

# Dumfries and Galloway Health and Social Care Partnership

## Carers Survey

November 2018

George Noakes

Asst. Performance and Intelligence Manager

### 1. Background

#### 1.1 Carers in Dumfries and Galloway

The results of the Scottish Census in 2011 showed that there were 14,995 Carers living in Dumfries and Galloway. The population of Dumfries and Galloway is estimated to be around 148,000 people. Therefore, approximately 1 in every 10 people from Dumfries and Galloway is a Carer. There were

- 948 Carers under the age of 25, including children and young people (2% of this age group)
- 10,369 Carers of working age, between 25 and 64 years old (13%) and
- 3,638 Carers aged 65 or older (11%)

The Census also showed that 3 out of every 10 Carers (29%) provided more than 50 hours of unpaid care and support per week.

It is understood that Carers are at greater risk of suffering from ill health and poor wellbeing compared to other population groups. The nature of caring means that time for day to day activities is limited and less flexible. The wellbeing of the cared for person is often given a higher priority than the Carer's own health. This can lead to poor health, poor wellbeing and increased isolation. In the Scottish Census 2011, 8% of Carers reported experiencing bad or very bad ill health. This experience was higher amongst Carers aged 65 and over (14%). Across the wider population of Dumfries and Galloway 10% of all people reported that day to day activities were 'limited a lot' by a long term health problem or disability.

More information on the Carers population in Dumfries and Galloway can be found in the Dumfries and Galloway Health and Social Care Strategic Needs Assessment (2<sup>nd</sup> Edition) ([here](#)).

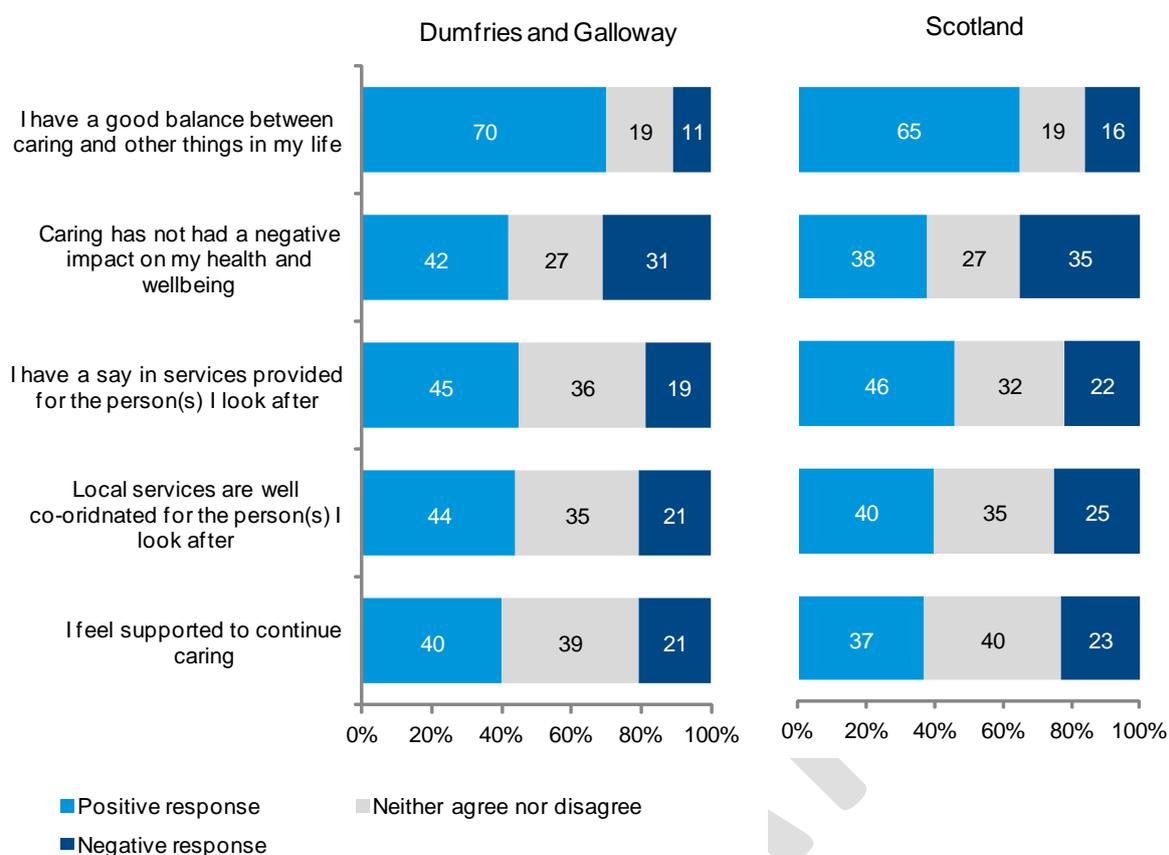
#### 1.2 Health And Care Experience Survey

