

# Getting it right for carers supporting someone at end of life

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## SUMMARY

The Carers (Scotland) Act (2016) places a duty on local authorities to prepare an Adult Carer Support Plan (ACSP) and a Young Carer Statement (YCS) for anyone they identify as a carer, or for any carer who requests one. The Carers Act requires Scottish Ministers to set timescales for preparing ACSPs and YCSs for carers of those in their final six months of life. The aim of this research was to provide evidence on the supportive needs of carers supporting someone at the end of life to inform recommendations regarding the optimal timescales for the creation of ACSPs under the Carers (Scotland) Act (2016).

The study triangulated data from a literature review, secondary analysis and two primary focus groups with bereaved carers of people with malignant and non-malignant diagnoses in Central Scotland. Identified themes included barriers to and triggers for identification, and support needs including physical support, psychological support, respite, information and communication, co-ordination and competing demands. End of life and speed of decline were also highlighted as key transitions in the caring journey.

The findings highlight the complex nature of identifying carers. There were many missed opportunities, for example a change in health status of the carer or cared-for person or their interaction with services. Overall, psychological support was valued, sometimes more than support with the physical aspects of caring, and this extended into bereavement. Peer support and basic compassion from health and social professionals were also highlighted as key to feeling well supported. Respite was essential, so carers could have time away from the caring role. The vital role of primary care health professionals and social workers was widely discussed by the participants, particularly with regard to co-ordination of care and the provision of information. The decline towards end of life was often faster than carers expected which necessitated a responsive service to meet their needs contemporaneously.

Assessing need doesn't necessarily open a Pandora's box as often knowing how and what can be accessed is sufficient. However, timely intervention is crucial to ensure carers feel supported and crises are avoided. Our ambition is that carers of people with terminal illness are identified early in the illness trajectory of the patient, ideally at diagnosis, so carer needs are assessed and met before end of life. In so doing, we anticipate that the number of carers requiring an ACSP to be fast tracked should be small, although the level of need may be great. Wide dissemination of the definitions and responsibilities of health and social care professionals is key to meeting the ambition of the Carers (Scotland) Act (2016).

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## 1. Introduction

The Carers (Scotland) Act (2016) places a duty on local authorities to prepare an Adult Carer Support Plan (ACSP) and a Young Carer Statement (YCS) for anyone they identify as a carer, or for any carer who requests one (Scottish Parliament 2016<sup>1</sup>). This replaces the current carer's assessment and broadens the definition of what a carer is, removing the 'substantial and regular' requirement. The Scottish Ministers must, by regulations, prescribe timescales for the preparation of an ACSP or a YCS in relation to adult and child carers of terminally ill cared-for persons but how this process will work is still to be defined. The Act defines being terminally ill as *"a cared-for person is terminally ill at any time if at that time the person suffers from a progressive disease and death in consequence of that disease can reasonably be expected within 6 months."* (Scottish Parliament 2016<sup>1</sup>).

The Scottish Health Survey (Scottish Government 2016<sup>2</sup>) estimated that there are 788,000 people caring for a relative, friend or neighbour. However, determining how many people are caring for someone with a palliative illness in Scotland is challenging due to lack of robust data and the difficulty of knowing when someone is in the terminal phase of illness. We do know that there are approximately 40,000-46,000 deaths of people with a terminal illness in Scotland every year (Murtagh et al 2014) and it has been estimated that in the UK that 500,000 of the 6.2million estimated carers are caring for someone with a terminal illness. This roughly equates to one for each person who died of a terminal illness. The absence of robust and routine data around caregiving at the end of life highlights the need for improvement, something which should be addressed in part by the 'Carers' Charter', now that the Carers (Scotland) Act (2016) is in force.

Palliative care is a holistic approach to the care of those with all conditions at the end of life. However, identifying when a person is approaching their final six months of life can be challenging, especially for those with a non-malignant, unpredictable illness trajectory. Therefore, it can be surmised that identifying their carers will be equally, if not more difficult. Carers UK (2017) reported that 65% of respondents had received an assessment of the impact of their caring role in the previous year. The Financial Memorandum accompanying the Carers Bill as it went through Parliament estimated that only 21% (153,811) of carers will have an ACSP and be receiving support, which highlights the potential for a significant identification gap (Scottish Government 2015<sup>1</sup>). This would likely include those caring for someone with a terminal illness.

Carer assessment should be carer led and practitioner driven, and a formal assessment helps ensure that, what should be a routine aspect of care, is. Assessment allows carers to exert some control over their supportive interventions and breaks their needs into manageable chunks (Aoun et al 2015<sup>1</sup>, Ewing et al 2016). Even those who are initially reluctant to engage in assessment are seen to engage in identification of need (Aoun et al 2015<sup>1</sup>). If issues identified are not easily solved, they can be lightened by identification

(Aoun et al 2015<sup>1</sup>). It may be that the carer does not need any, or significant, support at the time of assessment (Harrop et al 2014), but carers reported valuing knowing where and how to access support (Aoun et al 2015<sup>1</sup>, Carduff et al 2016, Aoun et al 2015<sup>2</sup>). Having the conversation itself legitimises their needs (Aoun et al 2015<sup>3</sup>). Identified needs don't require to be met by the assessor, and appropriate signposting was crucial requiring up to date professional and local knowledge (Harrop et al 2014, Aoun et al 2015<sup>2</sup>, Aoun et al 2017).

Timely identification, assessment and the initiation of support can reduce the overwhelming pressure of caregiving (Aoun et al 2015<sup>2</sup>), increase competence and sense of coping, decrease stress and increase satisfaction (Harrop et al 2014). Overall, the quality of care given by the carer is improved, if carer needs are identified and addressed.

