

Dumfries and Galloway Unpaid Carers Survey:

Key Findings

Draft Report

April 2024



sleeping
GIANTS

Executive Summary

Background

- An online survey was available for unpaid Carers and Carer support organisations in Dumfries and Galloway to complete between January and March 2024. The survey forms part of the Integration Joint Board's (IJB) response to the National Carers Strategy published in 2022 and its findings will be used to develop a local Delivery Plan. In addition, the findings will support the IJB's broader, ongoing work to support Carers who choose to continue in their caring role.
- 206 unpaid Carers and 14 respondents from a Carers support organisation submitted a survey response. However, because of the very partial completion of some of these, the analysis presented here is based on 199 unpaid Carer and five organisation respondents.

Experiences of the Unpaid Carer Role

- Carers were asked to indicate on a five point scale ('always', 'very often', 'sometimes', 'rarely' and 'never') how often they experienced feeling recognised, appreciated, involved and listened to in the survey. The responses suggest that Carers have mixed experiences:
 - Few Carers felt recognised and valued: only 3.8% (7, out of 185 answering the question) said that they 'always' experienced this and 8.7% (16) experienced this 'very often'. In contrast, 18.4% (34) 'never' and 30.3% (56) 'rarely' felt this way.
 - Even fewer 'always' or 'very often' (1.1%, 2 and 4.9%, 9 respectively) felt that others understood and appreciated how much unpaid Carers contribute to the economy, compared to 44.3% (82) who 'rarely' and 26.5% (49) who 'never' experienced this.
 - A small minority felt that their views and experiences are taken into account in decisions that affect them (1.6%, 3 answered 'always' and 9.2%, 17 answered 'very often'). A quarter (24.9%, 46) 'rarely' and 17.8% (33) 'never' experienced this.
 - However, many more Carers felt that they were involved in decisions made about the care and treatment of the person they care for (18.5%, 34 answered 'always' and 24.5%, 45 answered 'very often'). In contrast, 10.3% (19) and 8.7% (16) rarely or never experienced this (respectively).
- Reflecting these ratings, a perceived lack of support and feeling that they'd been left alone to provide care emerged as key themes from the survey's open ended responses.

Experiences of Support

- The survey explored Carers' experiences of support (using the same five point scale of 'always' to 'never') and the findings indicate that not all Carers felt they were being supported in the way that they needed:
 - Around a quarter could 'always' or 'very often' access information to help them in their caring role when they needed it (6.2%, 11 answered 'always' and 21.2%, 38 answered

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'very often'). But 15.1% (27) 'rarely' and 9.5% (17) could 'never' access information when needed.

- Slightly smaller numbers of Carers said that they can 'always' or 'very often' access advice and support from local agencies (6.2%, 11 and 16.3%, 29 respectively). 16.3% (29) answered 'rarely' and 12.9% (23) answered 'never'.
- Fewer still said that they felt supported by local agencies to look after their own health and wellbeing 'always' or 'very often' (5.6%, 10 answered 'always' and 10.1%, 18 answered 'very often'). In contrast, over half said that they 'rarely' or 'never' felt supported (25.3%, 45 and 26.4%, 47 respectively).
- Access to respite was particularly poor: only 2.8% (5) said that they could 'always' access it and the same proportion answered 'very often'. But 22.5% (40) could 'rarely' and 41.6% (74) 'never' access respite.
- A minority of Carers thought that the support they get helps prevent things from getting worse 'always' (5.7%, 10) and 'very often' (7.4%, 13). 19.9% (35) answered 'rarely' and 23.9% (42) 'never'.
- A small proportion of Carers felt that local agencies work well together to support them in their caring role: 2.3% (4) said they 'always' experienced this and 4.6% (8) experienced this 'very often'. In contrast, 20.6% (36) 'rarely' and 25.7% (45) 'never' experienced joined up support.
- Importantly, the survey also found that half of Carers (49.4%, 87) don't receive the support they thought they needed to continue in their caring role. Where the person being cared wasn't being supported by paid carers, this figure increased to 53.4% (62) (compared to 39.7% (23) of Carers caring for someone who is also supported by paid carers).
- Awareness of the available support and ease of access were identified as barriers for some. Reflecting this, awareness raising, signposting and referrals were commonly suggested as ways to improve Carers experiences.
- To find out more about how Carers were being supported, the survey asked if they had received support from the third sector, Dumfries and Galloway Council and NHS Dumfries and Galloway. 42.9% (78) of Carers hadn't received support from any of these and where support had been accessed, it was most often from the third sector (34.6%, 63).
- Providing further evidence of mixed Carer experiences, both local third sector and health and social care services received an average rating of less than three stars (out of five).

Local third sector services



Average rating: 2.8¹

Local health and social care services



Average rating: 2.3²

- While some Carers did describe a positive experience of support, others said that the lack of health and social care provision for the person being cared meant they were left to care

¹ Based on 143 responses

² Based on 153 responses

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alone. Carers also described how their role and needs weren't always recognised, leaving them feeling unsupported.

- Those in employment faced the challenge of managing both their unpaid caring and job roles. Over half 57.4% (58) felt supported by their employer, with flexible working and supportive managers being important here. In contrast, 22.8% (23) didn't get the support they needed from their employer and struggled to take the time off required or didn't feel that their caring role was understood.
- Where the person being cared for was at school, college or university, experiences of support from the education institution were more mixed: 42.6% (20) felt supported but 40.4% (19) did not and 17.0% (8) answered that they were unsure if they were.
- Overall, the findings suggest that where Carers felt listened to, recognised and supported, their experience was more positive. Where they did not experience these feelings, they were more critical of support provision.

Carers Rights

- The survey findings indicate that not all Carers understand their rights: 42.2% (73) gave a neutral response when asked to indicate how much they agreed or disagreed with the statement 'I understand my rights as a Carer' and a third disagreed (33.5%, 58 – either strongly disagreed or disagreed).
- In addition, only 18.3% (32) had been offered an Adult Carer Support Plan and 14.1% (25) offered support to plan for the future.

Developing a Local Delivery Plan

- As findings from the survey will be used to help develop a local Delivery Plan that will shape the region's response to the National Carers Strategy Action Plan, questions about what could be done to help achieve these actions were included. Both Carers and Carer support organisations were asked these questions and while the suggested actions were varied, they centred upon the following themes:
 - Carer support and recognition;
 - Awareness raising; and
 - Signposting and referrals.
- While each of the suggested actions should be considered by the IJB in developing the local Delivery Plan, the emerging key points can be summarised as follows:
 - **Carer recognition:**
 - Carers want the value of their role to be recognised and appreciated by health and social care services as well as by society more broadly. While financial support was synonymous with recognition for some, others just wanted to be acknowledged.
 - Not everyone providing unpaid care recognises themselves as a Carer; they might instead think of themselves as a spouse, parent or son or daughter.
 - Awareness raising was therefore important here amongst both Carers and organisations.

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- Health and social care professionals were also identified as important in helping Carers to recognise their role. Diagnosis and discharge in particular were thought to create opportunities to prompt discussions that could help people recognise their role as a Carer.
- **Access to support, advice and benefits**
 - Carer support organisations thought that the increased identification of Carers would in turn improve access to available support, but the capacity of the third sector to meet any increase in demand would need to be considered alongside this.
 - Awareness raising activities were needed to help Carers identify appropriate sources of support.
 - Interactions with health and social care professionals and third sector organisations were also important here and provided an opportunity to identify Carers' needs (including financial) and for broader information sharing, signposting and referrals.
 - More financial support to help with the cost of living crisis was also called for through, for example, expanding benefit eligibility or increasing payments.
 - Carers also wanted to see increased recognition of the additional costs associated with their caring role.
- **Equal partners**
 - Carers wanted to be heard by health and social services so that they could work with them as equal partners.
 - While this applied to all contact, listening to and involving Carers during discharge planning was especially important.
 - A more joined up approach – where Carers are involved and services co-ordinated – would also help Carers to be equal partners.
- **Respite and short breaks**
 - There is a need for more, and better funded respite care, with Carers often stating that it's not available to them.
 - Carers should be informed of the respite that is available and supported to access it.
 - Both support organisations and Carers wanted to see more creative and flexible provision.
- **Increasing uptake of the Carer Positive Employer Scheme**
 - Raising awareness was key here and it was suggested that good news stories and case studies could be shared to promote its benefits.
 - Some Carers thought that it wasn't enough to gain accreditation and wanted the Scheme to be enforced so that its principles were implemented across organisations.
- **Reaching and supporting Young Carers**
 - Schools were identified as playing an important role here, both in helping to identify Young Carers and supporting their needs.
 - Peer support was also suggested as a means of supporting their needs.

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1 Introduction

1.1 Background

The National Carers Strategy was published in 2022 and stated that:

“Unpaid care is vital to how social care is provided in Scotland, and the value of the dedication and expertise of carers cannot be overstated.”³

The strategy set out an Action Plan, with 89 actions to be taken by the Scottish Government. Dumfries and Galloway’s Integration Joint Board (IJB) are leading the region’s response to these actions, which will be set out in a new local Carers Strategy Delivery Plan (and replace the now outdated Dumfries and Galloway Carers Strategy).

Following a workshop with key regional stakeholders, an engagement plan was developed to involve Carers and Carer organisations in this work. A local social enterprise, Sleeping Giants, was commissioned to co-produce an online survey to support the engagement plan’s implementation.

In addition to informing the development of the local Delivery Plan, the survey findings will be used to shape the IJB’s ongoing work to support Carers who choose to continue in their caring role. The IJB therefore intend to survey Carers at regular intervals to provide an evidence base that can help strengthen support.

The online survey was available for a 12-week period between January and March 2024 and the key findings emerging from it are summarised in this report.

1.2 About the Survey

The survey took an average of 12 minutes for Carers to complete and included a mix of open and closed questions about the care provided, experiences of the caring role and support (see Table One for a summary). An additional question set, which aimed to inform the Local Delivery Plan and response to the national Action Plan, was asked of both Carers and Care support organisations.

Table One: Summary of the Survey Questions

Question Theme	Respondent Group	Question Topics
About the Carer	<ul style="list-style-type: none">• Carers	<ul style="list-style-type: none">• Key demographics (e.g. postcode area, age, gender, ethnicity, religion, disability)
Provision of unpaid care	<ul style="list-style-type: none">• Carers	<ul style="list-style-type: none">• Who they care for (or have previously cared for)• The condition of the person(s) they care for• Length of time providing care• Time spent each week providing care• Economic activity (e.g. in employment or education)

³ [National Carers Strategy \(Scottish Government, 2022, p5\)](#)

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Question Theme	Respondent Group	Question Topics
Experience as an unpaid Carer	<ul style="list-style-type: none"> Carers 	<ul style="list-style-type: none"> Perceived recognition and value of their caring role Involvement in decisions about care and treatment Whether they feel their voice is heard The impact of their caring role
Support for their caring role	<ul style="list-style-type: none"> Carers 	<ul style="list-style-type: none"> Support accessed and experiences of it Understanding of Carers' rights Whether they have an Adult Carer Support Plan or Young Carers Statement
Informing the development of a local Delivery Plan	<ul style="list-style-type: none"> Carers Carers support organisations 	<p>What can be done to:</p> <ul style="list-style-type: none"> Help people recognise themselves as Carers Help Carers access support and advice Help Carers receive the benefits they are entitled to Help the way health and social care professionals work with Carers Improve the experience of Carers when the person they care for is in hospital Improve respite and short breaks Better support Carers during the cost of living crisis Increase uptake of the Carer Positive employer accreditation scheme Reach and support Young Carers

206 Carers and 14 respondents from a Carer support organisation submitted a survey response. However, because of the very partial completion of some of these, the analysis presented here is based on 199 Carer and five organisation respondents.

1.3 About the Survey Respondents

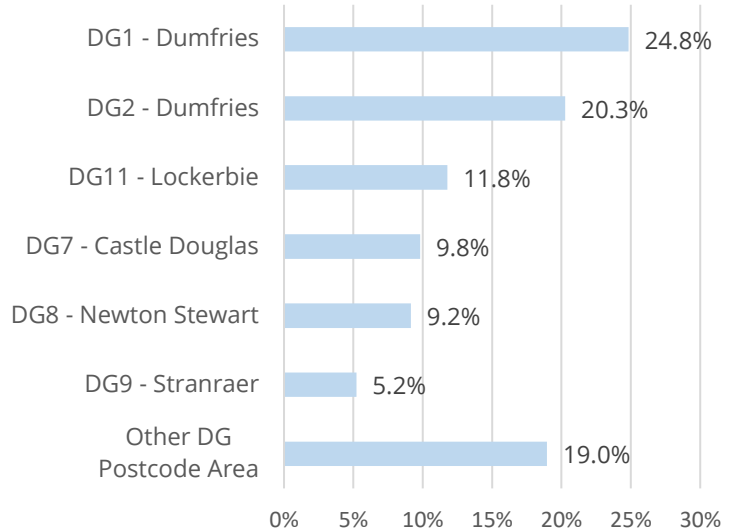
The survey invited unpaid Carers to provide demographic information and Table Two summarises these responses.

Unpaid Carers: Survey Key Findings

Table Two: Summary of Carer Survey Sample

Postcode area:

While responses were received from Carers in each of the region's postcode areas, the largest proportion were from the Dumfries area (DG1 – 24.8%, 38 and DG2 – 20.3%, 31). Conversely, five or fewer responses were received from eight postcode areas and therefore these figures are included in 'other DG postcode area'.

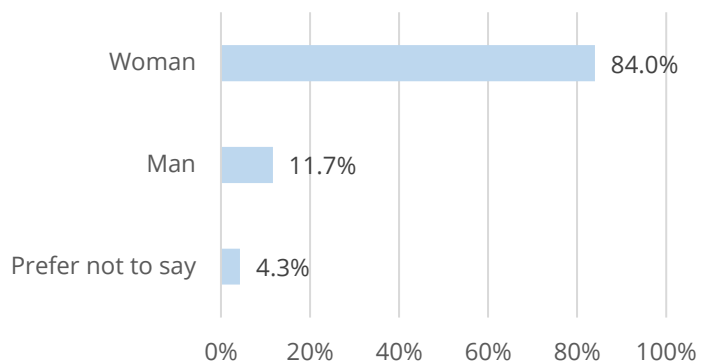


Base: All respondents providing their postcode area (153)

Gender

A large majority of Carers completing the survey were women (84.0%, 137) and only 11.7% (19) were men.