Every 2 years the Scottish Government publishes the Health And Care Experience (HACE) survey. HACE is a postal survey. The most recent version was published in May 2018. Across Dumfries and Galloway a random sample of 16,071 people from all backgrounds were invited to take part. 4,986 people responded of which 746 (15%) identified as Carers.

The HACE survey includes questions about people's experiences of GP practice and social care. There is also a section asking people about their caring role. The Carers results for 2018 are summarised in Figure 1.

DRAFT

**Figure 1: Responses from Carers to the Health And Care Experience (HACE) survey about their caring roles; by questions; Dumfries and Galloway and Scotland; 2018**



Overall the survey responses from Dumfries and Galloway were very similar to that of Scotland. There was only one Carers question where the responses from Dumfries and Galloway were statistically significantly different compared to Scotland: 70% of Carers agreed that they had a good balance between caring and other things in their lives compared to 65% across Scotland. The response in Dumfries and Galloway to this question was the same in 2018 as it was in 2016, both 70%.

Comparing the results of the Carers questions from the 2018 survey to those published in 2016 suggests that Carers experience in Dumfries and Galloway's has declined. This is most notable in the responses the statement 'I feel supported to continue in caring'. In 2016, 48% of Carers across Dumfries and Galloway agreed, whereas 40% agreed in 2018. Across Scotland there has also been a decline but not as much: 40% agreed in 2016 whereas 37% agreed in 2018.

### 1.3 A focussed question

The phrase 'supported to continue caring' has the potential to mean many different things to Carers. It is important to understand how Carers interpret this statement and what it means to them, so as to better inform how care and support for Carers is provided. Carers from

Dumfries and Galloway were asked to take part in a short local survey during August and September 2018. The focus of this survey was the question:

“What does ‘supported’ mean to you as a Carer?”

DRAFT

## **2. Method**

A short survey was designed consisting of 15 questions. There were 2 questions on consent to take part, 4 questions about a person's caring role and 9 questions for equality and diversity monitoring. The survey was open between 13 August 2018 and 21 September 2018. The survey was promoted through local Carers networks, third and independent organisations, social media and the local press. The survey was hosted online using SurveyMonkey.com. A paper version of the survey was available on request.

The results of the survey were analysed in November 2018. For the numerical analysis, statistical tests were used to compare figures. The threshold used for these tests was a significance level of 95%. Significance in this context means that we are confident that the results are genuinely different and not just by chance.

The free text responses were studied using a thematic analysis approach based on a method called grounded theory. This included two rounds of thematic coding: the first to identify how Carers interpret 'being supported', the second, to identify themes across the responses.

## **3. Results**

### **3.1 Responses and Demographics**

In total there were 378 responses to the Carers Survey submitted. Of these, 367 people consented to have their responses included in this analysis. The remaining 11 people did not give consent for their data to be analysed and their responses are not included in the results of this report.