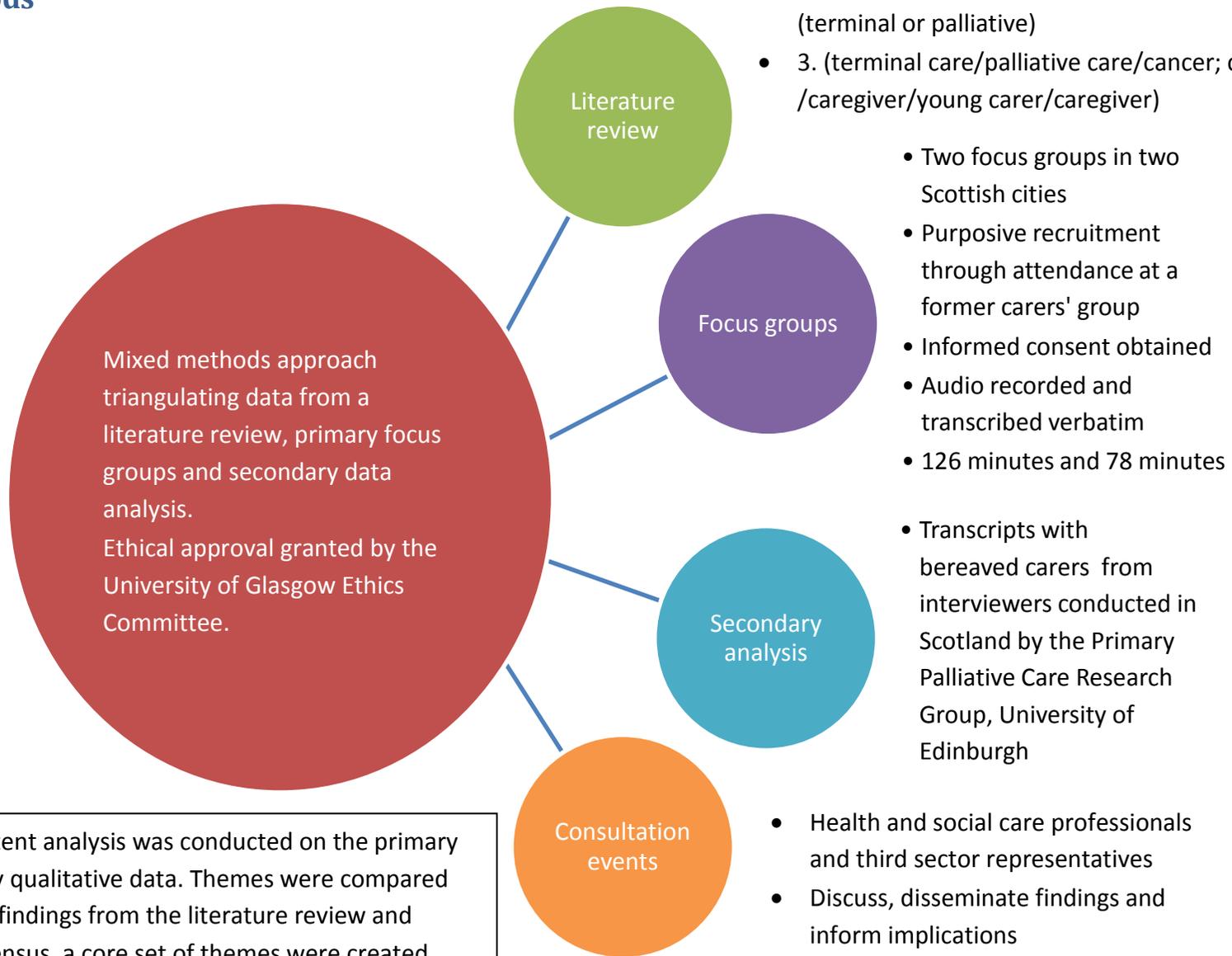
## **2. Aim**

The aim of this research was to provide evidence on the supportive needs of people caring for those in their final 6 months of life to inform recommendations regarding the optimal timescales for the creation of ACSPs under the Carers (Scotland) Act (2016).

### **2.1 Objectives**

- Explore the process of and barriers to identification of carers, both in terms of self-identification and identification by others.
- Determine when in the disease trajectory carers are identified as such.
- Determine the support needed and support received by carers.
- Identify triggers and potential opportunities for identifying carers which could be pertinent in initiating the creation of an ACSP.
- Discuss what really helped in their carer journey.

### 3. Methods



Thematic content analysis was conducted on the primary and secondary qualitative data. Themes were compared alongside the findings from the literature review and through consensus, a core set of themes were created (See the conceptual map in Appendix 1).

## 4. Results

### 4.1 Participants

*Table 1 Secondary Interview participant characteristics*

<b>Diagnosis</b>	<b>No of interview transcripts</b>	<b>Code</b>
Frailty	3	Fr
Glioblastoma	9	G
Metastatic colorectal cancer	3	Cr
Advanced liver disease	2	Li
Major stroke	2	St

Table 1 shows the characteristics of the individual interview transcripts included in the secondary analysis. There were an additional three focus group transcripts included in the secondary analysis from a project on the identification of carers (Carduff et al 2014, Carduff et al 2016).

Table 2 Primary Focus Group participant characteristics

Focus group	Sex	Relationship to cared-for person	Diagnosis of cared-for person
PFG1	M	Wife	Dementia/cancer
	M	Father	Stroke/multi-morbidity
	M	Wife	Cancer
	F	Mother	Frailty
	F	Husband	Cancer
	F	Husband	Cancer
PFG 2	F	Husband	Stroke
	F	Mother	Dementia/stroke
	F	Mother/mother in law/ brother in law	Heart disease/dementia/cancer
	F	Father	Parkinson's disease/dementia
	M	Wife	Dementia/cancer
Total number of carers			11

## 4.2 Collective findings

The themes identified were triggers and barriers to identification, the support needed and received, issues relating to end of life care and the impact of speed of terminal decline. A conceptual map of the findings is included in Appendix 1.

### 4.2.1 Identification

#### 4.2.1.1 Triggers to identification

The literature was scant on triggers for the identification of carers, but possible opportunities were advance care planning and power of attorney (Carduff et al 2016). The unrelenting nature of caring could result in carers neglecting their own physical health, resulting in frequent infections and the worsening of existing health complaints, triggering identification (Carduff et al 2014, Ewing & Grande 2012, DiGiacomo et al 2013). Crises and informing employers of carer responsibilities were also cited as possible opportunities (Carduff et al 2014, Carers UK & Age UK 2016).

The literature review highlighted the potential of palliative care and disease specific registers and electronic care summaries, but challenges included these being applied late in the disease trajectory: thirteen weeks prior to death (organ failure), 2.4 weeks prior to death (dementia) and 7 weeks prior to death (cancer) (Zheng et al 2013). System constraints and lack of time were cited as barriers to identification by professionals (Carduff et al 2016).

Many identification tools aim to identify those with palliative care needs across malignant and non-malignant conditions, including the RADbound indicators (Thoonsen et al 2012), Necesidades Paliativas (Gómez-Batiste et al 2013), e-Frailty Index (Clegg 2016) and Supportive and Palliative Indicators Tool (SPICT) (Boyd & Murray 2010). These include a variety of measures including clinical condition related indicators and general indicators of decline and 'the surprise question' – 'Would you be surprised if this patient dies within the next twelve months?' (Royal College of General Practitioners & The Gold Standards Framework 2011).

Work is on-going into the identification of patients with palliative care needs through the use of identification tools, initiatives such as the Gold Standards Framework and innovative community based models for care such as Alzheimer Scotland's advanced dementia practice model (Royal College of General Practitioners & The Gold Standards Framework 2011, Alzheimer Scotland 2016). Anticipatory care planning was advocated and the introduction of the Key Information Summary (KIS) has improved identification, with overall 60% of patients identified for a KIS (75% cancer, 41% organ failure and 66% dementia/frailty) (Tapsfield et al 2016). National data suggests that of the people who died in 2015-16, 58% of those who might benefit from a palliative approach had a KIS. There was considerable variation by NHS Board with 67% of those who died with a possible palliative need in NHS Dumfries and

Galloway having a KIS, compared to only 47% in NHS Lanarkshire (Scottish Government 2017).

Triggers for identifying carers by health and social care professionals were only raised in the focus groups with carers and included interactions with different health and social care professionals such as General Practitioners (GPs), condition specific input such as Marie Curie involvement and Community Psychiatric Nurse, and social workers. GPs and social workers were found to be particularly important. Triggers included both structured interventions such as use of registers,

**'it was the GP, my GP who said "you are a carer and I need to put you on the register" ...'** [FG 1]

but also opportunistic through identification of being entitled to the flu vaccine.

A change in health status, either of the cared-for or the carer, was also a prompt for identification, with increasing dependence of the cared-for encouraging both self and professional identification.

**'But it was only when he was in hospital last year, when I had a full carer's assessment done that they'd worked out that I was doing 25 hours a week for him that I thought "hm, I'm definitely a carer" right, so ... and that's been the only official time I kind of thought of myself... other than that it just kind of evolved.'** [FG 2]

This increase in dependence could also be more subtle, through taking on more practical tasks such as **'adminy stuff, like his bills'** [FG 2] or even through a loss of confidence of the cared-for. One carer spoke of an interaction with a hospital social worker who assumed she would be reinstating care when the patient was not receiving professional care and how this triggered an emotional outpouring.

**'And they said, we're just gonna reinstate your care, [patient name]. And I looked at my mother, and she looked at me, and I said, "My mum doesn't have any care." And I just broke down.'** [PFST 1]

Likewise, the development of ill health of the carer, sometimes necessitating hospital admission, was a prompt to recognising the level of input or effect that caring was having.

