States of Guernsey

Carers Action Plan
Summary of Carers Views

Consultation Evidence for the Carers Action Plan

30 April 2019

The Carers Action Plan aims to identify actions for change which can be delivered to improve the services and support for people who have a significant unpaid role caring for family members or friends.

The Carers Action Plan was initiated in response to the following resolution from the Supported Living and Ageing Well Strategy (Billet d'État III v.II of 2016):

> *"To direct the Policy and Resources Committee, in conjunction with the Committees for Health and Social Care and Employment and Social Security, and appropriate third sector organisations, to develop, as a matter of priority, a Carers Strategy and to report to the States with its recommendations no later than June 2018."*

This document summarises the consultation feedback that carers provided during the consultation phase of the project. An online survey was issued in January 2018 which sought feedback from carers on the services and support that are available and sought carers' views about priorities for the future that should be addressed in the Carers Action Plan. In total 289 responses were received to the survey.

In addition a number of discussion groups were held during 2018 with charitable organisations who work with or represent carers and a dedicated engagement event was held in order to elicit carers' views. This document summarises input from both the survey and the meetings and is intended to reflect the views that carers expressed.

The evidence presented here was used to inform the development of the actions in the Carers Action Plan. The Carers Action Plan sets out the Actions that the States of Guernsey and the charitable sector have committed to take to provide services and support to informal carers in the Bailiwick of Guernsey.

The Carers Action Plan can be downloaded at the following link:
https://gov.gg/carersactionplan

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Executive Summary

Carers are a diverse group with a wide range of experiences, and the views represented here reflect that. Some respondents felt satisfied with the support that they currently received, and they spoke positively about their caring role. Others felt like they were unsupported and felt that their caring role was assumed by professionals, and was not something that they felt they had a great deal of choice around.

Whilst responses were diverse, there were also some clear themes emerging. Whilst this was not a representative survey, we can see that taking on a caring role seemed to have had a significant effect on many carers. 70% of respondents felt that caring had negatively impacted their work/study/income.[1] 62% of respondents felt that caring had negatively affected their physical wellbeing, 64% felt it had negatively affected their mental wellbeing. This reflects a national picture: Carers UK in their 2018 "State of Caring" report in the UK 61% of carers said they had suffered physical ill health as a result of caring and 72% of carers said that they had suffered mental ill health as a result of caring[2].

In terms of social context for these responses, we know that 62% of respondents disagreed that people in the community were aware of carers' needs. The majority of respondents (55%) also felt that carers did not have a voice in the islands at present.

The four areas that respondents ranked as highest priorities for action were:

- **High quality health and social care services**: good communication, joined up working, availability of services, planning for the future, out of hours support, continuity of staff and the ability to develop a relationship with staff members were all desired.

- **Information and advice**: more than half (56%) of respondents indicated that they did not know where to go for information and advice about support for carers at present. A proactive approach to giving information was desired as well as a clear point of contact who carers could go to for advice.

- **Financial support and work arrangements**: 56% of respondents under the age of 54 disagreed or strongly disagreed that they had the financial support they needed to continue supporting their friend/family member, with some in the 55-64 age group indicating that they had retired early to care. Good access to formal care services,

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[1] Please note that throughout this report references to percentages of respondents refer to the percentage of respondents who answered the question and not respondents to the survey as a whole. Respondents who did not answer the question or selected 'not-applicable' are disregarded from the percentage figures quoted.
[2] Carers UK (2018) "State of Caring" p.6. Available at: https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2018-2 [accessed 11th December 2018].

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flexible working, and personal budgets were suggested as ways to increase the compatibility of work and care.

- **Time-off/respite**: The majority of respondents felt that they did not have enough time off (55%), did not have a choice about when they could have time off (50%) and did not have good information about short-break services (59%). There was a wide range of reasons for not accessing time-off and why different carers had difficulty accessing time-off, including (but by no means limited to) lack of availability and lack of suitability of the options that were available.

The Carers Action Plan (available at https://gov.gg/carersactionplan) offers the first steps to begin addressing some of these concerns.

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Introduction

As part of the Supported Living and Ageing Well Strategy the States of Guernsey committed to develop a Carers' Strategy which brought together action across different government service areas and the third sector to improve the services and support offered to informal and unpaid carers in the Bailiwick of Guernsey.