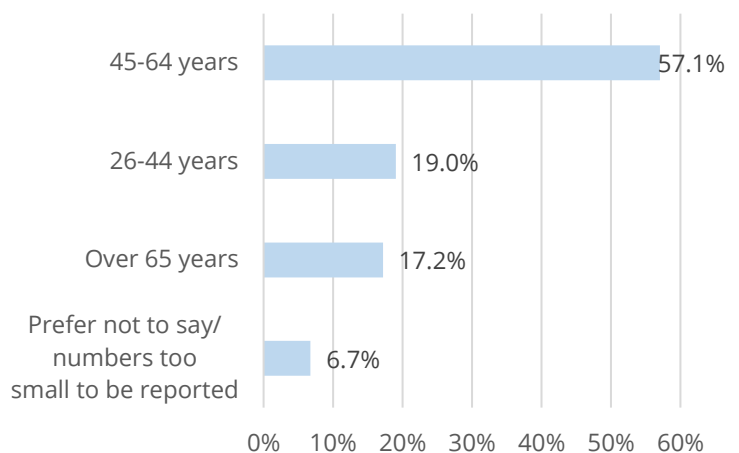
Nobody completing the survey identified as a non-binary or transgender person.



Base: All respondents answering the question (163)

Age

Everyone who completed the survey was aged over 18 years and more than half (57.1%, 93) were aged between 45 – 64 years. This means that the survey findings do not represent the views of Young Carers.

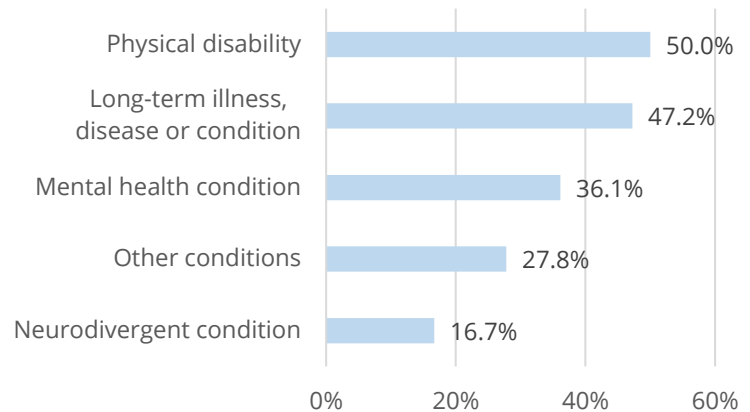


Base: All respondents answering the question (163)

Unpaid Carers: Survey Key Findings

Disability

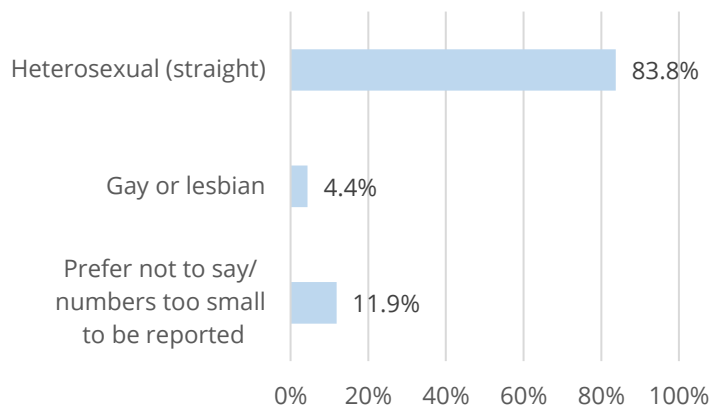
16.4% (27) of the 165 Carers answering this question considered themselves disabled and 5.5% (nine) answered 'not sure'. These respondents were asked to select from a given list how the disability affected them; a physical disability (50.0%, 18) and long-term illness, disease or condition (47.2%, 17) were the most frequently selected responses.



Base: All respondents answering the question (36)

Sexual orientation

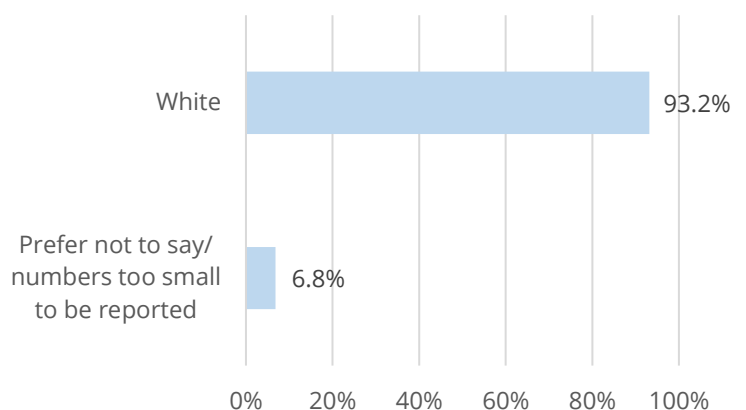
A large majority identified as heterosexual (83.8%, 134) and 4.4% (seven) as gay or lesbian. The remainder either chose not to answer or are not reported here because of the small number of responses.



Base: All respondents answering the question (160)

Ethnic group

Most of the Carers completing the survey were White (93.2%, 150) and the remainder either chose not to answer or are not reported because of the small number of responses.

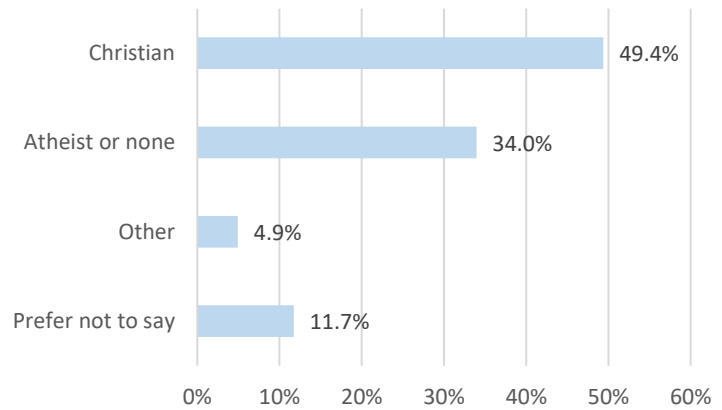


Base: All respondents answering the question (161)

Unpaid Carers: Survey Key Findings

Religion

Half (49.4%, 80) reported their religion as Christian (Church of Scotland, Roman Catholic or Other Christian) and a third (34.0%, 55) had no religion or were an atheist. Only 4.9% (eight) reported another religion.



Base: All respondents answering the question (162)

Because of the small number of organisation responses (only five answered the action plan questions), an overview of this respondent profile is not provided here.

2 Headline Indicators

2.1 Introduction

The IJB intends to survey Carers at regular intervals to find out if and how their experiences change over time. To do this, some of the questions provide 'headline indicators' of experiences of both the caring role and support provision. The responses to these questions are summarised in this section.

2.2 Carers' Experiences

The survey asked Carers how often they experienced each of the following:

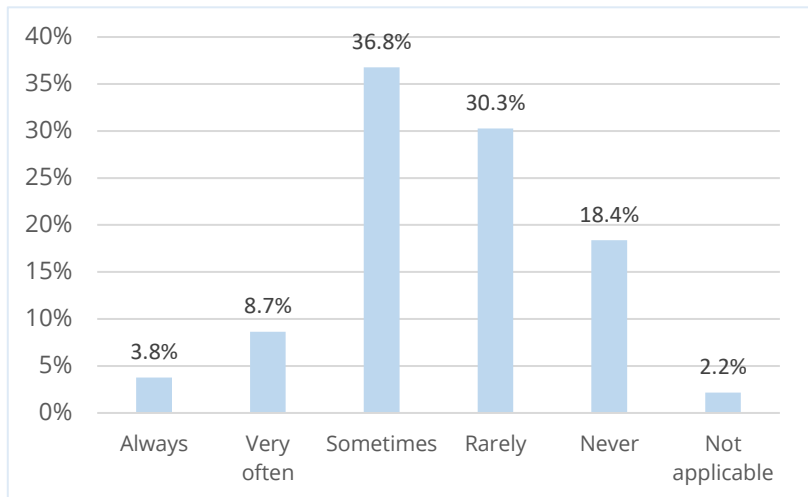
- I feel recognised and valued as a Carer;
- I feel that others understand and appreciate how unpaid Carers contribute to the economy;
- As a Carer, I feel that my views and experiences are taken into account in decisions which affect me; and
- I feel involved in decisions made about the care and treatment of the person(s) I care for.

The responses to each of these questions are summarised in Table Three.

Table Three: Headline Indicators – Carers Experience

Feel recognised and valued

While half (49.2%, 91) said they felt recognised and valued as a Carer at least some of the time (they answered 'always', 'very often' or 'sometimes'), half (48.6%, 90) said that they rarely or never experienced this.

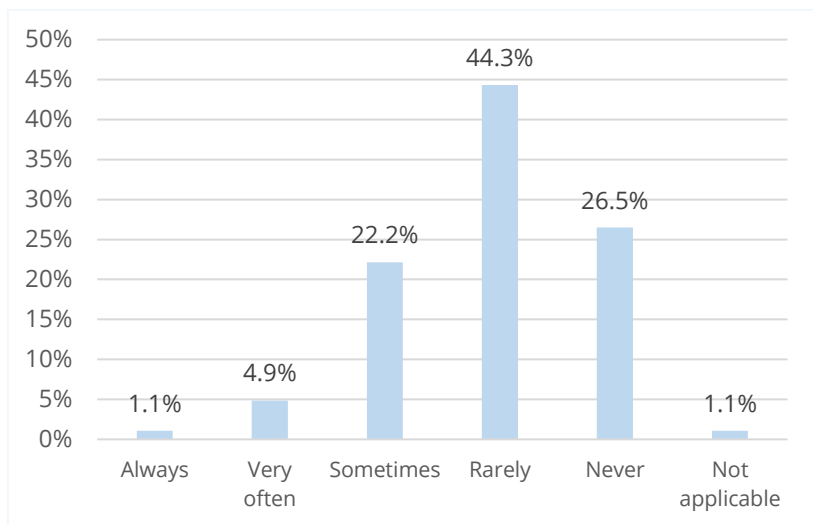


Base: All unpaid Carers who answered the question (185)

Unpaid Carers: Survey Key Findings

Feel others understand and appreciate how unpaid Carers contribute to the economy

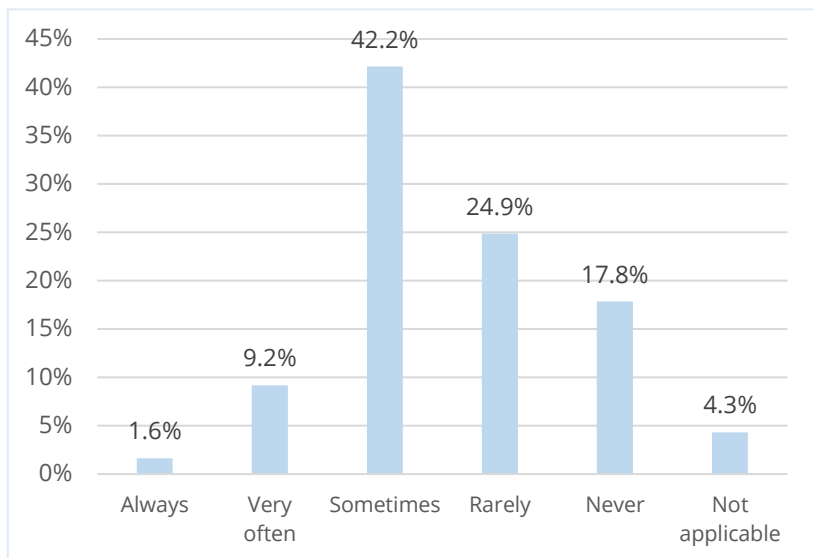
A large majority said that they rarely or never experienced this (70.8%, 131) and only 28.1% (52) experienced this at least some of the time (always, very often or sometimes).



Base: All unpaid Carers who answered the question (185)

Views and experiences are taken into account

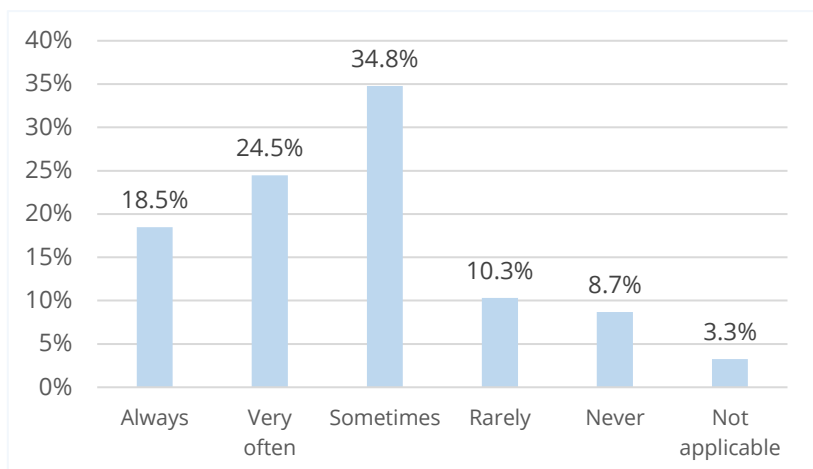
Half (53.0%, 98) of felt that their views and experiences are taken into account in decisions that affect them at least some of the time (always, very often or sometimes). In contrast, 42.7% (79) said they rarely or never experienced this.



Base: All unpaid Carers who answered the question (185)

Feel involved in decisions about care and treatment

Three quarters (77.7%, 143) of Carers felt that they were involved in decisions made about the care and treatment of the person(s) they cared for at least some of the time (always, very often or sometimes).



Base: All unpaid Carers who answered the question (184)

But 19.0% (35) rarely or never experienced this.

Unpaid Carers: Survey Key Findings

The factors and experiences that shaped these responses are explored and discussed in subsequent sections of this report.

2.3 Provision of Support

The survey also included a question set about experiences of support, which asked Carers to state how often they experienced each of the following:

- I can access information to help me in my caring role when I need it;
- I can access advice and support from local agencies to help me in my caring role;
- I feel supported by local agencies to look after my own health and wellbeing (including protecting myself from Covid-19);
- I can access training to help me in my caring role;
- I can access a break (or respite) from caring when I need it;
- The support I get helps prevent things from getting worse, or a crisis from happening;
- and
- I feel like local agencies work well together to support me in my caring role.