**'I started seeing myself as a carer when I was taken into hospital one night with a suspected heart attack because I was so stressed, basically.'** [FG 2]

#### ***4.2.1.2 Barriers to identification***

The primary and secondary data analysis largely reflected the literature review which demonstrated the complexity of caring and difficulties experienced with self and professional identification. There is a clear need for health care professionals to empower carers to self-identify and this is just as important as addressing the need itself. Self-

identification can be hampered by the perception that admitting to needing help is an admission of weakness and failing (Aoun et al 2015<sup>2</sup>). Historically, the professional focus is often on the patient's needs, so identifying carer need has been an ad hoc, informal, unstructured approach, often on the doorstep, which is poorly documented (Aoun et al 2015<sup>3</sup>, Carduff et al 2014, Ewing et al 2016, Aoun et al 2017). Identification is also affected by the ambiguity of the professionals' role. GPs and District Nurses (DNs) view their role as supporting carers, but it is suggested that carers view their situation as social rather than medical (Carduff et al 2014). Yet, in the past three years the number of carers identified by GPs has fallen, with only 9% of respondents to the Carers UK (2017) survey reporting that their GP knew they were caring and offered extra support to fit their caring role. The importance of not limiting carer identification to the next of kin was highlighted, as this neglects those from the wider social circle who are often instrumental in achieving a home death (Burns et al 2013, Carduff et al 2014).

Like triggers to identification, barriers to identification were only discussed in the focus group data. These could also be divided into those influenced by the nature of the caring role and professional barriers.

Caring was seen to be an often gradual process, epitomised through phrases such as **'evolved'** and **'grew into it'** [FG 1] where roles as family members or friends became extended or blurred and caring became **'...part and parcel of life.'** [PFG2].

One carer remarked,

**'Even at three o'clock in the morning, along the bypass, to pick him up off his floor, I'm still just his daughter.'** [PFG 2]

and there was an expectation that this was part of the relationship.

**'I would just do what anybody, what these guys would do...None of us are any special, we just do what we've got to do...And we try our best to... I don't know how to say it, we just try and...because it's somebody you love, so what do you do? She would do it for me...That's the way I look at it, if the shoe was on the other foot, she would have done it for me.'** [PFG1]

The busyness associated with the caring role was also a barrier with one carer reporting that

**'you don't have time to stop...'** [FG 2]

The invisibility of caring was recognised, contributing to the isolation and loneliness experienced but also limiting opportunities for identification and assessment. Targeting this group of individuals is incredibly challenging.

**'...there's a lot of people out there that are carers and they'll no discuss it with a single person. They're doing these things at home and nobody knows what they're doing and they never see a doctor so they're never recognised...' [FG 3]**

Misconceptions existed regarding what constituted a carer, with some lay carers feeling that their input wasn't substantial enough to qualify as carers or that the role was for professionals only. Professional misconceptions also existed with one participant being given opposing information from two different GPs. GPs were seen to be enablers and preventers to identification and the carers recognised improvements to their approach may result in increased professional identification. Suggestions were made such as a **'register of carers'** [FG 1] or a

**'letter going out to everyone to say, you know "do you care...?" And I think they could probably do with some kind of public information campaign about the definition of a carer.'** [FG 2]

with simple interventions such as having leaflets available in waiting rooms highlighted as being useful and reinforcing professional interest. Similarly, one carer suggested that professionals should be encouraged to consider that people requiring care at home may have lay people supporting them, who also require support.

**'Maybe they should think about "does this patient need care and who's giving them that care?...And do THEY need care?" '** [FG 1]

One carer commented,

**'Because for every carer, there's somebody that isn't well. So the onus has to go on GPs, receptionist, hospital people.'**[PFG1]

whilst another recognised that despite these potential triggers, there was still an expectation on self-identifying,

**'The onus is still on us to have done the approaching'** [PFG 1]

yet only one carer self-identified after seeing an advert on the television.

The importance of acting on identification in a meaningful way was also raised, ensuring that it was not just **'a piece of information that gets lost.'** [FG 2].

#### **4.2.2 Support needs**

The needs of those caring for someone with a terminal illness are diverse and can be divided into those which support the carer to care for the cared-for, and the distinct and separate needs of the carer themselves, with the former being easier for the carer to define (Ewing & Grande 2012).

For some, nobody enquired as to the specific needs of the carer during their caring journey or vague enquiries were made preventing recognition, identification and assessment. Uptake of support varied with one carer commenting that although staff offered support, she didn't feel the need to take up the offer.

**'...They said "if you need anything, just get in touch." But I never, you know, I never bothered, you know.'** [Li 2]

The majority of carers described accessing or needing support covering physical, psychological and informational domains with reference to the importance of good communication throughout. Co-ordination of care was key, and carers spoke of the difficulties in juggling demands. Replacement care enabled the carer to continue to care whilst maintaining their own health. Support was gained from health and social care professionals in addition to third sector organisations such as Marie Curie, Macmillan Cancer Support, Alzheimer Scotland, Chest Heart and Stroke Scotland, The Maggie's Centre, The Royal Blind Association and local carers' centres.

#### *4.2.2.1 Physical needs*

The literature review highlighted that involvement in hands on, physical care required a certain level of fitness and practical aspects of care can be increasingly challenging due to caring responsibilities being borne by the ageing population (Morris et al 2015). Training in symptom control was seen to improve self-efficacy in terms of bowel problems, pain, fatigue and managing medication (Havyer et al 2017). Direction was needed for support with benefits and finances as, if absent, appropriate monetary benefits were left unclaimed (Ewing & Grande 2012, Harrop et al 2014, Ventura et al 2014, DiGiacomo et al 2013). Financial strain was evident both from a loss of income but also due to extra expenditure (Khan et al 2012, Duggleby et al 2017). A physical need expressed in a study of carers of people having radiotherapy was unmet sexual need, a perhaps silent need, not identified in the primary or secondary analysis, but worthy of attention (Khan et al 2012).

At times, roles were undertaken as a result of a gradual decline without this being the wish of the carer, but due to a sense of there being no one else to help.

**'I found at the beginning it was sort of started off like getting the children ready for school and that but then gradually like my wife just deteriorated very quickly so I would end up having to like shower her and I said that's it I'm not doing it, if it gets any worse I'll..., but then she got catheterised so I started to change that, I had to do that and then her bowels started moving a lot and there's, there's no one else so you just had to.'** [FG 3]

For some, external support with personal care was only provided in the final days or weeks of life, yet this was acceptable and appropriate for the carer and cared-for. One carer cited concerns over whether rural living was a factor in the late initiation of services, expressing a desire that support had been available sooner. Even when a full package of care was in

place, often the carer was still involved in tasks such as shopping and regular visiting, several times a day. One carer spoke of a continuation in providing physical care, even when carers were in place, due to the reluctance of her mother.

**'We all know their time is limited, but there's certain things that a person won't let another person do, whether they're carers or not. So I did a lot of other things. Taking her to toilet, and of course, she didn't want anyone else to shower her and stuff like that.'** [PFG 1]

The caring role did not end once the cared-for person was out of the home and once admitted to a place of care such as a care home or hospital, attendance to holistic needs could still necessitate intervention by the carer.

**'Took her in books, magazines, read the newspaper to her every day, if she didn't feel fit to read it I would read it to her, you know.'** [Fr 2]

This was recognised by one bereaved carer who described himself as an **'ex carer'** [PFG 1] but acknowledged that those caring for someone in a place of care are not the same as him.

Administering medication was found to be an anxiety provoking role for the carers, often easily relieved by professionals recognising this by signposting to aids such as a dosette box or involving the carer in education.

**'And OK the medical profession can cope with the, you know, dispensing drugs and all the rest of it, and blah, blah, blah, but I needed to understand what the hell was going on..... And obviously, I figured it out for myself. But a few, 2 or 3 months doon the line, by that time I was exhausted.'** [G 23]

The carers were unsure of what financial support they were entitled to, denying them of benefits, with one saying she **'didn't even know what carer's allowance was.'** [FG 3]. The speed of this being put in place was important and support was generally obtained through input from social work with some third sector organisations such as Macmillan Cancer Support, Maggie's and carers' centres also identified.