Table 1 summarises who responded to the survey and, where information is available, makes comparisons to the wider Carer population in Dumfries and Galloway. There are differences between the group of people who responded to the survey and the wider Carer population. Overall, the group of people who responded to the survey included:

- a greater proportion of Carers aged between 35 and 64 years old (72.5% of responses were from this age group compared to 63.0% in the wider Carer population)
- a greater proportion of Carers providing 50 hours or more care per week (62.9% of responses were from Carers in this group compared to 29% in the wider Carer population)

Understanding these differences is important in interpreting the responses to the survey.

**Table 1: Comparison between responses to the survey and the wider Carer population of Dumfries and Galloway**

	Survey Responses			Scotland's Census 2011 (Carer Population)
	#	%	(95% Confidence Intervals)	%
<b>Age Group</b>				
Answered question	200			
0 to 15	0	0.0%	(0.0% - 1.9%)	1.9%
16 to 24	2	1.0%	(0.3% - 3.6%)	4.5% (S)
25 to 34	21	10.5%	(7.0% - 15.5%)	6.3% (S)
35 to 64	145	72.5%	(65.9% - 78.2%)	63.0% (S)
65 and over	32	16.0%	(11.6% - 21.7%)	24.3% (S)
<b>Time in Caring role</b>				
Answered "yes" to question	221			
Yes, 5 to 19 hours per week	33	14.9%	(10.8% - 20.2%)	53% (S)
Yes, 20 to 34 hours per week	21	9.5%	(6.3% - 14.1%)	10%
Yes, 35 to 49 per week	28	12.7%	(8.9% - 17.7%)	8% (S)
Yes, 50 or more hours per week	139	62.9%	(56.4% - 69.0%)	29% (S)
<b>Gender</b>				
Answered question	197			
Female	159	80.7%	(74.6% - 85.6%)	
Male	38	19.3%	(14.4% - 25.4%)	
<b>Sexuality</b>				
Answered question	188			
Heterosexual (Straight)	182	96.8%	(93.2% - 98.5%)	
LGBT+	6	3.2%	(1.5% - 6.8%)	
<b>Ethnicity</b>				
Answered question	194			
White Scottish	107	55.2%	(48.1% - 62.0%)	
White Other (including British, English, Irish, Polish)	87	44.8%	(38.0% - 51.9%)	
All Black and Minority Ethnic Groups	0	0.0%	(0.0% - 1.9%)	
<b>Religion</b>				
Answered question	185			
Christian: Church of Scotland	60	32.4%	(26.1% - 39.5%)	
Christian: Roman Catholic	14	7.6%	(4.6% - 12.3%)	
Christian: Other	17	9.2%	(5.8% - 14.2%)	
All other religions (including Muslim, Jewish, Sikh)	9	4.9%	(2.6% - 9.0%)	
No religion	85	45.9%	(38.9% - 53.1%)	

(S) = statistical tests indicate this is a genuine difference and not a chance finding

### 3.3 What does 'supported' mean to Carers?

225 people responded to the question "What does 'supported' mean to you as a Carer?" All responses were included in the thematic analysis.

The first round of thematic analysis looked at what Carers talk about when they are talking about support. This initial analysis revealed that there are a complex, often inter-related set of topics that constitute 'support' for Carers. These topics, together with example responses, are summarised in Table 2. The table also provides a summary of how often each of these topics was raised in people's responses.