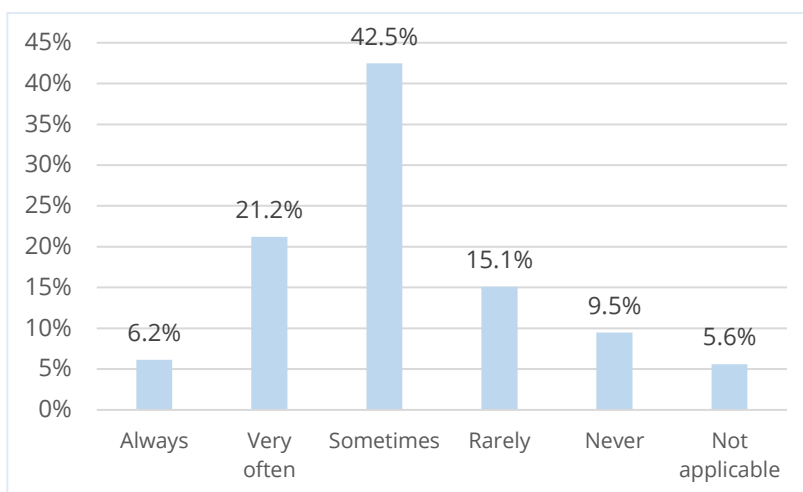
The responses to these questions are summarised in Table Four and indicate that the experiences of support provision are also mixed.

Table Four: Headline Indicators - Experiences of Support

Can access information to help in caring role

Over two thirds (69.8%, 125) of Carers could access information at least some of the time (always, very often or sometimes).

But, a quarter (24.6%, 44) said they could rarely or never access information.



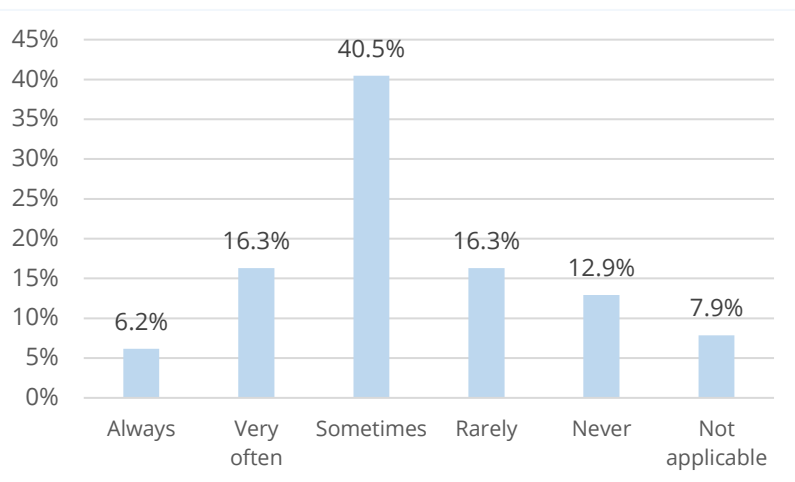
Base: All unpaid Carers answering the question (179)

Unpaid Carers: Survey Key Findings

Can access advice and support from local agencies to help in caring role

62.9% (112) said that they could access advice and support at least some of the time (either always, very often or sometimes).

But, over a quarter felt that they could rarely or never access it (29.2%, 52)

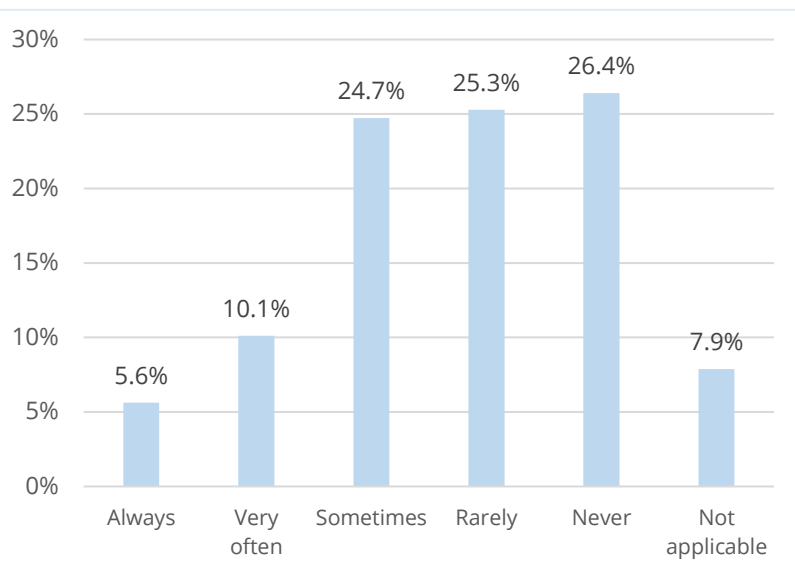


Base: All unpaid Carers answering the question (178)

I feel supported by local agencies

40.4% (72) felt that they were supported by local agencies to local after their health and wellbeing (including protecting themselves from Covid-19) at least some of the time.

But half (51.7%, 92) didn't feel supported (they answered rarely or never).

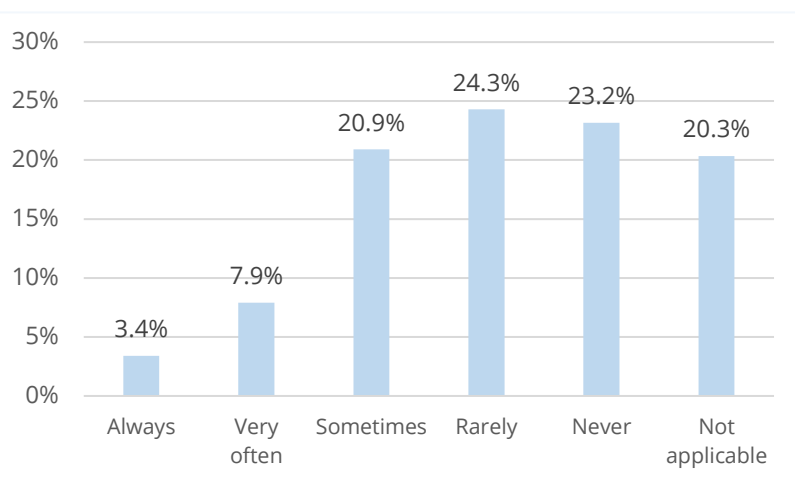


Base: All unpaid Carers answering the question (178)

I can access training to help me in my caring role

A fifth (20.3%, 36) of Carers gave a 'not applicable' response, which suggests that some haven't tried or needed to access training.

Around a third (32.2%, 57) said that they could access training at least some of the time (always, very often or sometimes) but almost half (47.5%, 84) said they never or rarely could.



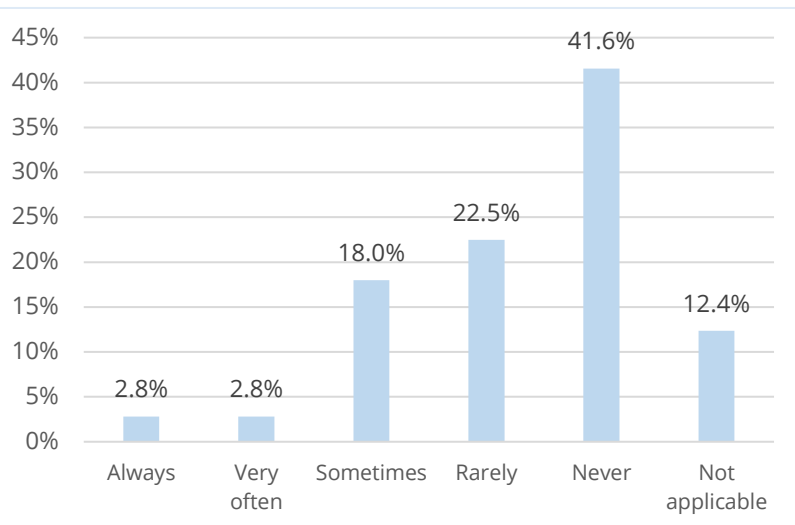
Base: All unpaid Carers answering the question (177)

Unpaid Carers: Survey Key Findings

I can access a break (or respite) when I need it

Two thirds (64.0%, 114) said that they could rarely or never access a break (or respite) from caring when they need it.

In contrast, around a quarter (23.6%, 42) could access a break sometimes, very often or always.

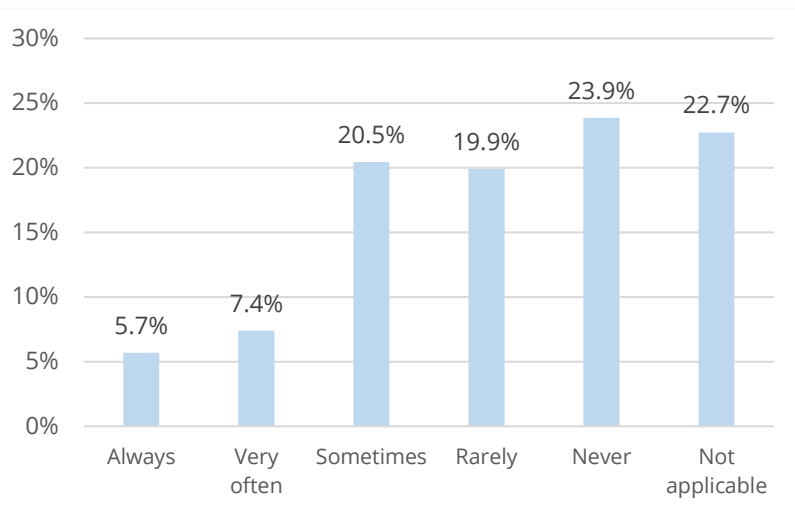


Base: All unpaid Carers answering the question (178)

The support I get helps prevent things from getting worse

Around a third (33.5%, 59) thought they could get this support at least some of the time (always, very often or sometimes).

But more (43.8%, 77) Carers said that they could never or rarely get this support.

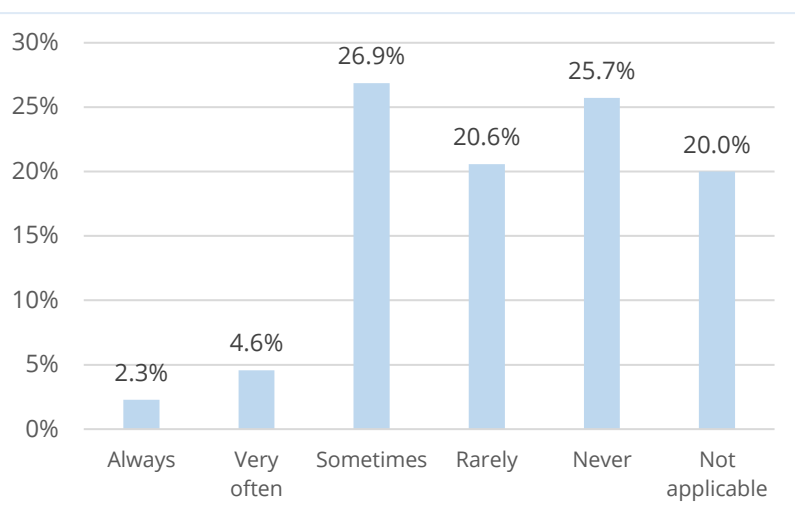


Base: All unpaid Carers answering the question (176)

Feel like local agencies work well together to support them

Around a third (33.7%, 59) said they did experience this at least some of the time (always, very often or sometimes).

But more (46.3%, 81) said that they never or rarely experienced this.



Base: All unpaid Carers answering the question (175)

Unpaid Carers: Survey Key Findings

While the responses summarised in Table Four indicate that for some Carers, experiences of support provision are poor, not all Carers need or want support. A more detailed discussion of Carer experiences is presented in subsequent sections of this report.

3 Unpaid Carers: Their Role and its Impact

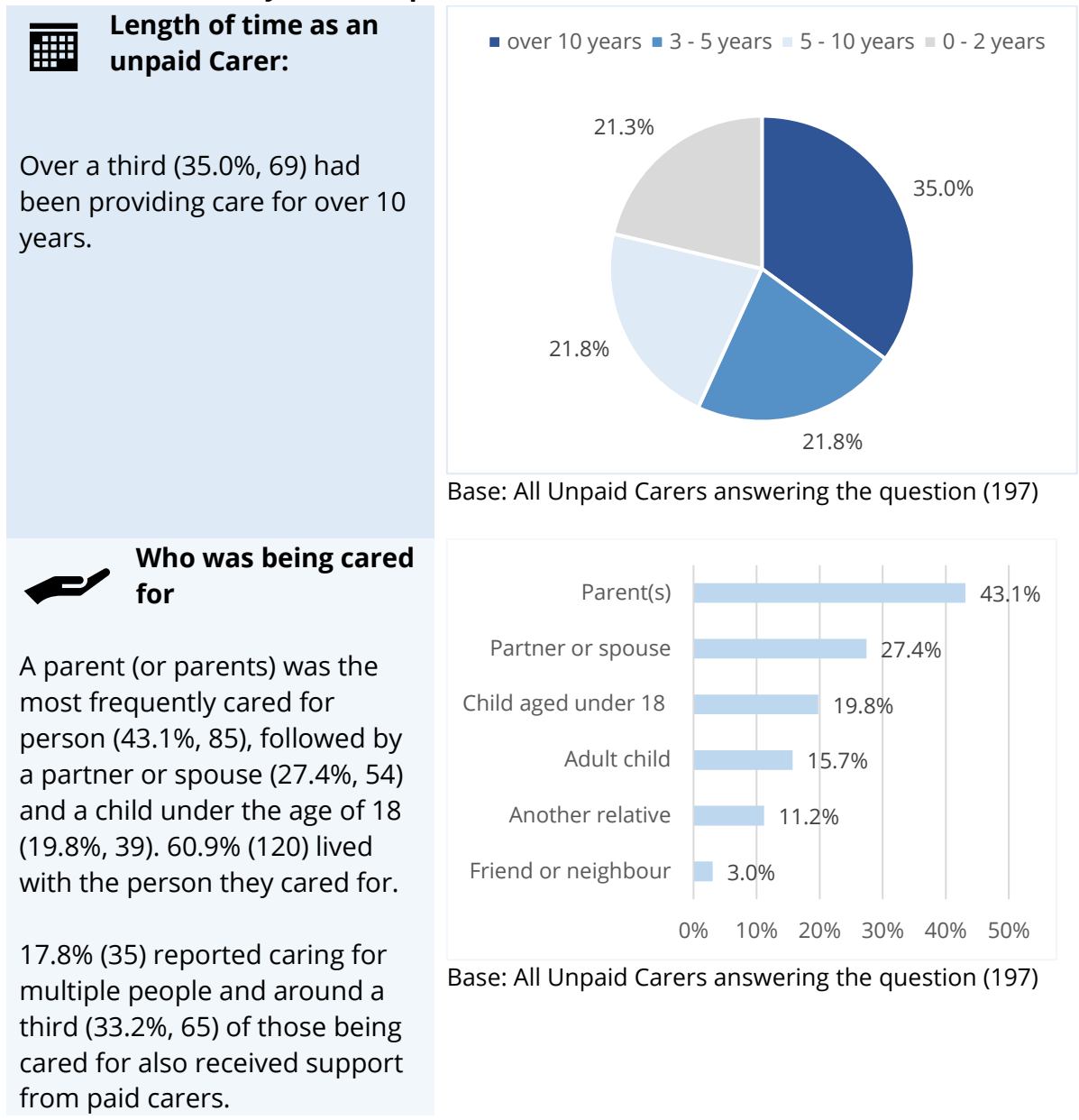
3.1 Introduction

The survey asked Carers to provide details of the care they provided and the impact that this had on their life and physical and mental health. The responses to these questions are summarised in this section.