#### ***4.2.2.2 Psychological support***

The provision of psychological support was very important in the primary and secondary data but there was less of an emphasis in the literature exploring general support needs. Emotionally, the sense of isolation which carers can experience can be further heightened when their input is not recognised by professionals (Morris et al 2015). The combination of being confined to the house and sleep deprived can have a negative effect on emotional wellbeing through increased isolation (Morris et al 2015). Additionally, the relationship with the person being cared for was often complex and existing difficulties in the relationship were magnified by the caring role (Carduff et al 2014, Duggleby et al 2017). The emotional needs of carers are often overshadowed by the physical needs of the patient, yet

assessment can bring this to the forefront (Aoun et al 2015<sup>2</sup>). Discussing needs and coping can prompt an emotional reaction and some carers spoke about how they had lost part of themselves through their role (Aoun et al 2017). Some carers are so proud of their sense of independence that discussing their needs prompts a sense of failure (Aoun et al 2015<sup>1</sup>). Many also expressed a fear of death and the future, complicated by the practicalities of ultimately dealing with the death of a loved one (Ventura et al 2014).

Emotional support was provided both by professionals and peers, although the quality of care given was highly influenced by the skills of the professional. Peer support was important in supporting carers and reducing isolation and carers reported being grateful for support from the wider community, often reciprocal from previous community engagement (Rainsford et al 2017).

This broad definition of peer support contrasts with the more narrow description of peer support provided by carers' centres which was found in the primary and secondary focus groups. Support from family and friends was very important in addition to support provided by health care professionals, yet support networks became strained as the disease progressed (Carduff et al 2016, Morris et al 2015, Rainsford et al 2017, Ventura et al 2014). Some carers also expressed difficulty in talking to family and neighbours about their caring role (MacLeod et al 2012).

The impact of place of care was highlighted by the primary and secondary data and the literature review reflected this in part. Hospital admission can be a challenging time for carers as it prompts a change in role which can result in an exclusion from care and decision making (Dosser & Kennedy 2012). A negative experience of institutional care can be a great source of distress for carers, coupled with communication challenges such as lack of information from nursing staff who lack the confidence to initiate difficult conversations (Dosser & Kennedy 2012). It was reported that nurses viewed their role as updating carers on the patient's condition and that communicating with them was secondary to the care of patients rather than integral, preventing the provision of informed, high quality care (Dosser & Kennedy 2012).

Aftercare in the bereavement period was seen to be very important in the primary and secondary data which was not identified in the literature review.

Isolation was a common theme, influenced by the often reluctance of the cared-for to have others involved in their care,

**'...I feel very isolated, there is only me. She won't have any kind of help of any description and my siblings don't really want to know. So very much on my own.'** [FG 2]

compounded by the overwhelming responsibility of having others depend on them. One spoke of the far reaching effect of this, even into bereavement. Depression and irritability were described as occurring. It was recognised that professional carers attending to the

physical needs of the cared-for person were also providers of psychological support to the carer,

**'I got on particularly well with the carers. So I hadn't realised that they were supporting me as well.... Yeah, and I was very grateful for that.'** [PFG 2]

and social stimulation to the cared-for.

**'In a way, they brought a bit of the world into her, because she'd been housebound for about four, five years. And she got a rapport with them, how's your family etcetera.'** [PFG 1]

Carers' centres were praised and recognised for their significance, particularly in the focus groups. It is important to recognise their benefit in reducing isolation, with one reporting they felt a **'...sense of belonging'** [FG 2]. Another spoke of how attending a carers' organisation legitimised her needs as it

**'gave me permission ...to have needs of my own which up until then I think I had felt I had to just put down because everybody else's needs were so overwhelming.'** [FG 2]

Meeting with others in a similar situation was also empowering for the carers in this focus group, encouraging them to say no and manage expectations of the cared-for. The peer support obtained was validating and allowed the carers to openly express their emotions. One male carer spoke of how hard this was, but also hugely beneficial.

**'...and I was greeting like a big wean, I must admit, when these guys came round me, and they told you, you know, 'cause they knew what you were going through. But that was the starts of it. And then I went to the Thursday group with the women, and they all welcomed me as well. But I was still emotionally, I don't know how to put it. I was still fragile, is that how you say it?...And the least wee thing, and I would start, right. But I must admit, up there, with everybody up there, they were great with me, and they helped me a lot, with that unit, at that particular time, it helped me.'** [PFG 1]

Attending a carers' centre was difficult for some and required support from the professional who had recommended going there.

Those caring for someone with a diagnosis which caused confusion or personality changes, such as a brain tumour or dementia, spoke of anticipatory grief and managing behavioural issues which were hugely distressing. The carers also recognised the psychological effect of watching someone deteriorate and die and described their reaction to the diagnosis as being **'just as devastated by it...'** [G 23].

Place of care was important in terms of the reassurance which carers felt, with one describing home care being **'so much better because then I was in control'** [G 1].

Conversely, issues were evident when the patient was admitted to a care home or hospital in terms of difficulty in letting that control go.

**'So it was letting that control go. Because I'd managed everything, letting that all go was really tough.'** [PFG 2]

The carer continued to advocate for the patient but also strived to have their high standards of care maintained. This was very important for their peace of mind and trust in the care provided.

**'I mean, I had to put Mum's rosary beads around her neck, I had to keep asking about the priest, you know. I had to keep making sure that religious artefacts which were important to my mother were beside her but they'd get taken away or put in a drawer or...you know. They just didn't seem to get it, that that was my mother's religion, that's what sustained her.'** [Fr 2]

Likewise, geographical proximity to the location of care was important in terms of availability for visiting and spending time with the cared-for person. Being provided with the required nursing based support whilst caring for someone at home also provided ease to be with the wider family which was reassuring for some, especially those with children.

**'I could never have done it if they never came in. He would have had to have gone to the Marie Curie. But erm, but no, it was erm, it just meant the boys could spend time with him as well. And they would just sit up all night if they wanted to and have the telly all night if they wanted the telly. They were in the same room. So that was that.'** [G 4]

Some carers spoke of the benefits of counselling, both during their caring experience and once it had ended. For some it was important that this was an impartial person who was not a member of the family or friend with whom the carer could be open and honest with, whilst another spoke of being grateful for being able to phone her sister.

**'My sister was at the end of a phone, so when I had a kick the filing cabinet moment, after I'd had a particularly challenging day, I could phone her up and sometimes there would be complete silence from her perspective, as I tried to get my breath back after howling for however long it was.'** [PFG 2]

Religious affiliation was also seen to be a spiritual and social support for carers, both in the hospital setting and at home.

Physical touch was described as beneficial and a simple comfort.

**'And it was nae just [patient], they looked after me as well. I mean, even when I went back over for his death certificate, the nurses gave me a cuddle. And that meant a lot to me, ken, it was nae just, oh he's no here noo, so get rid of you.'** [G 2]

One carer spoke of a frustration with their input from a specialist nurse as they did not feel that they were in need of psychological support and that this took up what was already limited time.

There was a general sense of being abandoned once the person had died and many carers spoke of a sadness in the lack of professionals who offered condolences. A few carers spoke of support from social carers into bereavement which they felt very comforted by.

**‘Some of them were very very good indeed, in fact two of them turned up at the cremation of their own accord entirely, which tells you something.’ [Fr 3]**

Likewise, this carer and others also had a visit from their mother’s GP after death **‘Not in a medical sense at all, just as a friend.’ [Fr 3]**. The carers who had attended carers’ centres spoke of the benefit of being able to attend into the bereavement period and maintaining significant peer support during this time.

#### *4.2.2.3 Importance of respite care*

The literature review highlighted that respite was an important support mechanism for carers of people at end of life, temporarily relieving the burden and addressing the consequences of sleep deprivation, yet Carers UK (2017) found that 23% of carers did not know how to get a break and evidence of the benefits of respite in the literature was scant. Home based respite was preferred to residential (Ewing & Grande 2012) and a lack of respite options for non-malignant patients was cited (Moore et al 2015). Respite was a complex issue with reluctance from both the cared-for and the carer affecting uptake (Ewing & Grande 2012, Moore et al 2015). There was also a desire that it be provided by palliative care services (Ventura et al 2014). There was a need for trust between the carer and person providing the care and it was vital that it was the right person providing the support (Aoun et al 2015<sup>3</sup>). Carers UK (2017) found that carers providing palliative care were most likely to report that the care needed for the cared-for was not available (44%) and that they were not confident in the quality of care available (33%).

