances.

By paying attention to gender as a carer characteristic, hidden and unspoken gender issues have been revealed. Gender emerged in this study as a characteristic that can influence how older men care for family members, how they construe care tasks, what coping strategies they develop to tackle the demands of this role, and some of its impacts. Gender also appears to be a significant factor in service access and take up, as well being a contributory factor in the social isolation experienced by older men. Many carry the personal and social losses they encounter alone, through the tendency of older male carers to not engage in emotionally sensitive conversations.

Our analysis has thus identified three different levels of gender conceptualisation and analysis:

- Firstly, 'Doing' and 'Performing' gender through caring functions and relations is relatively straightforward to elicit and identify;
- Secondly, more complex are the subtle influences on older male carer identities and their relationships with their cared-for family member;
- Thirdly, there is a marked impact on identity for older male carers, and an alienation from their previous lives, roles and relationships. This is in contrast to older female carers due to the significant role change caring is likely to bring about.

Importantly, our study also points to the ways in which gendered nuances subtly underpin care provider's experiences of older carers and their subsequent assessment of needs. Whilst we do not suggest that this is manifest in any overt gender allocation of services and resources, it is nevertheless clear that the gendered picture of care and care support needs is more complex than care providers initially, or consciously, recognise. This clearly warrants closer examination by care services and perhaps suggests a need to think through whether some services may benefit from, or be improved by, a greater acknowledgement of gender.

Through focusing on gender and bringing this carer characteristic to the fore, practitioners' awareness has been raised, facilitating the recognition of specific features of older male carer needs. This study also points to the benefits of developing gender sensitive and appropriate support for this group of carers.

Finally, we note that further research is warranted in order to better understand and explore these facets of older male carer experiences, which would enable the development



of gender sensitive assessment of need, the design of older male carer appropriate support services and a deeper analysis of the complex interplay of gender with other important carer characteristics.

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### Methods

#### *Phase 1*

By its nature, narrative correspondence is self-selecting. The only inclusion criteria for phase 1 were that participants must be male, over 50 years of age and caring for a spouse or partner in the north west of England. Participants responded to adverts placed in community and third-sector newsletters, libraries, local newspapers and other similar sources. It was not possible at the outset to assess the exact number of written narratives that would be gathered, but past experience of using this technique suggested that around fifteen to twenty narratives from older male carers are likely to be gathered. In fact a total of 19 older male carers responded indicating their willingness to participate and a total of 15 finally submitted narratives.

Narrative correspondence involves the gathering of written stories from participants around a pre-defined theme. Those responding to the initial advert were sent a more detailed participant information sheet along with a consent form to be signed and returned and a list of narrative prompts designed to help them structure their own narrative (see Figure 3). It was made clear, however, that respondents were free to include any additional themes that they felt were important to the telling of their story.

Participants could write as little or as much as they wanted and to structure their narrative however they liked. In order to ensure that those who may find it difficult to write a narrative were not excluded from the study, the option of submitting an oral (audio recorded) narrative was provided. Two individuals took up this option. Their oral narratives were transcribed verbatim.

The narratives thus varied in length from between a few pages of handwritten text to 5-6 pages of typewritten narrative or 10-15 pages of transcribed oral narrative. Written narratives were returned either by post or electronically.

**Figure 3: Male carers' narrative prompts**

In order to give some context to your story it would be helpful if you could start your story by giving a little detail about yourself and the person you care for - such as your age, and that of the person you care for, what sort of health and/or mobility problems the person you care for has, and whether you also have any health or mobility problems. It would also help to say a little bit about where you live and whether or not this helps you in your caring role in terms of ease of access to facilities and community support.

- Can you say something about when, approximately, you first started caring for the person you care for, what sort of care you were providing and how this has changed over time (or not)?
- Caring can be both a rewarding and mentally and physically demanding role. What are the biggest rewards and problems you have experienced in your caring role? Has it affected your own health and wellbeing?
- What support do you get in your caring role from family, friends and neighbours? (this might be practical support like shopping, cleaning, sitting with the person you care for to give you time off, help with the personal care of the person you care for or emotional support such as 'just having someone to talk to'). How does this help (or not)? You might want to illustrate this with examples.
- What sorts of support do you get from statutory, voluntary services or private sector services and how often? (this might be respite care in residential or day care settings, support with dressing, bathing or toileting the person you care for, support with shopping, cleaning or other types of support that helps you to continue caring).
- Can you say something about the process you went through to get these services and whether you were given any choice about the sorts of services you and the person you care for could receive. Has this changed over time?
- If it has been a struggle getting the right support, can you say something about the barriers you have faced and how you have addressed them?
- Can you say something about how you feel about the sorts of support you get to undertake your caring role and whether or not you feel this is the right kind of support for you? Are there types of support you feel would better support you and the person you care for?
- Was the person you care for offered a personal care budget and if so why did s/he choose to take it (or not)?
- If there are any other issues you feel are important to talk about in your story please include them in your narrative.

## Phase 2

Phase 2 involved a series of semi-structured individual and small group interviews with care providers across the north west of England. A total of nine care providers were interviewed in total. Providers were purposively selected from both the statutory (N=3) and third sectors (N=6) to include social workers, adult care support workers, dementia advisors and a carers' health worker (see Figure 2). The three statutory sector care-providers were interviewed individually, the remaining care providers came from two different third sector organisations and at their own request took part in two separate group interviews (Nos. 4-6 and Nos. 7-9) rather than individually.

Each interview lasted approximately 60 minutes. All interviews were audio recorded and transcribed in full. The themes raised for discussion in the interviews are outlined in Figure 4 below.

**Figure 4:** *Interview themes – care providers*

- Can you say something about your role in the commissioning, assessment or provision of support to older carers?
- To what extent does the commissioning process take account of any potential differences in the support needs of older men and women carers?
- How are the needs of older male carers assessed? (explore any differences between how the needs of male v female carers may differ)
- Can you say something about the sorts of support older male carers most frequently request?
- Can you say something about the sorts of support older male carers are most frequently offered?
- In your view, how do the needs of older male carers differ from those of older female carers? To what extent is this sufficiently addressed in the assessment process?
- How do personal care budgets impact on carers?
- Is there any evidence of a differential uptake of personal care budgets between older men and older women – and if so why do you think that might be?
- Is there any evidence that older men and older women use the personal care budgets to buy in different sorts of services?
- Are there any other issues you feel are important to talk about not covered so far?

## Analysis

All data was content analysed. Initial codes were identified using constant comparison techniques and a final coding framework developed. This was further refined through an iterative process. This technique ensures that codes are derived from the data itself rather

than developed a priori. Codes were then grouped into conceptual themes and subthemes that form the basis of the written analysis in this report. Given that qualitative data relies on small sample size, it was important that 'outliers' (themes that appeared in only one or two transcripts and did not appear to 'fit' with the broader emergent categories) were not ignored as these may be a factor of sampling bias. Outliers are thus included in the discussion, though it is made clear that these do not fit the general emergent pattern in the study. Direct quotations have been used to highlight emergent themes and are indicative of the diversity of views elicited.

In undertaking narrative research it is important to ensure the integrity of the story is not lost in the analysis, hence in addition to the thematic approach we have also drawn on narrative analysis to ensure the social and cultural context of the individual stories are preserved.