**Table 2: Topics identified from Carers responses to the survey illustrating what 'supported' means to Carers; Dumfries and Galloway; 2018**

Topic	Frequency	Example response
The impact of their caring role on their mental health and wellbeing, and the impact of their mental health and wellbeing on their caring role	(26%)	"Share concerns and issues and emotional feelings about how caring affects me and help me understand how to deal with the daily changes in my role. Problems shared and understood in a caring way is a huge support and helped me massively."
Support and understanding in their local communities including family, friends and local services such as shops, GP practices, schools and other community facilities	(15%)	"Acceptance as a 'normal' person situated by doctor, family, friends, cafes and restaurants, supermarkets and small shops, church, neighbours and the population as a whole. This is there from all in abundance."
Access to structured or formal support provided by social work services or third and independent sector organisations	(14%)	"Having care package - other people can take on caring role, short period of time - to enable me to go and have time to self."
Being able to access appropriate support at the time of need	(14%)	"Knowing I can access support as and when needed."
Access to short breaks and respite	(13%)	"Having a useful break to recharge to care better and stay healthier mentally."
Access to relevant information	(11%)	"[Supported] means that I know where to access more information and support."
Access to financial support	(8%)	"Having financial resources to live without the added stress of worrying about surviving from month to month on low level support."
Support and understanding from	(4%)	"Being able to arrange time off work to

their employer

attend appointments easily.”

Access to training and educational opportunities related to their caring role

(2%)

“Training about son’s condition”

A second round of thematic analysis was carried out considering the context in which each of the topics were discussed and how Carers talked about them. Four overarching themes emerged from this analysis.

### 1) Sharing the caring responsibility with others

Many of the Carers who responded to the survey associated the concept of ‘being supported’ with sharing their caring responsibility with others. This included sharing the responsibility with social work services, third and independent sectors organisation, friends, family and their local communities. Often short breaks and respite services were mentioned. It is important to note that none of the Carers who responded suggested that they did not want to provide care. Instead, it appears that people suggesting ways to share caring responsibilities are seeking to ensure that their caring role is sustainable. As a large of proportion of people responding to this survey provide more than 50 hours of care per week, the emergence of this theme is understandable. Here are some of the responses that illustrate this theme:

“[Being supported is] Someone else sharing the load, appreciating what I do and offering a listening ear, providing regular breaks for me where she is still cared for appropriately.”

“Practical support such as respite from caring and a pro-active attitude towards making sure that options, funding and information are easily available and promoted.”

“Other agencies involved.”

“Support to me means someone else other than myself helping in a physical way.”

### 2) Flexibility and Understanding

A recurring theme through the responses was the need for flexibility and understanding on the part of others, not directly involved in providing care, to the Carer’s situation and responsibility. This is associated with promoting Carer Awareness in communities.

A repeated example of this was the relationship between a Carer and their employer:

“[Being supported is] Knowing that if I require time off work to take my parent to appointments that I will not be penalised.”

“[Being supported is] My employer understanding and allowing me flexibility in my start and finishing times or time off at short notice.”

Here are some responses that demonstrate Carers' desires for greater awareness throughout their local communities:

“[Being supported is] Simple things like time of relatives, many appointments and discharge times from hospital mean I can continue to work and not feel I am failing in my caring responsibilities...”

“[Being supported is] People realising what it is like to care for someone who needs care everyday of their life.”

“In terms of my 7 year old autistic son's education it [being supported] would mean that he was welcomed into mainstream primary classroom as a 'regular' class member not a 'guest' in someone else's classroom.”

“Timings of events etc should not just be in the day, a lot of Carer's also work, how are they supposed to get the cared for person to these activities, events if they work.”

“[Being supported is] People understanding how it impacts every single aspect of your life and making accommodations for you where possible. Or even just asking how you are.”

### **3) Accessibility**

In their responses to this survey, Carers repeatedly expressed a desire to easily access support at the point of need:

“[Being supported is] That there is someone you can get in touch in times of stress and distress.”

“[Being supported is] Help and advice available when you need it.”

“[Being supported is] Knowing where to get help and advice when I need it.”

Some of the responses explored the issues around enabling easier access to support for both the Carer and the person being cared for. These included ensuring services were better co-ordinated so that a Carer only needed to tell their story once and reducing the perceived bureaucracy and input from Carers in seeking support, for example when applying for financial support.

“[Being supported is] having help when I need it, not having to fight for

every solitary thing you need...”