Time away from the caring role was widely discussed as being significant in allowing the carer to maintain their physical and emotional health, described by one as allowing her **‘to be a better person’ [FG 1]**.

Sleep disturbance was commonly described with carers frequently being woken or being fearful of going to sleep, often sleeping in the same room as the person they were caring for. Basic human needs were affected with one carer speaking of even being unable to go to the toilet through the night due to how agitated her mother was.

**‘And that was about nine o’clock we got her into bed. By half past ten I had her out of bed and in the living room because she was screaming “Don’t leave me, don’t leave...!” I couldn’t even go to the toilet, when I went to go to the toilet she was screaming. So her and I sat up all night, me in one chair and her in the other.’ [Fr 2]**

Another spoke of how grateful she was when the carers arrived in the morning and it allowed her to shower, **'So that I knew he was in good hands' [G 4]**. Sleep disruption was seen to lower the threshold for not coping with one carer stating,

**'Maybe we felt we could just manage ourselves but then, er, that was OK if you were getting a sleep during the night.'** [G 5]

Replacement care for the cared-for was not without challenges. For example, when away from the cared-for there was a sense of watching the clock, resulting in anxiety about any unexpected hold ups. Often the cared-for were reluctant to be left with someone else, preventing the carer from accessing this much needed support.

The carer was also observed to prioritise the needs of the person they were caring for over their needs, preventing them accessing support.

**'...I suppose I did need some form of counselling actually, but I don't suppose there was time and I couldn't get away on my own. I wasn't going to leave him. He had to have somebody with him all the time.'** [G 20]

The time away was not necessarily put to enjoyable use but sometimes just to manage life,

**'And then when you get very tired, you tend to use that time, not to go to the pictures, but to go to get a dental appointment, you know, do necessary things, because you're just so tired.'** [PFG 2]

or reflect on their caring role.

**'That's when I went to Costa. But what I used that time for, I realised, looking back, was catching up with my life. You know, with the nature of dementia, you're always running behind the process. So there, I was thinking back over the week, and thinking, what did I do right, and what didn't I do right and what do I do now? And I always found that that space, three hours, with good coffee, and a catching up with myself, was really another lifesaver.'** [PFG 2].

Although often limited by the wishes of the cared-for, when external care was provided, benefits for the cared-for person were clear with some reports of them getting a real social stimulus from the services provided.

#### **4.2.3.4 Co-ordination**

Many carers spoke of a lack of knowledge as to how to access services to meet their needs and what services were available (Ewing & Grande 2012, Harrop et al 2014). Carers reported being unclear who the main contact person should be for the person they were caring for, influenced by poor communication between professionals (Ewing & Grande 2012, Harrop et al 2014, Aoun et al 2017, Duggleby et al 2017). They were unclear who to contact

in an emergency and greatly valued having a named contact day or night, seven days a week (MacLeod et al 2012).

Co-ordination of care was discussed in terms of co-ordinating care for the cared-for, but also specifically related to concerns if the carer was to become unwell, with one carer commenting

**‘And I, I just feel that there’s a wee link missing there and that worries me, that’s one of my main worries is that if something happened to me suddenly you know.’ [FG 3]**

Communication between professionals was crucial with one carer commenting on the reassurance of knowing that her GP could contact the hospice if symptom management advice was needed and another acknowledged the exhausting effect of answering the same questions multiple times.

**‘And I remember that first day, there was a procession of people I didn’t know coming to see me, and they were all asking the same questions, and I was absolutely shattered.’ [PFG 2]**

The primary and secondary analysis particularly highlighted the important role of primary care in supporting carers with examples of how influential the degree of support provided from GPs and DNs was, citing both positive and negative experiences. This was largely with the provision of practical symptom management but also in terms of general emotional support and having someone to answer their questions. The majority of experience cited was positive, yet some carers reported feeling let down by their GP or DN with two reporting that the GP had not visited once throughout the course of illness and another recognising that due to intense hospital input, contact with the GP was non-existent.

In the final days to weeks of life, there was a general consensus that frequent input from GPs and DNs was beneficial with one carer reporting that the GP was in every day. This particular carer only required intensive support for the final four days of life but spoke strongly about her appreciation for this input at what was an appropriate time for their situation.

**‘Then (GP) come in every day. I mean that was over four days but that felt like weeks. Oh no, the nurses were perfect.’ [Li 1]**

Input from DN staff was largely driven by the need for physical care for the patient but psychological support was often provided during these visits. One carer also spoke of the benefit of early support visits for later care.

**‘... the district nurses at the local health centre, came to see him once a week. So that they all tend to know him. Basically because they knew he would get worse.’ [G 13]**

DN visits were also helpful for triaging concerns and liaising with the GP which was reported as being very reassuring.

**‘But the district nurses were fantastic, they were great for a lot of things. Because I was able to use them as a sounding board. Because if I had to phone up the doctor, the receptionist, I used to feel they used to put a block about sending a doctor out.’ [PFG 1]**

One carer spoke of the DN service visiting the house, but the focus being purely on the patient and the detrimental impact of this on her wellbeing,

**‘...they didn’t recognise what a terrible life I was having and I was so busy and I was so heart-broken with them.’ [FG 1]**

whilst others described DN input being opportunistic for identifying when additional support was needed, particularly with regard to overnight care.

**‘And then one day the DN said to me “Would you like a Marie Curie nurse to come and sleep overnight for a night, just to let you get a good sleep?” [FG 1]**

Different opinions were expressed in terms of the time and support which GPs should be offering to carers, with recognition of the limitations on their time. One of the focus groups included a debate about GPs regularly assessing carers or asking after their specific needs, criticised by one as being unrealistic who felt that carers had a responsibility to speak up for themselves. The carers spoke about the need to be forthright and using their initiative to access the support required with one stating that they had to

**‘...push my way in there, rather than be invited.’ [G 23]**

Some carers reported being encouraged to and keen to take a solution focused approach to care and being

**‘...happy to sort of organise those things myself, it was just knowing, initially, that I was entitled to it.’ [PFG 2]**

One carer suggested a formal questionnaire or assessment to be conducted by the GP with scope for reassessment, acknowledging the importance of **‘getting the right questions’ [FG 3]**. Some carers didn’t consider approaching the GP at all for support.

Communicating well with the GP was important with one carer writing to her father’s GP with her email address and work and home numbers attached to allow two-way communication. Another spoke of the importance of power of attorney in enabling open discussion.

**‘If you have power of attorney for care and welfare then they will happily talk with you... [Agreement]...but it can be very difficult if you don’t.’ [FG 2]**

Having an assertive professional who would take the lead in times of crisis was welcomed and it was important that any professional involved in care respected any advance care planning discussions, something which unfortunately did not always happen. Crisis was a trigger for acknowledging that additional help was required and this could occur suddenly,

**‘I think at first you think you can do it all, and then you very quickly realise you can’t.’  
[PFG 2]**

or as a result of a build-up of issues.

**‘It’s the bashing your head against a brick wall, it’s going from crisis, to crisis, to crisis. And knowing, not knowing when the next crisis is coming, not knowing what that crisis is going to be, but knowing that it’s coming. And just expectations are high that it’s gonna be there.’ [PFG 2]**

Consistency and a high quality service was recognised as being important, and frustration experienced when carers felt let down by services initiated to support them and the person they were caring for. Two carers spoke of ‘slipping through the net’ resulting in delays which were devastating to them.

**‘...just slipped through the system three times, they hadn’t even a record of her name. That’s how important she was.’ [PFG 1]**

#### ***4.2.2.5 Information and communication***

The importance of good relationships with health care professionals was a pervasive theme in the literature with poor communication being synonymous with poor co-ordination (Morris et al 2015, Ventura et al 2014). Lack of open communication was the most commonly cited unmet need (Ventura et al 2014). Effective communication and feeling competent was seen to lower stress and increase empowerment and a sense of preparation for death and was integral to meeting personal, social and spiritual needs (Harrop et al 2014, Ling Look et al 2017).