3.2 Summary of Unpaid Care Provision

The majority of respondents (91.9%, 181) were currently providing unpaid care (8.1%, 16 had provided care in the past) and the largest proportion did so for more than over 50 hours a week. Some of these cared for more than one person and some provided unpaid care alongside full or part time employment.

Table Five: Summary of the Unpaid Care Provided

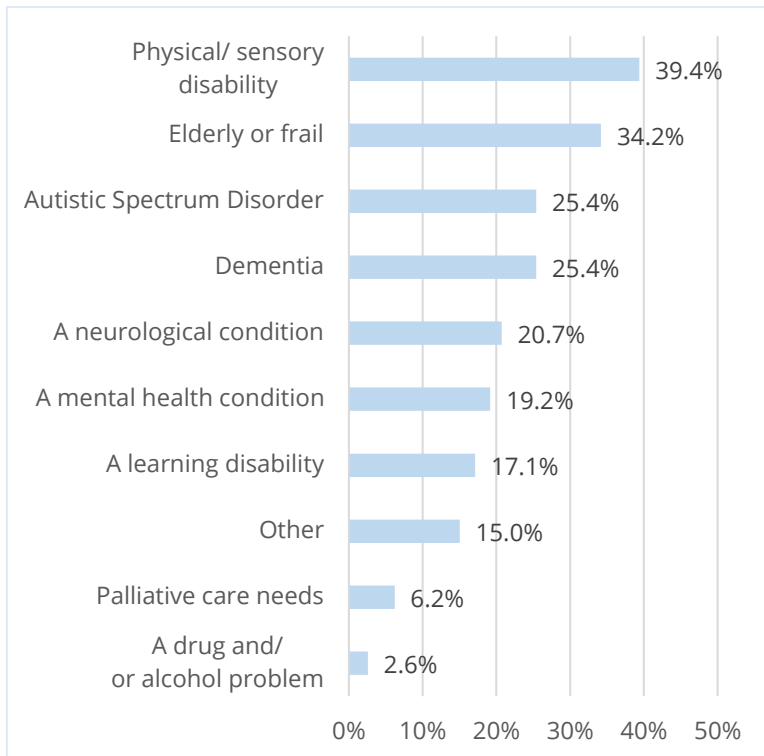


Unpaid Carers: Survey Key Findings



Condition of the Person(s) being cared for

The survey presented a list of physical and mental health conditions and asked which were experienced by the person(s) being cared for. The most commonly reported were 'a physical or sensory disability' (39.4%, 76) and 'difficulties because they are elderly or frail' (34.2%, 66). A quarter of respondents were also caring for someone with Dementia or Autistic Spectrum Disorder (both 25.4%, 49).



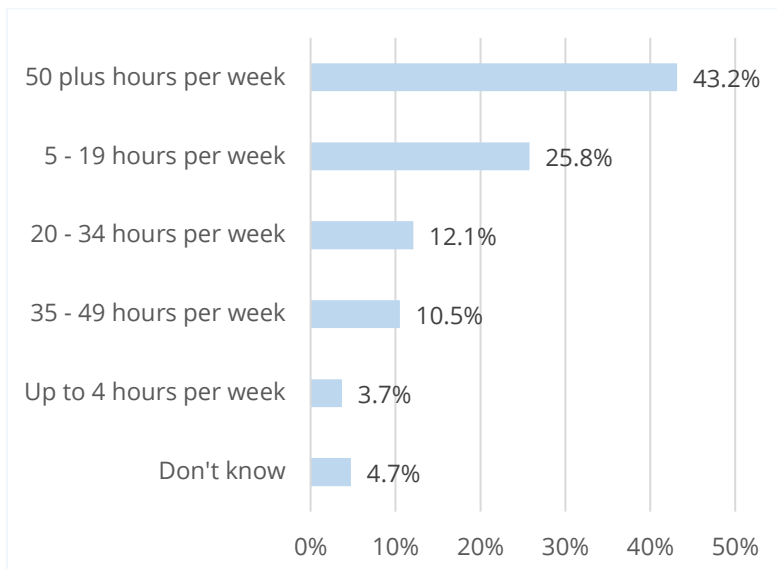
Base: All Unpaid Carers answering the question (193)



Time spent each week providing care


43.2% (82) spent over 50 hours a week providing care and a quarter between 5 and 19 hours a week (25.8%, 49).

The survey data indicates that the amount of care provided each week varies across the different conditions being cared for. For example, higher proportions of respondents caring for someone with a learning disability and Autistic Spectrum Disorder provided over 50 hours of care a week (69.7%, 23 and 63.3%, 31 respectively) than any other condition.

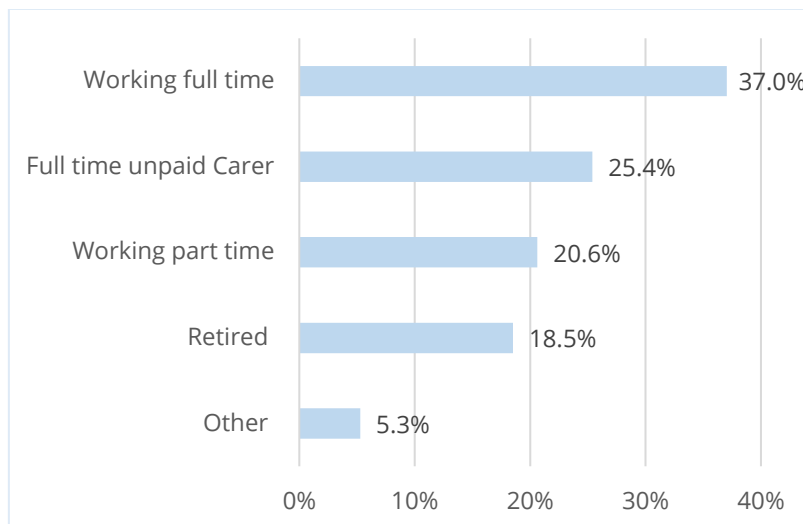


Base: All Unpaid Carers answering the question (190)

Unpaid Carers: Survey Key Findings

 **Economic activity**

Over a third (37.0%, 70) of Carers were working full time and 20.6% (39) working part time. A quarter were full time Carers (25.4%, 48).



Base: All unpaid Carers answering the question (189)

3.3 The Impact of Unpaid Caring

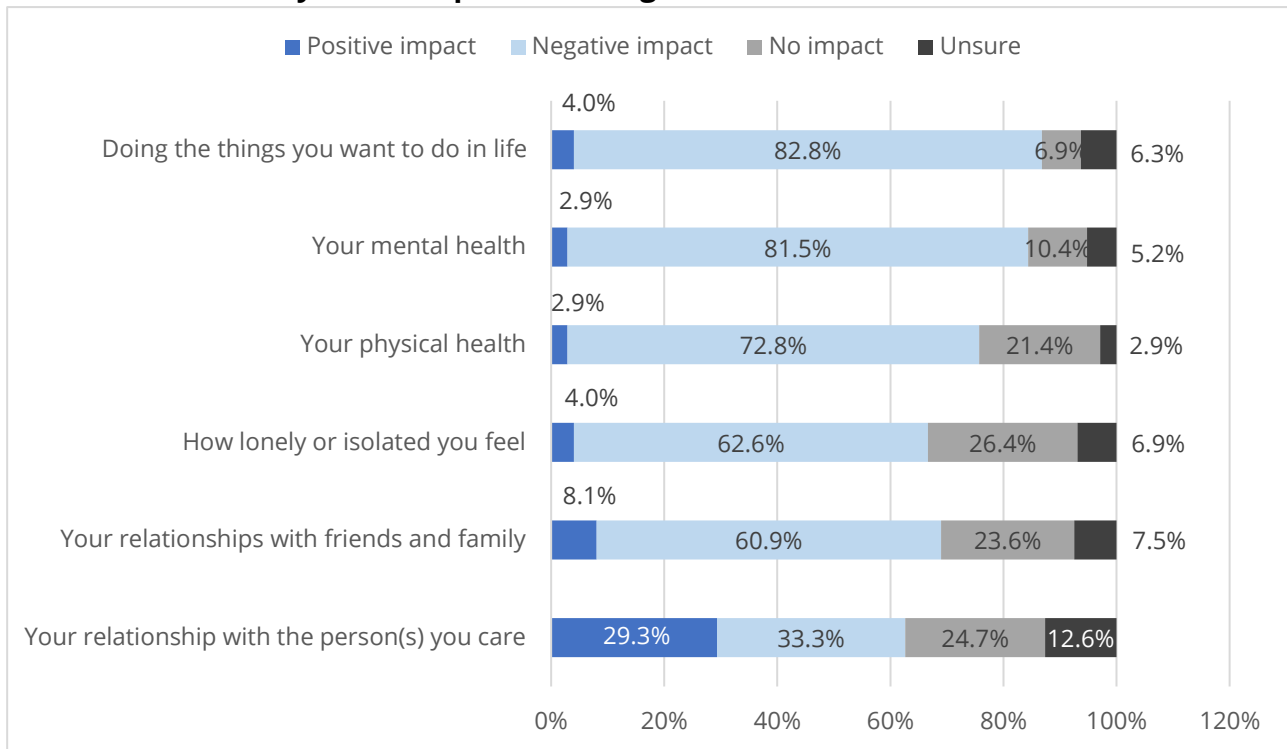
Respondents were asked what impact (if any) their caring role had on each of the following:

- Doing the things they wanted to do in life;
- Their physical health;
- Their mental health;
- Their relationship with the person(s) cared for;
- Their relationship with friends and family; and
- How lonely or isolated they felt.

The majority of Carers thought their role had a negative impact on each of these (see Chart One). For example, 82.7% (144) thought that it had a negative impact on doing the things they wanted in life and 81.5% (141) said it negatively affected their mental health. However, the impact on the relationship with the person they cared for was the exception to this: ratings here were more mixed, with 29.3% (51) saying that their caring role had had a positive effect and 33.3% (58) a negative one.

Unpaid Carers: Survey Key Findings

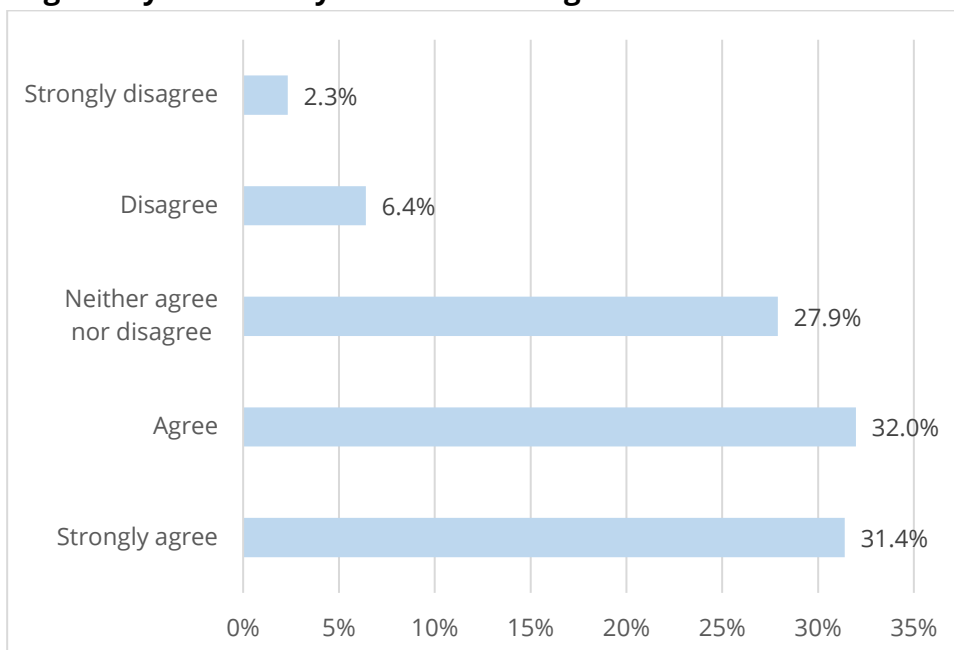
Chart One: Summary of the Impact of Caring Role



Base: All unpaid Carers answering the question (173-174)

A separate survey question provided further insight into the financial impacts of caring; respondents were asked if they agreed or disagreed with the following statement: 'as a Carer, I have been affected negatively by the cost of living crisis'. As Chart Two shows, 63.4% (109) agreed (either strongly agreed or agreed) with this.

Chart Two: Percentage of Unpaid Carers who Agreed/Disagreed that they had been negatively affected by the cost of living crisis



Base: All unpaid Carers answering the question (172)

Unpaid Carers: Survey Key Findings

Follow up comments given to explain these responses, together with answers throughout the survey, provide further insight into how Carers have been affected by their role. Examples of these comments are shown in Table Six.

Table Six: The Impact of Unpaid Caring – Illustrative Quotes

Mental health

The negative effect that caring had on mental health emerged as a key theme; while some respondents said they felt stressed or anxious, others had been left exhausted and felt unable to continue in their caring role.

“I often feel resentful and exhausted, trapped and as though my life is passing by, my health is failing due to stress and I feel at a loss as to how to do anything about it, my life revolves around looking after others.”

“We have adapted and we would not wish to not be able to care for them but of course the worry, stress, commitment is enormous. We just continuously try to do our best and manage despite not receiving support.”