“Supported means not fighting for a temporary hoist for my severely disabled and complex child only to be told that I may have to pay the service charge myself... [Supported means] Not getting letters from one department because they haven't been contacted by another department and so lack of communication means horrible letters come to us...”

“[Being supported] means if I request assistance with minor details in caring it would be available e.g. I requested an application form for a blue-disabled-parking badge from the council and it took 3 requests before it was sent, that was [Date]. Here were sit [today] and still the request is pending...”

“[Being supported is] Not having to fight for benefits every step of the way. Not having to keep producing documents which makes you feel like you are trying to defraud the system. Having a one stop shop for help instead of getting sent all over the place.”

#### 4) Promoting good mental health and wellbeing

Overall, the people who responded to this survey were very aware and concerned about the impact of their caring role on their mental health and wellbeing and, the impact of their mental health and wellbeing on their ability to continue in their caring role:

“I find it emotionally difficult being a Carer, watching the person who was fit and healthy descend both physically and mentally.”

By far the most common phrase amongst the responses was having ‘someone to talk to’:

“Having a ‘listening ear’, someone to talk to.”

“Someone who listens and appreciates the barriers I experience trying to juggle all of the responsibilities I have.”

“The ability to speak to someone who understands my problems...”

“...someone to talk to and bounce things off.”

“[Being supported is having] someone to talk over issues that are causing concern.”

One Carer identified in their response, succinctly, why having someone to talk to would enforce a sense of being supported:

“[Being supported is] Knowing that there is someone at the end of a phone in the event of a crisis. Even although you may never need it, it is very reassuring.”

Carers identified that sharing the caring responsibility with others (such as with short breaks), improving flexibility and understanding in their communities and enabling easier access to support and services would contribute to improving their mental health and wellbeing and feeling supported to continue in their caring role. Carers also identified other areas of support that would positively impact on their mental health and wellbeing. This included providing appropriate training to improve their confidence in their caring role:

“Help to understand how to move a person who is getting more and more unable to help themselves without hurting me.”

Carers also identified that regular contact with health and social care professionals about their caring role would provide reassurance and improve confidence:

“Supported means someone checking in or someone you can go to with problems/worries etc.”

“[Being supported is] To know that a regular review timetable exists where both my parents care needs... are assessed.”

“Somebody to check that all are coping and assisting if need be.”

Some responses discussed the need for communities and paid for services to recognise and value the contribution of Carers. Recognising the valuable contribution Carers make to their communities could also help to promote positive mental health and wellbeing:

“[Being supported means] that my contribution is recognised, valued and validated by the statutory agencies who have responsibility for the care and support for those who need it.”

#### 4. Discussion

It is clear from this survey that the concept of being supported in a caring role means different things to different Carers. What constitutes support includes help with the day to day activity of caring, awareness in local communities, financial support and services, and help with mental health and wellbeing. The context in which people responded to the question “what does ‘supported’ mean to you as a Carer?” revealed four themes:

- Sharing the caring responsibility
- Flexibility and understanding
- Accessibility
- Promoting good mental health and wellbeing

Underpinning how people described what ‘support’ meant to them and the four themes that emerged, is the heightened sense of isolation and lack of freedom experienced by Carers. The clearest evidence for this is Carers’ desires for someone to talk to, and to be listened to. The responses suggested a range of ways that Carers could feel supported to continue in their caring role

- identifying ways to better share the caring responsibility
- increasing the awareness of the caring role
- encouraging the flexibility and understanding of communities
- enabling easier access to support at the point of need
- supporting Carer’s mental health and wellbeing

It should be noted that this survey had a high proportion of responses from Carers providing 50 or more hours of care per week compared to the wider Carer population in Dumfries and Galloway. Consequently, this survey may not accurately reflect the opinions and experience of Carers who provide less intense, but by no means less necessary, levels of unpaid care. The insights provided by Carers responding to this survey have the potential to positively influence how Carers are supported to continue in their caring roles.