Carers valued having the opportunity to discuss the person’s illness and found great benefit from being able to talk to people, ask questions and check their understanding (Ewing & Grande 2012, Ventura et al 2014). The greatest support need was accurate and timely information and many carers were keen to know more about the disease, symptoms and prognosis (Ewing & Grande 2012, Morris et al 2015, Ventura et al 2014, Aoun et al 2015<sup>2</sup>). Two studies showed this to be the highest need at first and second assessment, emphasising the importance of on-going information giving and reassessment (Aoun et al 2017, Aoun et al 2015<sup>2</sup>). Lack of knowledge on the dying process is a need which must be handled sensitively and individually, but should not be avoided due to professional reticence to address due to fear (Harrop et al 2014). Preparedness for end of life can be enhanced by person centred, individualised education (Harrop et al 2014). Carers of those with a non-malignant diagnosis often saw the person as ‘invincible’ due to their unstable trajectory

(Moore et al 2015) and a proposal is made for the provision of early education of practical, technical and emotional aspects of caring for this group of patients (Morris et al 2015). How information is given is seen to be just as important as the information itself (Duggleby et al 2017). Issues can present when staff are unavailable or lack the time to spend with carers and give mixed messages, and some carers would source the information elsewhere if their needs were not being met by professionals (Ewing & Grande 2012, Duggleby et al 2017). Information giving is also pertinent in terms of the carer being involved in advance care planning and acting as the person's advocate (DiGiacomo 2013).

Information regarding accessing support and services and illness and prognosis was obtained from a wide range of sources, some through signposting from health and social care professionals, others opportunistically and also self-directed through use of phone lines such as those offered by Chest, Heart and Stroke Scotland, the internet and information booklets. Written information had a place but needed to be supplemented by verbal explanation.

Seeking information was complex due to the multitude of issues on a carer's mind at point of consultation, as was retaining what had been said.

**'They advise you to take a notepad when you're talking to the consultant. But you don't even, when I looked at what I'd wrote, it wasn't even legible...It was like shorthand. And she was saying, what did they say, and I'm saying, aye well it's okay, you've got to go...I hadn't a clue.'** [PFG 1]

Additionally, language used could be misleading and carers were keen for clarity in information giving. Generally, it was important to have an understanding of what was happening at any particular time, and in the future.

**'...I was told he had a tumour, a glioblastoma or whatever it was, aggressive, blah, blah, blah. But nobody ever sat me down and said, you can expect this to happen or you can expect that to happen.'** [G 23]

The depth of information provision was important with vague statements from hospital professionals such as **'be prepared'** [Li 2] not enhancing understanding of what to expect, complicated in this case by an avoidant GP.

**'The GP used to come in and we just used to talk, but they never said nothing, you know, about her condition. They just said that she was ill, you know? They never discussed nothing, you know?'** [Li 2]

In addition to avoiding conversations regarding prognosis and dying, some professionals were seen to approach these with an awkwardness which the carers found challenging.

Some carers acknowledged that their coping mechanism was denial whilst one thought that an honest, direct means of communication was cruel.

**'In fact it was the doctor when I, the Monday when he went out and I said, "How long has he got?" and he says, "Monday" and oh I felt terrible when he said that. I thought, "Oh how cruel". He was telling the truth but it...horrible sometimes the truth, eh?' [Li 1]**

Conversely, another welcomed a direct approach,

**'...although it was very difficult, unpalatable, if you don't know exactly what the situation is, you can't manage it.' [G 5]**

and found that vagueness actually caused her more distress.

Some carers struggled to have open conversations with the person they were caring for, due to both their reluctance and the reluctance of the cared-for. This was sometimes resolved through facilitation by professionals when there was a good relationship with the cared-for and carer, allowing the professional to consult with the cared-for alone and then update the carer.

Not knowing who to call for help or advice resulted in the carers struggling with additional difficulties in isolation. One carer described watching her husband in pain,

**'And, I mean I was just in a terrible state not knowing how to make my husband comfortable. And that, I found that bad, you know, not... that there was nobody I could call, yeah.' [FG 1]**

whilst another struggled for days not appreciating that their GP could help.

**'And I don't know why I had got it into my head that, you know, it was the [hospital] now and the doctors and staff there and not my surgery. So I sort of, went for several days, floundering I suppose. Not knowing what to do.' [G 20]**

Concern was also raised by one carer about how quickly help would arrive even once a call for help was made.

There was an acknowledgement that although support was available, knowing how to access it was an issue.

**'...maybe it was my state of mind at the time, I don't know, I wasn't thinking straight – I didn't even think "Where can I go for help?" ' [FG 1]**

One carer said that she wasn't

**'aware of even the term – believe this or believe it not – social worker.' [PFG 1].**

The timing of information giving was also seen to be significant with many carers reporting that they would have welcomed information and advice earlier on in the disease process.

#### 4.2.2.6 Competing demands

Carers spoke of trying to work whilst caring being a ‘juggling act’ in which they were trying to balance competing demands but with the consequence that they felt they had not done either their caring role or working role well (Ewing & Grande 2012). Not only does a disruption to working have a financial impact, but it also impacts on socialisation and sense of identity and self and can increase isolation (Carers UK & Age UK 2016). Barriers to working and caring include a lack of flexibility, poor support when dealing with emergencies and a poor attitude towards carers (Carers UK & Age UK 2016). There is an onus on social care to provide ‘replacement care’ to allow carers to continue to work and for this to be economically viable for the carer (Carers UK & Age UK 2016). Carers UK (2017) found that over 7 in 10 carers said that their need to combine paid work and caring was either not properly considered in their carer’s assessment or in the support they received. Challenges also presented in maintaining and juggling existing relationships and the caring role, particularly when also caring for children (Carduff et al 2014).

Some carers described continuing to work whilst caring with one describing the benefits of a supportive workplace in terms of flexible working and access to car parking, which allowed her to continue in paid employment whilst caring. Another spoke of the inflexibility of his work hindering his ability to care and creating additional stress, which was resolved when he was offered redundancy.

**‘It was a 24 hour a day job [caring]. And there was no way on this earth I could have worked and done that. Because the last year I was at my work was absolutely horrendous. Because I was fighting everybody in the world.’ [PFG 1]**

External commitments such as work and family were seen to frame the caring experience as were existing complex family relationships. One carer spoke about supporting her adult children emotionally in addition to caring for her mother whilst another spoke of dealing with the anticipatory grief of her youngest son.

**‘He [son] was getting really angry that his dad was going to thingmy [hospice], and he couldn’t really understand why everyone was happy. Like his friends and stuff.’ [G 4]**

Complex relationships within the family and with the cared-for person were magnified by the caring role with varying degrees of input and agreement.

**‘...sometimes you think your family will be able to give a bit. But often, that’s where tensions come, too, because people don’t see the situation in the same way, and don’t see, you know, the need that you may see, or don’t feel as guilty about not meeting that need.’ [PFG 2]**

Conversely, a lack of extended family placed a huge burden on the often sole carer to care in isolation.

**'I've got no brothers and sisters, so there was never any doubt in my mind that I would be looking after her. So, it was difficult working full time, because she wouldn't have any carers in the house. And I felt I had to respect that because it was part of her independence.'** [PFG 1]

Trying to juggle caring with other family responsibilities was difficult and added to the already emotional aspects of caring.

**'So I nipped home and [daughter] was in floods of tears. I am missing you, I'm missing you. I said I know, but I have to be with your dad just now, and whatever. And she got really upset and I was thinking, oh God, you know, what am I going to do?'** [G 23]

#### *4.2.3 Speed of decline*

Speed of decline emerged as being important in the literature in terms of the availability of equipment but was discussed across many different domains in the primary and secondary analysis. As care needs increase, often the requirement for equipment to support care at home presents which can be disconcerting for carers and patients (Morris et al 2015, Ventura et al 2014, Aoun et al 2017, Duggleby et al 2017). Carers need to be supported with information on what is available and how to access this and also trained on how to use equipment safely (Ewing & Grande 2012).