“I don’t allow it to impact relationship with my son but I am close to breakdown and Council simply don’t care!”

“I am happy to be a Carer. It is a role I chose and take responsibility for. But, it can often feel like drowning and/or never being good enough. Sometimes it's about me as a Carer. Sometimes it's about the person I'm caring for. Something will happen and I just don't know how to handle it or help process it for myself let alone the person I care for who needs the extra help. Most times I simply need information and online is inundated with incorrect or bogus information that is mindbogglingly exhausting and time consuming.”

Loneliness and isolation

The following examples illustrate how, despite providing care in very different circumstances, respondents felt lonely and isolated.

- A Carer, who was providing care for a parent, found it difficult to manage their role alongside full time employment and without the support of all family members:

“...I have never felt so isolated and alone in my life even though I am surrounded by people.”

- Another, who was providing care for an adult child, said that “...because I've spent my life caring for my daughter, my social life is almost non-existent” and that “...it is lonely caring for an adult child...”
- For a third Carer, it was the lack of understanding of what was involved in caring for someone with dementia that left them feeling isolated: “no one understands this dementia journey.”

Comments made elsewhere in the survey highlighted how the loneliness experienced could be compounded by living in more rural and isolated communities.

Unpaid Carers: Survey Key Findings

"It's the most challenging, isolating thing I've ever done and there's no relief, no end in sight, just excuses as to why there's no support (because I live in a rural situation)."

"More information is required for rural areas. We are so isolated here. I have a Carers card from my previous group which allowed me to access discounts in local businesses such as cafes and hospitals. Also travel agents etc but this requires people getting together to support unpaid carers and actually care about us. We are after all humans too."

Life on hold

Respondents described how they felt that their life was on hold because they were caring for someone.

"Both my husband and I feel restricted with our own lives as we are conscious we may get a call at any time relating to my in-laws that they have fallen etc. We are trying to keep 'living' but it is always in back of mind..."

"My life has dramatically changed over the last year in particular. As I've previously stated, my life is not my own any more..."

"I can't plan or do anything. Whenever I try to plan something for myself or my son, we have to cancel at short notice and so we rarely try. Social work don't listen. I no longer want to be a Carer, I am worn out."

Lack of support

As the above quotes highlight, support provision shapes the experience of many Carers and, in the absence of the support needed, Carers felt abandoned, exhausted or isolated.

"My caring role is intense and complex. We access respite when we can but we do not have a life outside of our caring roles. If it was not for my husband, I do not think I could continue in my caring role. How can we plan for the future when no professionals are putting in that preparation? There is a huge lack of supported accommodation in D&G so my daughter will be living with us until we die - how supportive is that?"

"...I would like to have a plan for the future i.e. knowing what the basic steps might be to transition my parent into a care home setting when the time comes, but when I broach that subject I am passed from one agency to another without resolution, nobody seems to agree on what the steps are i.e. I am passed between GP to Mental Health Services to Social Work. It is confusing and then I give up and just carry on, without resolution."

"I often feel I am drowning and unsure if the dementia is normal, I'm often given links to websites and phone numbers when all I really need is someone face to face to listen and understand. This makes me isolated. I had imagined my latter years to be focused on me but sadly once again there is no time for me and I feel my purpose in life has been to care for people. My parents' dementia means they are no longer who they were and are often difficult, argumentative and pushing my buttons which impacts on both my physical and mental health as well as relationships with other family members."

Unpaid Carers: Survey Key Findings

Financial stress

Some Carers described the worry created by a lack of financial support. Eligibility criteria for benefits and cost of living payments were key factors here. For example, some didn't receive Carers Allowance because of their pension and others had reduced their working hours but, despite their decreased income, weren't eligible for any financial payments.

"... I'm tired and stressed due to constant caring with no financial benefit as I will lose Carers Allowance as my OAP is higher than the allowance. A slap in the face as I've paid in for well over 45 years and will still be caring in my retirement..."

"I feel very isolated and alone and worry about the future. I do not want my Mum to have to go into residential care. I am having to give up my job to care for my Mum full time to relieve my husband from caring during the day whilst I work. I will no longer have any income from paid work and having to take early retirement from work. As such, I have been hit with penalties in taking early retirement as I am only age 57yrs. My pension won't even pay the gas and electric!"

"When it became obvious my mother needed care I had to reduce hours I worked and so reduce wage and eventually retire although if I hadn't had to care for my mother I would have worked longer. Because I have an old age pension I'm not entitled to any financial benefit."

Some Carers felt that the lack of financial support was synonymous with the lack of recognition of their value:

"Minimum wage if we are valued and saving the health service we should be helped."

"My husband receives Carers Allowance but it's not enough especially as I too am now having to give up full time work to care for my Mum and will receive no financial assistance. We Carers save the government money but receive nothing in return for the love, care and support we give to our loved ones and to keep them living in familiar surroundings with family members."

For another respondent, the cost of living crisis meant that they faced difficult choices about which basic essentials they could afford but the financial payments available were too difficult to access.

"The cost of living has had such a huge impact on our finances. It is so difficult to juggle do we eat today or heat our old drafty house. People have no idea the pressure and undue stress that is causing on both myself and my husband. Eating and heating isn't a luxury it's a necessity. I have seen advertisements for grants etc but you have to jump through massive hoops to apply if you can get past the 100 unnecessary questions. Not everyone has access to the internet nor understands how to use it."

4 Unpaid Carers' Experiences

4.1 Introduction

A key aim of the survey was to provide a better understanding of Carers' experience of their role and support provision. Section 2 summarised the headline findings relating to these experiences and the factors that shape these are discussed further here.

4.2 Experiences of the Unpaid Carer Role

The survey included a set of headline indicator questions that sought to determine if Carers felt recognised, valued, heard and involved and as reported in Section 2.2, experiences of these were mixed. For example:

- While half (49.2%, 91) said they felt recognised and valued as a Carer at least some of the time (they answered 'always', 'very often' or 'sometimes'), half (48.6%, 90) said that they rarely or never experienced this;
- Half (53.0%, 98) of unpaid carers felt that their views and experiences are taken into account in decisions that affect them at least some of the time (always, very often or sometimes). In contrast, 42.7% (79) said they rarely or never experienced this; and
- Three quarters (77.7%, 143) of unpaid Carers felt involved in decisions made about the care and treatment of the person(s) they cared for. But, 19.0% (35) rarely or never experienced this.

The following responses were provided by respondents who reported more positive experiences of their caring role and further demonstrate the importance of support provision (see Table Six, Section 3.3):

"CAMHS are very supportive."

"Because I have taken a very active role in developing a care plan and the paid support is from a very good person centred support agency."

"Great support from Carers Centre."

Another described how they felt recognised and valued by some of the organisations that support them, but not by wider society:

"I do feel recognised or valued as a Carer by external people, our GP is very good and do feel involved with the decisions about the care also. I'm not sure there is an appreciation for contributions to the economy from others."

However, others described their contrasting experience and did not feel that they were recognised, valued and listened to. These Carers felt unsupported in the provision of care:

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"As a generality, I think NHS and Social Care services in D&G do not listen these days. They do not have staff, resources and/or time to treat people as individuals. They work in "silos" and not collaboratively towards their own departmental goals and targets. Not always in the best interests of the patient and/or client."

"The entire experience of being a Carer is very difficult, and I don't think systems are in place to help everyone that needs it, particularly younger Carers in 20s/30s who are often juggling work or study or both. I don't think there is much understanding from people of what actually is involved and how difficult it is to switch off, even if you are given a 'break'."

"Undervalued, underappreciated and left to fend for selves. Council should be ashamed."

"...In my experience, nobody from the NHS has ever asked how I am, how I'm coping. Aren't GPs supposed to keep a register of Carers and offer them health checks or something? I feel overlooked and taken for granted."

A few respondents described their frustrations with what they perceived as expectations that they would continue indefinitely in their caring role:

"Please rethink the narrative. We may be a Carer through choice, or not. But we should be entitled at any point to assess when, for whatever reason, we can no longer perform that role. We should be supported with an exit strategy. It can't be the case that once the Carer, always the Carer. That's what you seem to be saying."

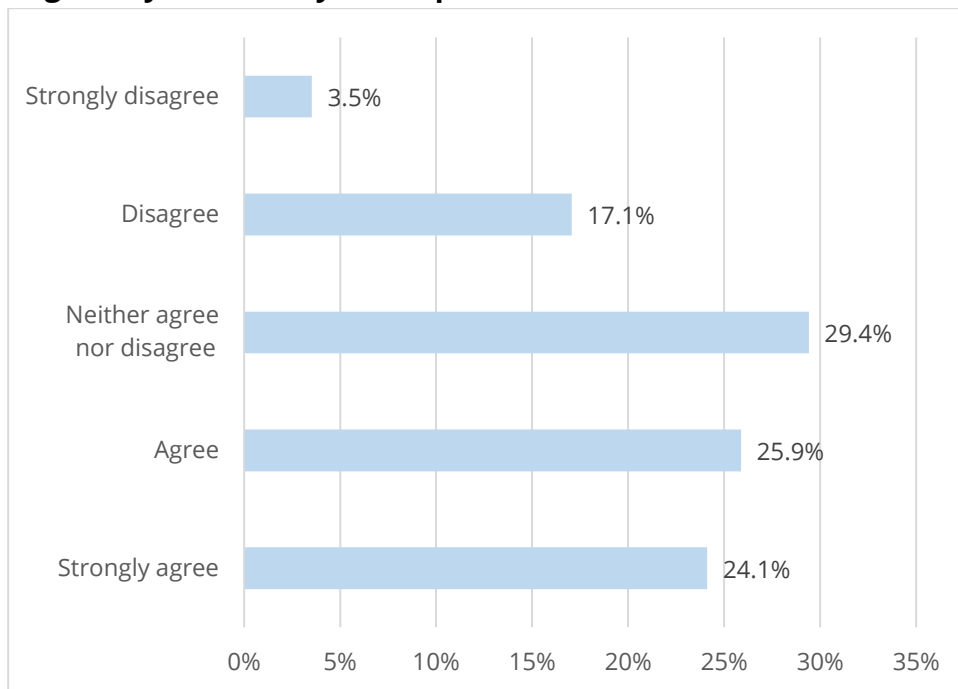
"One of the hardest things is never knowing how long you will be a Carer, and all the emotional guilt that also comes with that. I think there needs to be better direction given about longer-term planning. I've been doing this for 4 years now and I'm tired, but I don't know what other option I have. There should be a protocol for when the time comes so I know I can say 'I can't do this anymore' and something kicks in. But it seems like I will never be allowed to say that, since there is no Plan B. I'd like to see more help or signposting for Power of Attorney as that seemed overly complicated and even once I had that in place, social work sent me back to the solicitor to check wording."

4.3 The Ongoing Impact of Covid-19 on Carers' Experience

The National Carers Strategy Action Plan includes a series of actions around living with Covid-19 and the survey therefore sought to identify if and how it continued to affect Carers. Carers were asked if they agreed or disagreed with the statement, 'some negative impacts of the Covid-19 pandemic are still affecting me and/or the person I care for' and as Chart Three shows, half (50.0%, 85) agreed and a fifth (20.6%, 35) disagreed.

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Chart Three: Percentage of Carers who agreed/disagreed that they continued to be negatively affected by the impacts of Covid-19



Base: All unpaid Carers answering the question (170)

Some of the follow up comments highlight the worries that remain about infection:

"I don't think people understand the catastrophic impact that contracting Covid would still have, today, on the person I care for, and therefore the steps I still take (e.g. wearing masks, not socialising) to protect the people I care for."

"We fear any viral infection due to husband's clinically vulnerable state. I remind him about hygiene and touching door handles etc and then washing hands before eating, rubbing his eyes and so on, to reduce risk of cross infection from viral or bacterial infection. Hygiene remains in the back of your mind."

"Prior to Covid, none of my household was on prescriptions for mental health conditions, years on 3 out of 4 of us are on prescriptions for support to our mental health. The impact of covid affected my son greatly and he is still struggling today with anxiety of being around people, not because of Covid itself, but the return to normal and being busy again."

Covid-19 was also described as affecting access to services and activities:

"Since Covid, it's very hard to get nurses to come out and see my husband when something is wrong. A doctor hasn't seen him in a long time."

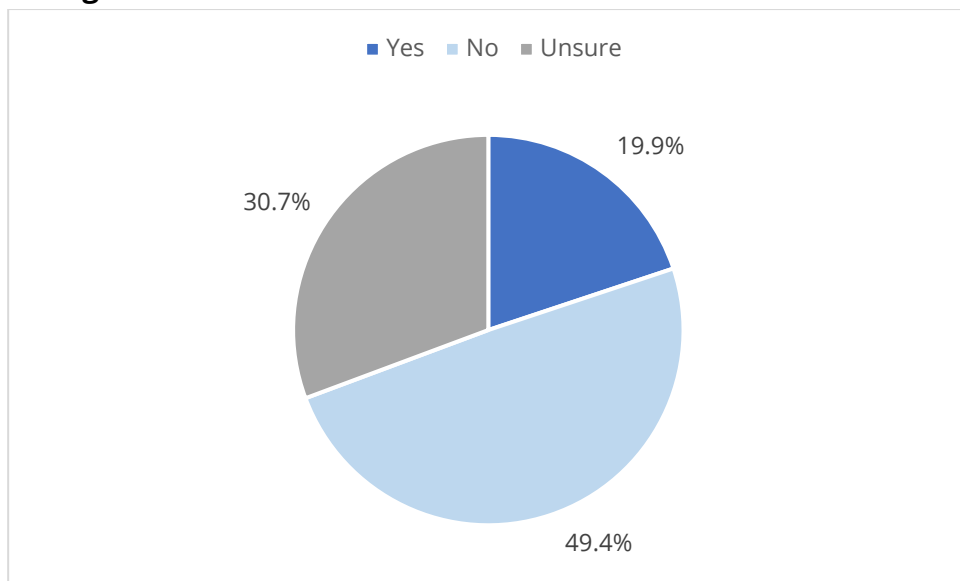
"Since the pandemic some of the groups/activities that were available prior to this have not restarted. This has had a negative impact on mental health of people generally. People seem to be less carefree following the pandemic and this has impacted the person I care for and wider family."

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4.4 Support Needs

The needs of Carers vary according to their personal circumstances and those of the person they care for; the required support will reflect this. Indeed, while 62.3% (114) respondents said that they needed support, 19.1% (35) didn't and another 18.6% (34) answered 'unsure'.⁴ Importantly though, the survey also found that half of Carers (49.4%, 87) don't receive the support they need to continue in their caring role.

Chart Four: Percentage of Carers who receive the support needed to continue in their caring role



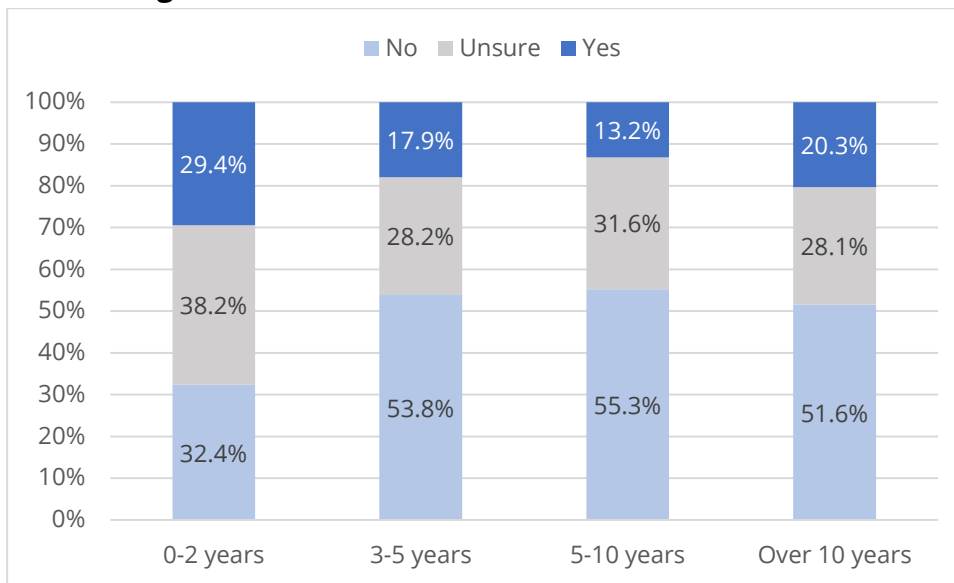
Base: All respondents answering the question (176)

Responses to this question were analysed further to identify any differences but the small numbers in some of the respondent categories meant that it was difficult to identify clear patterns. For example, a higher proportion of respondents who had been caring for 0-2 years felt that they received the support they needed to carry on than Carers who had been providing care for longer periods of time (see Chart Five). However, across all Carer durations, a minority felt that they received the support they needed to continue in their caring role.

⁴ 183 unpaid Carers answered this question.

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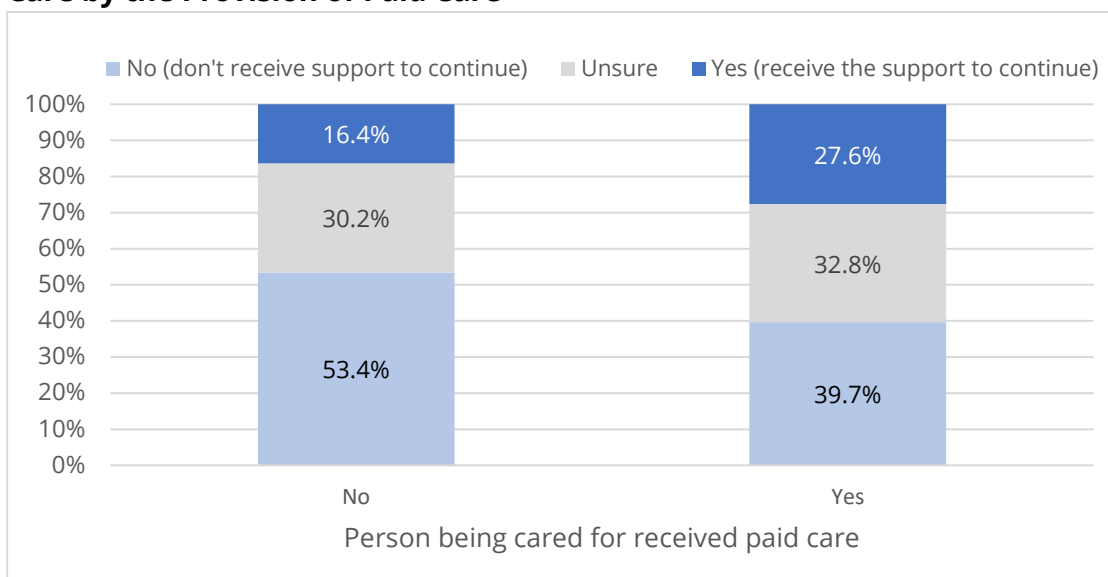
Chart Five: Percentage of Carers who receive the support needed to continue by length of time caring



Base: Unpaid Carers who had provided care for 0-2 years (34); Unpaid Carers who had provided care for 3-5 years (39); Unpaid Carers who had provided care for 5-10 years (38); Unpaid Carers who had provided care for over 10 years (64)

The survey responses do however suggest that whether the person being cared for receives support from paid carers is important. As Chart Six shows, where paid carers were also providing care, 27.6% (16) thought they received the support they needed to continue. Where paid carers weren't providing care, only 16.4% (19) thought they received the support needed to continue in their caring role.

Chart Six: Percentage of Carers who Received the Support Needed to Continue Providing Care by the Provision of Paid Care



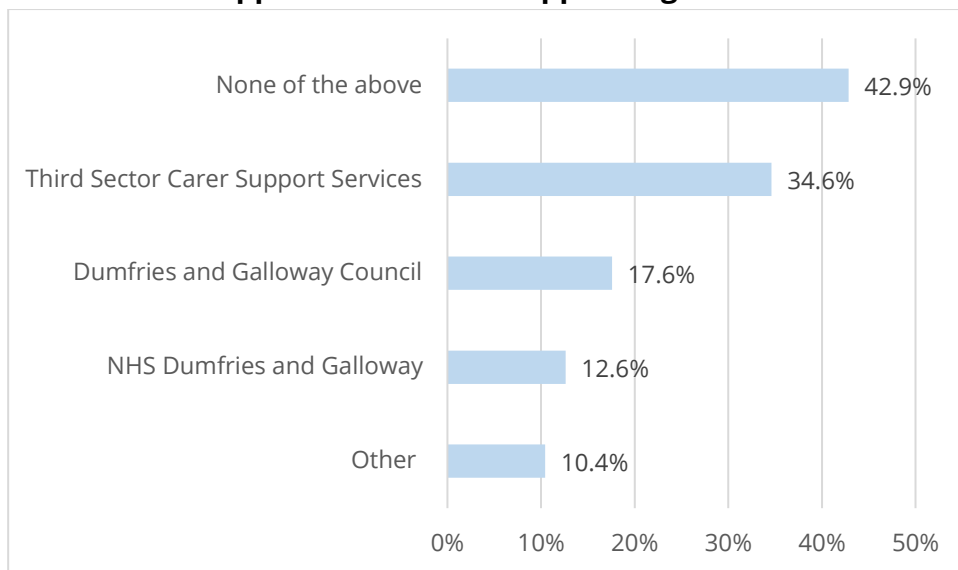
Base: All respondents caring for someone who receives paid care (58) and All respondents caring for someone who doesn't receive paid care (116)

Unpaid Carers: Survey Key Findings

4.5 Access to Support

The survey presented a list of organisations who can provide support and asked respondents to select all those who had supported them. As Chart Seven shows, the largest proportion (42.9%, 78) hadn't received support from any of the listed organisations. While more than half of those who hadn't received support (59.0%, 46) said they either didn't need to or were unsure if they needed to, 39.7% (31) did need support. Where support was provided, it was most often from a third sector Carer support service (34.6%, 63).

Chart Seven: Support from Carers support organisations



Base: All unpaid Carers answering the question (182)

Comments made throughout the survey suggest that awareness of available support and ease of access can act as barriers for some Carers:

"It's knowing where to ask for support or what is actually out there that could help! Then there is the issue of the support being timely, a lot of people don't ask till they really need it!"

"I don't know how to access proper support for either myself or my child!"

"I have not been given any guidance in what is available or appropriate as support. I do not know where to turn."

"The need to formally 'come out' and identify myself as an unpaid Carer is a barrier. For example, I can't just turn up at the new drop-in space at the Carers Centre without formally registering with them first."

Another respondent also highlighted the issue of supporting Carers who are not formally recognised, especially where the person they care for is also unknown to health and social care organisations.

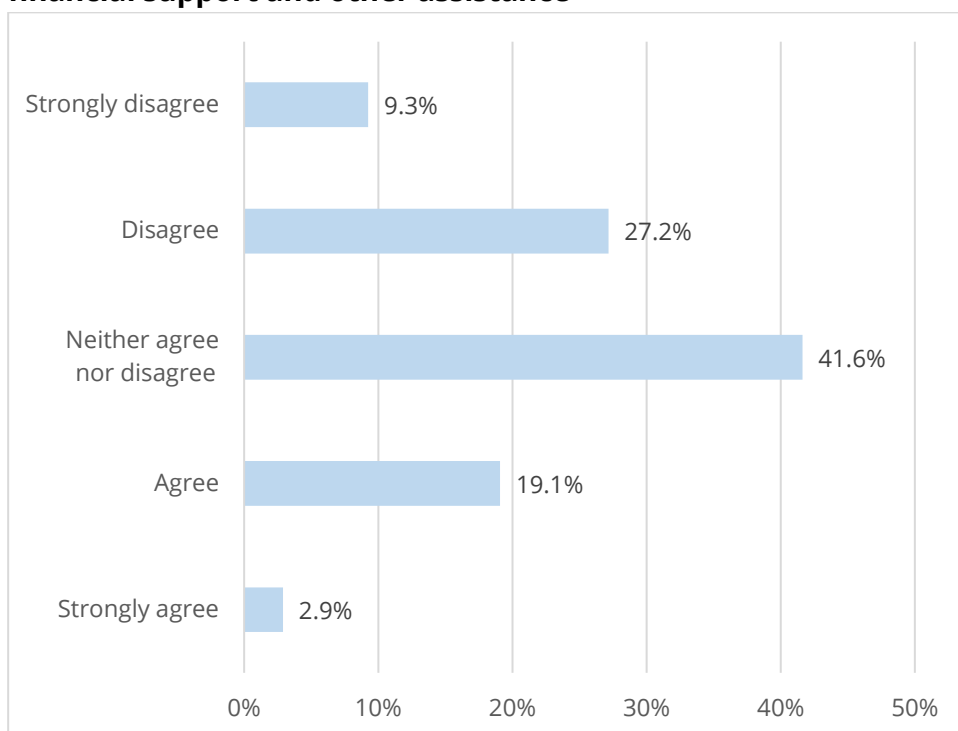
"I am hugely aware of the needs of unpaid Carers and their valuable contribution to others in the community however the people they care for informally are not always known to the

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health and social care sector due to the support unpaid Carers provide out of neighbourliness and kindness. These actions then become expectations on the unpaid Carer."

The survey also included a more specific question about access to financial support and asked Carers if they agreed or disagreed with the statement, 'I feel able to access the financial support and other assistance I am entitled to.' Just over a fifth (22.0%, 38) agreed (either agreed or strongly agreed) and, as Chart Eight shows, the remainder either gave a neutral response or disagreed.

Chart Eight: Percentage of unpaid Carers who agreed/disagreed that they could access financial support and other assistance



Base: All unpaid Carers answering the question (173)

Follow up comments made by some of the respondents again highlighted how awareness of the available support and ease of access can act as barriers:

"I get benefits so feel I can manage financially but if I was struggling, I wouldn't know where to get help."

"Because I work full time not sure if I am entitled to any financial support and feel penalised because I do work..."

"Applying for Attendance Allowance was not straightforward. As a result I lost out on that help for over 12 months until the dementia link worker helped me with the form. It was overly complex... couldn't have done it without help."

As reported in Section 3.3, the eligibility criteria for different forms of financial support meant that some Carers were unable to receive benefits or cost of living payments. For example:

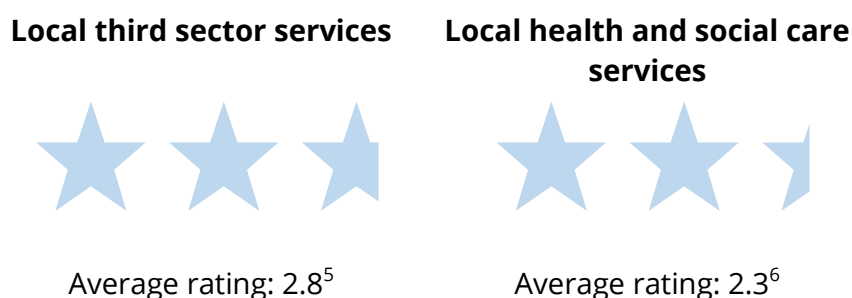
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"...Our heating bills are through the roof. Because we're lower than state pension age don't get the support, it's very difficult."

"I'm a hidden carer. It's disgraceful that Carers Allowance stops when you retire - the costs of caring don't go away and the cost of everything is going up and up. There is no recognition of the impact my role has on my life and society more generally."

4.6 Experiences of Support

The survey findings show that Carers' experience of support is mixed; half (51.7%, 92) said that they rarely or never felt supported by local agencies and even more (64.0%, 114) said that they could rarely or never access respite when needed (see Section 2.3 for a summary of these headline indicators). The ratings given to local services provide further evidence of these mixed experiences: respondents were asked to rate the support they had received from local services using stars (where one star represented poor and five excellent). The average ratings were 2.8 out of five for local third sector services and 2.3 for local health and social care services.



Inadequate health and social care provision for the person being cared for emerged as a key theme from the explanations given for these star ratings. As the following quotes illustrates, where the appropriate provision was not in place, the demands on Carers increased:

"When requesting additional support from services my needs and my parents' needs are often played down by social workers due to lack of funding and paid care staff availability. We are 'encouraged' to struggle on by ourselves."

"Right now there is very little support. It's very much left to the Carer to "get on with it". You are told there are not services available. I provide care for my daughter and my mother. My mother has paid carers but is told they are over run so are cancelled regularly and family still have to provide support."

"The NHS are held back by resources/waiting times/underfunding this creates a massive back log, delayed diagnosis or access to services which has had a huge impact on us!"

⁵ Based on 143 responses

⁶ Based on 153 responses

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"Receive 15 mins care for 5 days per week at lunchtime. Have been waiting 11 months for help with personal care morning & evening."