Many of the carers, predominately of those with a malignant condition, made statements relating to the speed of decline of the person they were caring for. This was generally much shorter than they had anticipated with many talking about a terminal decline lasting a few months or even days. One acknowledged the change in their supportive needs as the condition of the cared-for person deteriorated.

**'...it was a short period, you know, he started to be not well in the January and he died in the July. But as you know, you gradually need this, that and the other.'** [FG 1]

In addition to this gradual decline, one stroke carer spoke of the immediate change in condition which occurred due to sudden, unexpected, stroke.

**'But then the next day her condition changed and during the course of the next ten days she deteriorated and became confused. And the two doctors who saw her thought that she'd probably had another stroke so that's it.'** [FG 1]

Another carer spoke of the prolonged resuscitation of his wife who had suffered a cardiac arrest and had not had any anticipatory care planning carried out prior to this.

Some carers had been given a professional estimate of prognosis but this was challenging and often inaccurate which caused distress.

**‘And then my own doctor, [name of doctor], she came in a couple of days after to see how I was coping and she says “we didn’t expect it so quick” so whatever happened in the end I don’t know.’ [CR 2]**

A quick speed of decline also affected the carer’s ability to process and cope with what was happening.

Many professionals were involved in care across social care (social work, professional social carers), health care (DNs, GPs, specialist nurses, occupational therapy, physiotherapy, speech and language therapy) and third sector organisations (carers’ centres). The speed of availability of these professionals and equipment was found to be significant with one commenting,

**‘But because Mum went downhill quite quickly physically and we needed occupational...like the wheelchair and whatnot, within days it was out and assessed and everything that we needed, I couldn’t believe...’ [FG 2]**

Conversely, when input was late or lacking, the burden on the carer magnified. Carers were often left to purchase equipment themselves due to lack of knowledge of access or it was not available when needed, impacting on their ability to care.

**‘The commode I had, had nae wheels on it. Er, [patient] went into [hospice] and what did they bring me? A commode with wheels on it. I thought, it’s too late noo.’ [G 2]**

Progressive disease brought about an increased dependency and falls risk, resulting in more manual caring and the provision of appropriate aids could be limited by what was deemed acceptable by the cared-for, limiting support for the carer.

#### **4.2.4 End of life care**

Feeling supported and informed and having a positive end of life experience were found to be important into bereavement. It is therefore imperative that carers are identified and supported to improve health during caring and beyond (Morris et al 2015, DiGiacomo et al 2013, Moore et al 2015, Harrop et al 2014). Loss and the importance of being present at time of death were discussed in greater depth in the primary and secondary analysis, where end of life care emerged as an additional theme.

Although loss was generally associated with a sense of sadness, one carer admitted to realising that death would be accompanied by relief as it signified the end of the demands of caring.

**‘But, you know, when you’re recognising that you’re dealing with, say, a terminal illness or a condition that isn’t going to get better and the demands of dementia, say, are just going to get heavier and heavier, I think it’s very difficult for the carer to acknowledge**

**that what they really are looking for is the end of this and the end of this is often going to be the end of someone else's life.' [FG 1]**

There was also recognition that this is complicated by the complexities of the existing relationship of the person being cared for. Loss also related in broader terms to the multiple losses of the cared-for person and the carer in terms of independence and sense of self.

**'I mean I've spoken to people here, you know, and people phoning, who've maybe been caring for someone round the clock for 20 years, you know, and when that person dies, you know, what is their life?' [FG 2]**

Misconceptions around medication use at end of life were evident with some believing that opioids and syringe drivers were used to hasten death.

An emphasis was often placed on being present at time of death with a sense of failure if this was not the case.

**'That upset me, that she died on her own because I'd been there all the time, apart from my sister going in on the Saturday.' [Fr 2]**

Carers who had been present at time of death spoke of the comfort that this gave them, and perceived comfort to the cared-for person. When the death was perceived to be a 'good death', fond words were spoken and touching anecdotes were shared.

Four of the six carers in PFG 1 recounted feelings of guilt. One carer remarked,

**'And I still think about it [death of the cared-for person], probably we're all, to a certain extent, we're all the same, could I have done something better, did I do something wrong, why did she die, was it something I did? It still haunts me to this very day, about, could I have did something?' [PFG 1]**

showing the depth of his distress years on. Others spoke about feeling that they '**killed**' the person they were caring for or '**gave permission**' for staff to withdraw treatment. The guilt surrounding end of life persisted long into bereavement.

### **4.3 Additional findings**

Three areas were explored in the literature review which were beyond the scope of the empirical research, but worthy of discussion.

#### **4.3.1 Rural carers**

The majority of research covers an urban demographic, however a review of research based on rural areas revealed some distinct challenges and differences for this group (Rainsford et al 2017). The importance of community was emphasised and was why people valued living in a rural location. Despite this, peer supportive aspects could be lacking. Geographical

distance was seen to be a challenge, both in terms of driving distances for professionals and in the out of hours period. Due to reduced numbers of available health care professionals, a lack of palliative care experience and poorer access to services was described (Rainsford et al 2017). Care risked being fragmented due to poor communication. Many similarities between rural and urban carers also existed with emphasis placed on the importance of education and communication and recognition of the importance of emotional support and having a wide network of support. Carers also highlighted the importance of being valued as a carer and were often unable to find the time or energy to self-care.

It was highlighted at the dissemination event that accessing support, such as carers' centres, could be more challenging for rural carers and it was suggested that initiatives such as befriending have a real value for this group of carers.

#### *4.3.2 Carers of children requiring palliative care*

A review of the literature demonstrated a stark paucity in published research into the needs of carers of children requiring palliative care. The 'Children in Scotland requiring Palliative Care' study recognised the emotional needs of adults caring for children and recommended that specialist psychological and emotional support should be available to family members (Fraser et al 2015). Parents can live in a state of raised anxiety and need to manage their complex emotions whilst striving to provide support to their child. They often have a responsibility for complex treatments in the home and experience frustration, loneliness and anger in dealing with services. The conflict of managing paid employment while caring can be challenging, as can maintaining a relationship with their partner who can respond very differently to the same demands (Cadell et al 2014, Monterosso et al 2009, Schneider et al 2011).

The provision of breaks from responsibilities was important, in view of the emotional impact of caring coupled with the high physical demand, where care needs attended to by parents can include bathing, toileting, feeding, administering treatments, comforting, monitoring physical health and symptoms, assisting mobility, communication and ensuring safety. Even when respite care was provided, some carers reported their sense of responsibility was relentless, whilst others received great benefit from a short break. Confidence in those providing the respite support was crucial. Family relationships were often adversely affected by the caring role. Similarly, sleep could be disturbed by nocturnal care needs and, even when provided, breaks were used by some to catch up on domestic tasks. Specialist residential care was advocated as a means to allow focus on the family unit and permit parents to spend time with siblings (Fraser et al 2015).

#### *4.3.3 Young carers*

There is also limited evidence on the issues faced by young carers. Cited consequences of caring as a child include physical and mental health issues such as depression and fatigue with an impact on socialisation, education and sense of self (Kavanaugh 2014, Boquet et al

2011, Marziliano et al 2014). A lower life satisfaction can be reported by some with others reporting a positive and gratifying experience (Pakenham et al 2006, Fam et al 2013, Gates & Lackey 1998). There is a need for friends to be supportive and information to be available (Gates & Lackey 1998, Nicholls et al 2017). Interestingly, there was a significant and positive correlation between unmet need and stress, anxiety and depression but inversely with quality of life (Nicholls et al 2017).

Like adult carers, young carers face significant challenges in identification. In a survey conducted with 11,200 pupils from Glasgow Secondary Schools, nearly 1 in 8 pupils said they provided care for someone in their household with almost a third stating that no one knew about it (Robison et al 2017). It is not possible to determine the number caring for someone with a terminal illness but a third of those caring cared for someone with a long term condition. Barriers to identifying young carers are just as significant, if not more so, than those of adult carers and include stigma, concerns of accusations of poor parenting, lack of knowledge of support available, negative previous experiences, fears of unwanted intervention and forced separation, not identifying with the term carer and just 'helping out' (Robison et al 2017).

## **5. Strengths and Limitations**

This study was relatively small in scope but is strengthened by the triangulation of existing literature, qualitative primary focus groups and secondary analysis. The sample of caregivers in the primary focus groups was recruited from third sector carer organisations and therefore they had very positive experiences of carers' centres. The caregivers cared for a broad range of malignant and non-malignant conditions in a variety of settings (including home, hospital and nursing homes) which is a strength. Both the primary and secondary data were collected across Central Scotland, meaning the experiences of caregivers in rural Scotland, or those at a distance from hospice or tertiary centres were not captured. The primary and secondary data was generated from interviews and focus groups with bereaved carers, which subjects it to recall bias. However, it was a strength that we captured meaningful data on the importance of post-carer support and bereavement support.

## 6. Implications

Our ambition for supporting carers in Scotland is that they will be identified early in the disease trajectory, ideally around the time of diagnosis, and have an ACSP with an early, preventative focus. Therefore, it is anticipated that the number of carers needing to take advantage of the fast track process would be small, but that their burden of need is likely to be high.

### 6.1 Key implications

#### 6.1.1 Speed of access

The fast track process will be significant in two circumstances:

1. To ensure that those who have not been identified as carers earlier, but develop need, are responded to quickly.
2. For those caring for someone with a sudden or late diagnosis and poor prognosis.

In both of these circumstances, the cared-for person is likely to be in the last 6 months of life and their condition likely to deteriorate quickly. Thus, prompt response is vital to minimise crisis and ensure support is provided when needed.

In part, the success of having an ACSP created depends on the timely response to the needs identified (including access to professionals, information, services and equipment).

#### 6.1.2 Identification

If carers can be identified early in the disease trajectory, implications of the fast track will be minimised. Identifying carers is everyone's responsibility, but although anybody can do this, many health and social care professionals often think it is someone else's responsibility, and consequently the carer remains unidentified. This research suggests that there should be a presumption that people have a carer rather than not, and that this presumption should lead to the offer of documented identification (i.e. on the KIS) and assessment for a carer.

The requirement of the Carers (Scotland) Act (2016) Section 28 to involve carers in hospital discharge is an excellent opportunity for highlighting those providing care, and subsequently communicating this information across all those delivering care, in all settings. It may be that this is the first time the carer is identified, and as well as being involved in the discharge planning of the patient, an assessment of their needs should also be conducted. However, hospital discharge for the cared-for person should be considered more as an opportunity for reassessment of need, rather than initial identification of the carer.

Frequent admission to hospital and completion of a DS1500 are other prompts, which might allow for the identification of a carer. However, we propose that earlier identification is preferable, perhaps achieved through raising the profile of opportunistic interactions such

as entitlement for the flu vaccine, attendance at pharmacies and public health approaches such as prompting at cancer screening.

The addition of carer information to the KIS should be a requirement, not an option. In so doing, professionals must appreciate their responsibility to inform identified carers of their right to have an ACSP created. Likewise, disease specific registers in GP practices should be used as a means of pro-actively identifying carers.

### ***6.1.3 Education and raising awareness***

In order to reduce ambiguity surrounding the caring role and the ACSP, it is essential that the implementation of the Carers (Scotland) Act (2016), and subsequent fast track for carers of those with a terminal illness, is supported by promotion and wide dissemination of definitions and responsibilities of professionals. Dissemination should include the Royal Colleges for General Practice, Physicians, Nursing, Pharmacy and Allied Health Professionals. As previously described, the culture shift to include presumption to enquire about the presence and needs of carers should be encouraged.

### ***6.1.4 The importance of primary care professionals***

The research demonstrated that primary care professionals are critical in the identification and support of carers. Interdisciplinary communication between primary and secondary care was found to improve co-ordination of care. Communication with carers and patients about diagnosis and prognosis and the support available was significant in improving preparedness for end of life caring. However, it is vital that this is considered within the context of existing pressures on primary care provision.

## **6.2 Additional implications**

Additional implications have emerged which are beyond the immediate aim of this project but are significant to the implementation of the Carers (Scotland) Act (2016) and the ambition of the Strategic Framework for Action on Palliative and End of Life Care (Scottish Government 2015<sup>2</sup>).

### ***6.2.1 Post carer support***

The research evidence strongly highlights the importance of support for carers extending into the bereavement period. Guilt was seen to have far reaching implications as was 'slipping through the net'. Aftercare was significant and support was gained in many ways including continued professional and peer support. The evidence shows that transitioning into a non-caring role was challenging, and the loss of identity experienced by some when caring was difficult to recover from.

### *6.2.2 Carers of those not in the home environment*

The research highlighted that those caring for someone who is transferred to a place of care such as a care home, hospital or hospice continue their caring role in this alternative location. It is acknowledged that their needs are likely to be different to those caring at home, but nonetheless are worthy of recognition. These carers will benefit from an ACSP looking at their specific needs.

### *6.2.3 Further research*

This project has highlighted areas for research including,

- a. Young carers (to inform guidance and implementation relating to the YCS)
- b. Carers of children with palliative care needs
- c. Rural carers
- d. Carer Identification

## 7. Impact

This research project has already had significant impact in raising awareness of the issues identified for caring for someone with a terminal illness.

The findings have been discussed at three key events including:

1. The Scottish Parliament's Cross Party Group on Carers
2. A Research into Practice Event, which enabled the findings to be shared with key stakeholders from local authorities, NHS Boards and the third sector
3. A conference of key stakeholders to hear and discuss the results of the research and the implications for improving support to carers.

Cumulatively, these events were attended by over 150 people. Many of those that attended are involved in the development of the new local carer strategies, as well as the planning and delivery of carer services, and from carer services, including carers' centres.

Furthermore, an article on caring at the end of life, highlighting the research findings was published in the Scotsman's Friends of the Scotsman section (Scotsman 2018), which has a print readership of over 30,000 people.

This findings from this project will also inform the publication of policy report, which will be published by Marie Curie and Macmillan Cancer Support in spring 2018. This report will be widely disseminated to key audience groups in health, social care and the third sector, as well as the general public. It is hoped that, as well as informing the Scottish Government on the development of regulations to support sections 7 and 13 of the Carers (Scotland) Act (2016), the outcomes of this project will also help inform the wider implementation of the Act and inform those responsible for supporting carers. The findings of this study will also be written for academic publication.

## 8. Conclusion

Identifying carers of those looking after someone at the end of life care is a complex issue with many missed opportunities. Ensuring that those caring for someone in the last six months of life gets the support they need as quickly as possible is crucial if they are to effectively carry out the caring role they have taken on. Depending on the nature of the condition of the cared-for person the care required can be highly demanding, and the need for support rapid. A lack of support leaves both the carer and the cared-for person at risk of a breakdown in the care provided, which may lead to much greater complexities in the care provision needed, and quality of life available to the cared-for person and carer, beyond death and into bereavement. Carer identification is everyone's responsibility and with a view to increasing the numbers of carers identified for a ACSP, health and social care professionals need to move towards the presumption that a patient has a carer and ensuring they are aware of their entitlements.

With Carers UK (2017) finding that 73% of respondents did not feel that the government understood their contribution or value at all, the publication of the Carers (Scotland) Act (2016) is an encouraging step towards giving Scottish carers the recognition and support they deserve. Through the use of ACSPs and YCSs, carers will be able to receive appropriate input, tailored to their individual needs. However it should be the ambition of the Act that carers be identified for a ACSP early in the illness trajectory, so their needs can be met before the terminal phase of illness. In so doing, those carers requiring a fast track ACSP should be small, although the level of need may be great.

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## Appendix 1 Conceptual map of the findings