"The problems with care provided by local authorities is low staffing levels, often care company get in touch to say they're running late because they're short staffed so I tell them not to bother I'll deal with my mother."

"Support is there but often when it is too late. I understand the pressures that the NHS and Social Work are under but if it isn't able to help when it's needed then it shouldn't be offered as that. Both of them have helped but due to their pressures it has meant that my relative isn't always safe."

"Services don't communicate. There is no person centred care it's "we have no support available". Breaks don't exist it's "can someone else do the care work" it's always put back on the carer."

A lack of support for Carers themselves was also a key theme here and respondents described how they felt that their needs weren't always considered:

"The support from NHS & Local Authority is zero – none!!! No recognition that is all unpaid Carers in D&G stopped the whole system would break never mind the economy."

"Nobody ever checks to see if I'm ok. When I get admitted to hospital no one cares about how my daughter is being cared for. Telling people I'm a Carer, I might as well tell them I'm a gymnast – no one cares."

A small number of respondents highlighted what they experienced as specific gaps in support provision, including for adults with neurodiversity, third sector support for children with mental health conditions and supported living for adult children:

"I am a Carer with a neurodiversity myself. There is little to no support to help me manage my life challenges due to neurodiversity because there appears to be no services for adults. Help with my own neurodiversity would absolutely allow me to support better and take care of the people I support and myself."

"There are very few reliable, safe and good quality services for children with MH conditions - there are some good support groups but no third sector organisations where I live that I can use. The NHS (CAMHS & Psychology) have been very helpful."

"...We want to plan for our future but we have no way of knowing what is going to happen in the next few years as far as supported living is concerned for our daughter. There is a chronic lack of facilities in this region and I don't see a satisfactory way ahead. Despite starting the ball rolling, SW staff have changed yet again and we have not had any feedback. When asked

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they did not know what was available or what may be available in the future. It is very worrying."

"As a parent carer, I don't see any other option in my life, I'll be doing this for the rest of my life and I worry what happens when I'm not here."

However, positive aspects of support provision were also highlighted by respondents (albeit some of these experiences varied across organisations). For example:

"CAHMS and children's nurse have tried to accommodate needs of cared for person which in turn helps me provide care."

"Carers visit twice per day and they are all excellent and very professional."

"I have been offered phone call support from Carers Centre which has been helpful. Both my parents have different social workers and whilst they have been lovely, they do not have the capacity to assist when you are in crisis because the resources are not there e.g., care home places..."

"Any time I've asked for advice from Carers Centre, always received in a timely manner. The fact that I'm a Carer is no longer recognised by my GP practice, due to caring duties took 1YEAR to even get a phone conversation with my own doctor. Let alone a 1-2-1 appointment!!!"

"I think there is plenty of resources and ways to get support and advice, doctors, mental health nurse, google and social services OT's."

"Services are doing all they can. Everyone recognising Third Sector support services as equal to NHS and LA services."

Where respondents were most positive though, Carers described feeling listened to, recognised and supported:

"The Carers Centre is a lifeline for me and a lot of others. A sympathetic ear who are able to give impartial advice and assistance."

"The GP has been very supportive and has recognised me as a Carer and treated me as an individual as well as seeing my son. I have used the Carers Centre and have had useful recommendations for further support. I have also signposted this centre to my step-mum for support with my dad also."

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4.7 Support for Carers in Employment

Those in employment were asked if they got the support they needed from their employer and over half said they did (57.4%, 58). The follow up comments suggest that these employers accommodated Carers needs through, for example, offering flexible hours or giving time off to attend appointments. Both formal policies and approachable, supportive managers were identified as important here. For example:

"My current line manager is very approachable and flexible so if I need to finish early/start late she accommodates this."

"Council carers register allows emergency leave if needed. Supportive management."

"I requested flexible hours and then a reduction in hours, both were approved."

"We have a Carers Leave policy which allows me extra days off work and emergency time off work if needed."

However, despite feeling that they were supported by their employer, two of these respondents described the pressure created by managing the demands of both their job and caring role:

"Allowances are made for me being late, not getting work done on time, adjusted work pattern, and moral and emotional support. But regardless, there is a toll on me professionally as my work standards have dropped significantly and I am professionally accountable for my work. This is a question you should be asking about."

"Yes, although I am a [] manager and the job can be very demanding, it is not always possible to walk away."*

In contrast, 22.8% (23) of those in employment said that they did not get the support they needed from their employer (the remaining 19.8%, 20 answering this question said that they were unsure). Some of the respondents who chose to answer the follow up question highlighted the difficulties faced because Carers Leave did not enable them to take the time off that they required:

"I am only entitled to emergency carer's leave and the needs of my family members can exceed what I am able to ask for meaning I need to use my annual leave of work later to make up lost working hours."

"...Carers leave will only be given in an emergency but most of the time when I need to take leave, it isn't an emergency and I either need to work the time back (which becomes a lot and very stressful) or take it as annual leave. Parenting leave is allowed for non-emergency care for children but carers leave isn't as flexible."

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Others said that their employer either didn't understand the amount of support they needed or that they couldn't provide it. For two respondents, working alongside their Carer role wasn't manageable and they had to leave employment.

In the final comments section of the survey, one Carer identified improved employer support as the change that would have the biggest impact on them:

"The greatest thing that would help me is support and understanding from my employer (NHS) and more equal leave to that which parents receive, as well as it being more flexible than the rigid rules it has just now. Sadly the NHS doesn't seem to understand or care about the impact of caring (outside work) on their staff / health / wellbeing."

4.8 Support for Carers Caring for someone in Education

Those caring for someone who is at school, college or university were asked an equivalent question about support from the education institution and the responses were more mixed: 42.6% (20) thought they did get the required support but 40.4% (19) did not and 17.0% (eight) were unsure. Eight of those who said they were supported gave a follow up comment to explain their answer; these responses were varied and included:

"Following a change in headteacher, our relationship with the school is positive. Son has a plan and is supported. Prior to this, "support" was condemning, despite a plan and regular meetings."

"School are very supportive."

The eight responses to explain why the education institution wasn't supportive, or they were unsure if they were, included:

"Child plan was in place but no support from school now home ed."

"School have been very unsupportive. They prefer my child to be at home than in school as they say they don't have a quiet space for study and don't have resources to help my child catch up on work on the days they've been ill and off school..."

Another respondent said that their child's school were unable to fully meet their needs because of a lack of teachers and support assistants, which meant that:

"...Although my daughter is kept safe physically, and is receiving some sort of education, I would question the damage to her nervous system by coping for 6 hours a day in an environment which is not tailored to her specific needs but to those who are neurotypical."

Unpaid Carers: Survey Key Findings

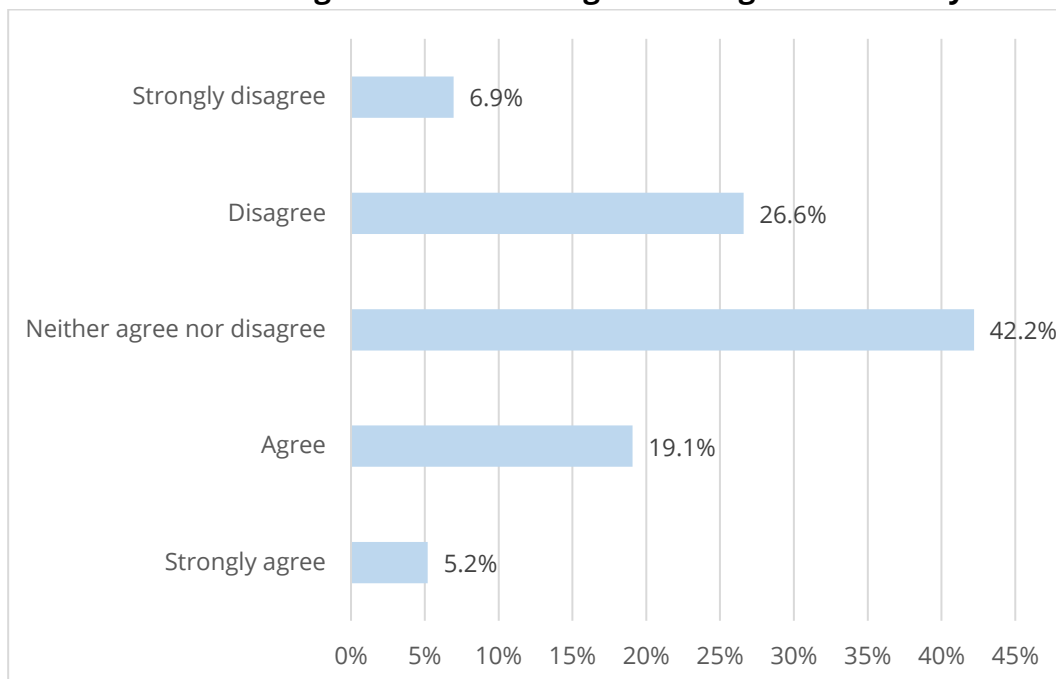
4.9 Carers Rights

Carers (Scotland) Act 2016 provides the right to an Adult Carer Support Plan or Young Carer statement⁷ and requires local authorities to provide Carers with information and advice on issues including future care planning. However, the survey found that both these had been offered to only a minority of respondents:

- 14.1% (25) had been offered support to plan for the future but 71.7% (127) had not been and 10.2% (18) were unsure if they had.⁸ Of the 127 respondents saying that they hadn't been offered this support, 61.4% (78) said that they needed support.
- Similarly, 18.3% (32) had been offered an Adult Carer Support Plan but 62.9% (110) hadn't and 12.6%, 22 were unsure if they had.⁹ Of the 110 who hadn't been offered a Plan, 57.3% (63) said that they needed support.

The survey findings also indicate that not all Carers understand their rights: Chart Nine shows the percentage of respondents who agreed or disagreed with the statement, 'I understand my rights as a Carer'. The largest proportion (42.2%, 73) gave a neutral neither agree nor disagree response and a third disagreed (33.5%, 58 – either strongly disagreed or disagreed).

Chart Nine: Percentage of Carers who agreed/disagreed that they understood their rights



Base: All unpaid Carers answering the question (173)

⁷ None of the survey respondents were aged 18 years or younger

⁸ Based on 177 responses

⁹ Based on 175 responses

5 Developing a Local Delivery Plan: Unpaid Carers Suggested Actions

5.1 Introduction

The findings from the survey will be used to help develop a local Delivery Plan that will shape the region's response to the National Carers Strategy Action Plan and questions about what could be done to help achieve these actions were therefore included. These questions asked:

What can be done to:

- Help people recognise themselves as Carers;
- Help Carers access support and advice;
- Help Carers receive the benefits they are entitled to;
- Help the way health and social care professionals work with Carers;
- Improve the experience of Carers when the person they care for is in hospital;
- Improve respite and short breaks;
- Better support Carers during the cost of living crisis;
- Increase uptake of the Carer Positive employer accreditation scheme; and
- Reach and support Young Carers.

5.2 Summary of Suggested Actions

There was some repetition in the responses to these questions, with information sharing, signposting and referrals, and increased support and recognition emerging as common themes. Table Seven therefore summarises the responses by these themes.

Unpaid Carers: Survey Key Findings

Table Seven: Summary of Suggested Actions

	Support and recognition	Awareness raising	Signposting/ referrals	Other (question specific theme)
How to help people recognise themselves as Carers (79 responses)	<p>37 respondents called for action that would either increase recognition amongst others or improve support provision (rather than helping people recognise themselves as Carers).</p> <p>10 of these comments specifically related to the financial support available to carers and called for improved support payments or the provision of a wage.</p>	<p>Some form of awareness raising activity was suggested by 16 respondents. While some of these referred to the generic provision of information or awareness raising, others specifically suggested the use of social media or leaflets (e.g. DGWO Facebook page and local news).</p>	<p>Health and social care services and professionals were identified by 10 respondents as playing an important role in increasing recognition, particularly at the point of diagnosis or discharge. The suggestions made included asking the patient who might care for them and providing information about Carer support services.</p>	<p>Definitions: Some described the difficulties they had faced in recognising their own caring role as different to being a 'daughter', 'son' or 'partner' (five respondents).</p> <p>Six called for action to distinguish a Carer from these other family roles (i.e. at what point does helping someone become caring?).</p>
How to help Carers access support and advice (83 responses)	<p>Five respondents called for more or better support provision, including out of hours service, post-diagnostic dementia support, respite and a falls support service.</p> <p>Another two respondents wanted more joined up working across organisations.</p> <p>Five called for some form of Carer check-in or needs assessments to help ensure that the available support was being accessed.</p>	<p>23 suggested that available support should be promoted through, for example social media and leaflets. Local radio and television were identified as an important communication channel by one respondent, who highlighted poor connectivity as an issue in more remote parts of the region.</p> <p>A one stop shop or single point of access approach was also suggested (by nine respondents).</p>	<p>17 Carers called for a more direct approach, including signposting, referrals or targeted communications (phone calls, texts, emails and letters – for those without connectivity). For one respondent, trying to find support themselves was a humiliating experience and they therefore thought signposting and referrals were needed.</p> <p>Again, the point of diagnosis or discharge were identified by some of these respondents as an opportune time for signposting and more direct forms of information sharing.</p>	<p>Carers Centre: The Centre was identified as playing a role by six respondents, through, for example, developing closer links with social work, providing informal support to those not registered as a Carer, providing check-ins and support more broadly.</p> <p>Training: Two also suggested offering training to Carers.</p>

Unpaid Carers: Survey Key Findings

	Support and recognition	Awareness raising	Signposting/ referrals	Other (question specific theme)
How to make sure Carers receive the benefits they are entitled to (77 responses)	<p>Seven respondents thought that organisations supporting Carers should carry out regular benefit checks to identify their entitlement.</p> <p>12 respondents called for support either with applications or the benefits process more broadly.</p> <p>Other examples of the type of support suggested included dedicated benefits officers or social workers, drop-in clinics, home visits (<i>"it's not easy going somewhere"</i>) and outreach advocates.</p>	<p>19 mentioned raising awareness of benefits through some form of information sharing such as online, leaflets, payslips, social media, community events and local benefit clinics.</p>	<p>13 respondents called for targeted signposting so that Carers could be directed to the support available to them. Some of these described how, despite being in contact with support organisations, the availability of benefits had never been mentioned to them.</p>	<p>Eligibility: Eight thought eligibility should be expanded by removing means testing or extending criteria to include those in receipt of a pension or in employment. Another wanted to see financial support tiered according to the amount of care being provided.</p> <p>Easier access: This was mentioned by seven respondents; some did not specify how this could be achieved but others called for simpler forms.</p> <p>Empathetic approach: Four respondents emphasised the importance of an empathetic approach by organisations.</p>
How to help health and social care professionals work with Carers as equal partners (86 responses)	<p>Carers said that they wanted to be heard and their knowledge of the person they care for recognised (25 respondents). There was often a perception here that professionals 'thought they knew better.'</p> <p>13 Carers also called for a more joined up approach, with both the involvement of Carers in decision making and increased co-ordination across services being mentioned here.</p>		<p>Provide information about available support at time of diagnosis (one respondent).</p>	<p>More staff: Seven respondents reflected on the challenges within social care and called for more staff.</p> <p>Other comments:</p> <ul style="list-style-type: none"> • Data protection legislation acts as a barrier to Carer involvement; • Use Adult Carer Support Plans and Young Carer Statements to ask questions; and • More Carer engagement (like this survey).

Unpaid Carers: Survey Key Findings

	Support and recognition	Awareness raising	Signposting/ referrals	Other (question specific theme)
How to improve the experience of Carers when the person they care for is in hospital (73 responses)	<p>29 Carers described how they wanted to be recognised and involved in care planning. Simply being listened to by professional and involved in decisions would make a difference to these respondents.</p> <p>Discharge planning was specifically referred to in 14 of these comments, with respondents wanting more consideration of how best to meet the needs of both the patient and Carer before the patient was sent home (particularly where there had been a change in care needs).</p> <p>11 respondents called for some form of support for Carers while the person they care for is in hospital. These included: needs assessment; input from Carers Centre; and support hubs.</p>	<p>Two suggested that disability and Carer awareness for staff would help (one of whom specifically referred to autism and anxiety here).</p>		<p>Enable Carers to stay with the person they care for: This was mentioned by 12 Carers and the suggested actions included accommodating an overnight stay and offering flexible visiting hours.</p> <p>Other suggestions:</p> <ul style="list-style-type: none"> • Training to help the Carer prepare for discharge; and • Policies to support those needing time off from work.

Unpaid Carers: Survey Key Findings

	Support and recognition	Awareness raising	Signposting/ referrals	Other (question specific theme)
How to improve respite and short breaks for Carers (87 responses)	<p>Many of these responses highlighted the frustration experienced by Carers in accessing respite and short breaks, with 41 stating there isn't any or that more is needed. For example: "... <i>the question is a nonsense. Respite is non-existent.</i>"</p> <p>Funding was also mentioned here, with seven wanting more funded places and two stating that respite shouldn't be means tested.</p> <p>More specific suggestions about the type of respite care that should be provided included:</p> <ul style="list-style-type: none"> • More flexible and creative respite for parent Carers: "<i>i.e. taking the other children out and leaving me with the child I care for...</i>" • A home respite service. 	<p>Raising awareness of available respite and how to access it was also suggested (by 14 respondents). Some thought that the Carers Centre could provide information about available services while others didn't specify how this could be done.</p> <p>Related to this, eight Carers said that they either didn't know about the respite and short breaks that might be available for them, or how these services might work for them.</p>		<p>Make access easier: Eight comments related to making it easier for Carers to access respite, through for example increased flexibility or offering places closer to home.</p> <p>Other suggestions:</p> <ul style="list-style-type: none"> • Paid carers should be better paid, which would in turn lead to more availability of care services; • A respondent called for "<i>...More capacity building for services such as Crossroads</i>"; • Extend the eligibility criteria of Acorn House; • Reopen local cottage hospital and provide respite beds there; • A pool of short term paid carers could make respite more accessible when there is no care package in place.

Unpaid Carers: Survey Key Findings

	Support and recognition	Awareness raising	Signposting/ referrals	Other (question specific theme)
How to better support Carers during the cost of living crisis (66 responses)	<p>27 called for some form of financial support including help with energy bills, travel costs, food or equipment. Some of these also wanted the additional costs associated with caring for someone to be recognised.</p> <p>Two respondents wanted Carers to be paid a wage, but a third felt that discounts was a more feasible way of better supporting Carers.</p> <p>Another 19 referred explicitly to benefits, either in terms of increasing payments, expanding eligibility or providing support accessing benefits.</p>		Nine respondents called for Carers to be signposted to available sources of support.	<p>Other suggestions:</p> <ul style="list-style-type: none"> • A need to make it easier to access financial support, without specifying how; • Recognise that the support needs of Carers differ; • A call to keep Dumfries and Galloway's financial inclusion team; and • A respondent simply said, <i>"Again, offer support YOU DO NOT."</i>
How to increase the uptake of the Carer Positive employer accreditation scheme (46 responses)	<p>Some Carers used this question to call for broader understanding and recognition of their needs as a means to increase uptake (10 respondents).</p>	<p>The responses suggest that there is a need to increase awareness of the scheme: 10 said that they didn't know about it and one had left their job because they hadn't been aware of the scheme.</p> <p>Its promotion was suggested by 16 respondents. While some didn't specify how this could be done, sharing good news stories with employers, using case studies to demonstrate benefits and informing Carers about it were all suggested.</p>		<p>Scheme enforcement:</p> <p>Seven respondents wanted to see some form of accountability or enforcement of the scheme so that the principles it promoted were enacted across organisations.</p> <p>Other suggestions:</p> <ul style="list-style-type: none"> • Carers should have the same rights as other groups (e.g. parents); and • Enable Carers to use their salary to purchase extra days leave to boost Carers leave.

Unpaid Carers: Survey Key Findings

	Support and recognition	Awareness raising	Signposting/ referrals	Other (question specific theme)
How to reach and support Young Carers (49 responses)	<p>20 responses identified schools as playing an important role; while some of these didn't specify what could be done in schools, others suggested helping teachers and support staff to better identify Young Carers, recognise their needs and support them.</p> <p>14 responses referred to support more broadly and suggested ways to increase or improve provision. For example, five identified some form of peer support as potentially beneficial (e.g. buddies and social events). Other suggestions included: A Carers' ambassador; training for Young Carers; dedicated Young Carers team to provide tailored support; and respite.</p>	<p>16 suggested raising awareness of Young Carers more broadly by sharing information through, for example, social media, direct mailouts and the provision of resources in community facilities (e.g. GP surgeries and libraries).</p>	<p>Five respondents thought that organisations and agencies working with families could identify where there is a Young Carer and signpost to available support or monitor their needs more broadly.</p>	<p>A respondent called for region wide provision, rather than a single base in Dumfries.</p>

6 Developing a Local Delivery Plan: Carer Support Organisations Suggested Actions

6.1 Introduction

Organisations who work with or support unpaid Carers, such as third sector organisations, NHS Dumfries and Galloway, and Dumfries and Galloway Council, were also invited to complete the survey and 14 employees from these organisations did so. They were asked the following questions:

- Which organisation they represented;
- How often they were in contact with unpaid Carers; and
- What actions they thought should be taken to improve different aspects of Carers' experiences (Action Plan question set).

However, only five staff respondents chose to answer the action plan questions and the summary presented here is therefore based on these five responses.

6.2 Summary of Carer Support Organisations' Suggested Actions

The small number of Carer support organisation employees answering the action plan questions limits the ability to identify key themes, the responses are therefore presented as a bullet-point summary in Table Eight.

Table Eight: Summary of Suggested Actions

<p>How to help people recognise themselves as Carers:</p>	<ul style="list-style-type: none"> • Train Health and Social Care Partnership staff in EPIC principles and to <i>"Think Carer in all they do"</i>, with the suggestion that Think Carer training be made mandatory; • Organisations interacting with families and parents should make Carers aware of the available support; • Include questions to aid recognition within registration paperwork; • Consider the capacity of third sector organisations to support an increase in the number of people recognising themselves as Carers; and • Being able to access the appropriate support is more important than self-identification as a Carer.
<p>How to help Carers access support and advice:</p>	<ul style="list-style-type: none"> • <i>"Increased identification by all working in and around health and social care field."</i>; • But, there needs to be consideration of organisations' capacity to meet any increase in demand for support; • Joined up working across organisations to increase awareness support provision; • Provide easy access to information e.g. through Community Link Workers and other <i>"health sources"</i>; and • Carer Aware training to help raise awareness of Carers.

Unpaid Carers: Survey Key Findings

<p>How to make sure Carers receive the benefits they are entitled to</p>	<ul style="list-style-type: none"> • Increase awareness amongst Carers of available support; • Organisations to be aware of available support and signpost as appropriate; • Increased CAB presence in community settings; • Use Community Link Workers to promote awareness; and • Information and help with applying <i>"at source for everyone."</i>
<p>How to help the way that health and social care professionals work with Carers as equal partners in care</p>	<ul style="list-style-type: none"> • Acknowledge the <i>"vital role"</i> of Carers and ensure their voice is heard; • Recognise that unpaid Carers support health and social care and <i>"should be included and heard in the care package/discharge of the cared for"</i>; • Staff awareness and understanding of Carers and their needs was identified as important in enabling this; • Staff need to understand <i>"what the concept of Carers as equal partners really means"</i>; • Good communication skills; • Transparency; and • Joined up working: <i>"All signing from the same hymn sheet – working together to support carers – less paperwork."</i>
<p>How to improve the experience of Carers when they person they care for is in hospital</p>	<ul style="list-style-type: none"> • Identify Carers after admission; • Involvement in discharge process: <i>"A process where the Carer signs off on the discharge like the ward would sign someone fit for discharge would make sure that Carers are involved and consulted with prior to the process – it would be beneficial to have a tick list of issues/ questions/ topics discussed with the Carer that could be on the discharge paperwork so that the process is somewhat standardised."</i> • Communication and acknowledging the Carer's voice in the cared for person's treatment; • Signpost to Carers support organisations; and • Provide appropriate care in hospital <i>"then the Carer would get a break (instead of spending all of the time at hospital caring)."</i>

Unpaid Carers: Survey Key Findings

<p>How to improve respite and short breaks for Carers</p>	<ul style="list-style-type: none"> • Increase respite availability; • Less bureaucracy and easier referral process to improve access; • More creative provision: <i>“what would work best for them...”</i> and <i>“wider understanding of what constitutes a break for Carers and not just the more usual traditional approaches to what is offered...”</i> • Increased flexibility in the use of Self Directed Support; • Provide Young Carers with access to respite; • Increase awareness of its availability; • Address staffing issues: <i>“Quality care staff leaving providers because SSSC not allowing them to continue to work unless they take SVQs...”</i>; and • Funding opportunities.
<p>What could be done to better support Carers during the cost of living crisis</p>	<ul style="list-style-type: none"> • Ensure Carers are identified and referred to available support; • Grants and funding to support Carers; and • Easy access to available support.
<p>How can update of the Carer Positive employer accreditation scheme be increased</p>	<ul style="list-style-type: none"> • Increase awareness; and • Suggested that a dedicated person could help do this.
<p>How to reach and support Young Carers</p>	<ul style="list-style-type: none"> • Consider and build the capacity of Carer support organisations to support Young Carers by increasing referrals; • A cross over service would address the gap in support available in the transition from child to adult services; and • Increased awareness and understanding of the Young Carer role to support early identification; and • Increase understanding of support provision.

7 Summary

7.1 Introduction

The survey findings provide valuable insight into what its like for unpaid Carers in Dumfries and Galloway, which can help inform action to improve experiences. In this final section of the report, the key points emerging from these findings are summarised.

7.2 Summary of Key Points

- The survey indicates that the experience of unpaid Carers in Dumfries and Galloway is mixed; while some feel that they are recognised, valued, heard and supported, others do not.
- Where Carers do not receive the support they need, they can feel exhausted, isolated and stressed.
- While the support needs of Carers differ, half of those surveyed don't think that they receive the support they need to continue in their caring role.
- Providing more support, and improved support, was often called for, both in terms of Carers support provision and the health and social care received by the person being cared for.
- Where the person being cared does not receive the health and social care they need, the survey findings suggest that Carers face increased demands.
- The inclusion of a series of questions based around the National Carers Strategy Action Plan has provided an understanding of what Carers and Carer support organisations think could be done to improve experiences. While the suggested actions were wide ranging and should be considered by the IJB in the development of the local Delivery Plan, the following key points emerged:
 - **Carer recognition:**
 - Carers want the value of their role to be recognised and appreciated by health and social care services as well as by society more broadly. While financial support was synonymous with recognition for some, others just want to be acknowledged.
 - Not everyone providing unpaid care recognises themselves as a Carer; they might instead think of themselves as a spouse, parent or son or daughter.
 - Awareness raising was therefore important here amongst both unpaid Carers and organisations.
 - Health and social care professionals were also identified as important in helping Carers to recognise their role. Diagnosis and discharge in particular were thought to create opportunities to prompt discussions that could help people recognise their role as a Carer.
 - **Access to support, advice and benefits**
 - Carers support organisations thought that the increased identification of Carers would in turn improve access to available support, but the capacity of the third sector to meet any increase in demand would need to be considered alongside this.

Unpaid Carers: Survey Key Findings

- Awareness raising activities were needed to help Carers identify appropriate sources of support.
 - Interactions with health and social care professionals and third sector organisations were also important here and provided an opportunity for Carer check-ins to identify needs (including financial) as well as broader information sharing, signposting and referrals.
 - More financial support to help with the cost of living crisis was also called for through, for example, expanding benefit eligibility or increasing payments.
 - Carers also wanted to see increased recognition of the additional costs associated with their caring role.
- **Equal partners**
 - Carers wanted to be heard by health and social services so that they could work with them as equal partners.
 - While this applied to all contact, listening to and involving Carers in discharge planning was especially important.
 - A more joined up approach – where Carers are involved and services co-ordinated - would also help Carers to be equal partners.
- **Respite and short breaks**
 - There is a need for more, and better funded respite care, with Carers often stating that it's not available to them.
 - Carers should be informed of the respite that is available and supported to access it.
 - Both support organisations and Carers wanted to see more creative and flexible provision.
- **Increasing uptake of the Carer Positive Employer Scheme**
 - Raising awareness was key here and it was suggested that good news stories and case studies could be shared to promote its benefits.
 - Some Carers thought that it wasn't enough to gain accreditation and wanted the Scheme to be enforced so that its principles were implemented across organisations.
- **Reaching and supporting Young Carers**
 - Schools were identified as playing an important role here, both in helping to identify Young Carers and supporting their needs.
 - Peer support was also suggested as a means of supporting their needs.