At the beginning of 2018 work began on developing a Carers Action Plan. In order to inform the priorities within the Carers Action Plan input was sought from people who have a role supporting or caring for family members or friends on an unpaid basis and their views were sought on current services and support and priorities for the future. This analysis has helped to inform the actions that are included in the Carers Action Plan. The Action Plan itself can be downloaded at the following link: https://gov.gg/carersactionplan
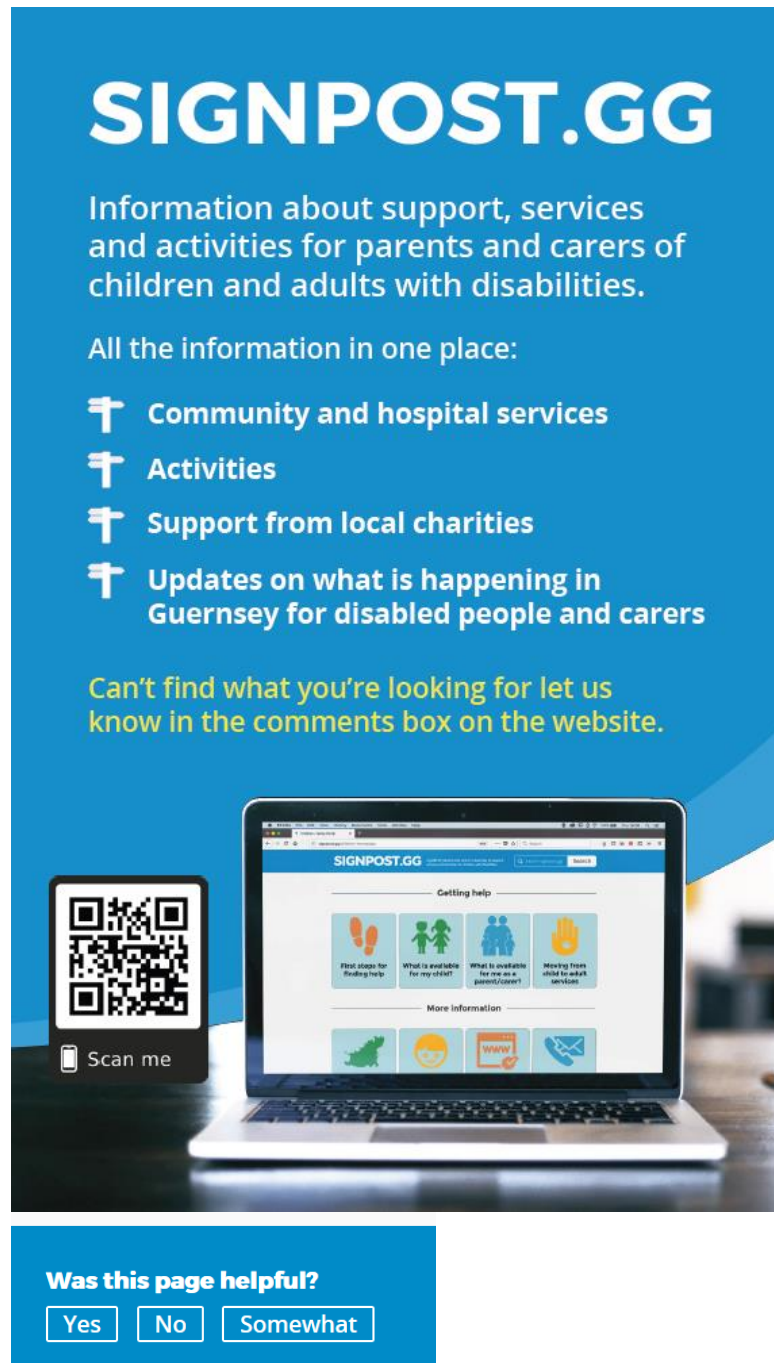
Who's views were gathered and how?

The primary aim was to seek views of current carers themselves. However, we have also invited the views of people who used to be carers, and people who work with carers (in community organisations or professional roles) to comment.

A survey was launched in January 2018 online (with paper copies available on request) which was circulated to organisations that worked with carers and disabled people. A letter about the survey was sent to all Carer's Allowance claimants and parents of pupils of Le Murier and Le Rondin. Front-line Health & Social Care staff also helped to distribute the survey. A media release was issued about the survey in February 2018. The survey closed on 7th March 2018. In total 289 responses were received although not all respondents answered all questions.

Discussion sessions with existing carers groups were undertaken. These included the Parent Carer Council; Wigwam; Carers Coming Together and the Guernsey Alzheimer's Association Carers' Support Group.

An evening engagement event was also held at Les Cotils in February 2018 which was advertised with the survey by email to key third sector organisations who work with disabled people and carers, key staff contacts and to Carer's Allowance claimants and parents of pupils of Le Murier and Le Rondin. This document summarises input from both the meetings and the survey and is intended to reflect the views that carers expressed. The write up follows the structure of the survey.

Sources of information and help

SIGNPOST.GG

Information about support, services and activities for parents and carers of children and adults with disabilities.

All the information in one place:

- Community and hospital services
- Activities
- Support from local charities
- Updates on what is happening in Guernsey for disabled people and carers

Can't find what you're looking for let us know in the comments box on the website.

Scan me

Was this page helpful?
Yes | No | Somewhat

As part of the Disability & Inclusion Strategy the States of Guernsey have developed a website www.signpost.gg which has information that might be useful for carers.

If the site does not have the information that you need please use the feedback box at the bottom of the page to let us know, this helps us to improve the site.

For advice on services and respite you can call Adult Community Services on 01481 725241 ext. 3313; or Disability Services for adults with a Learning Disability 01481 230000.
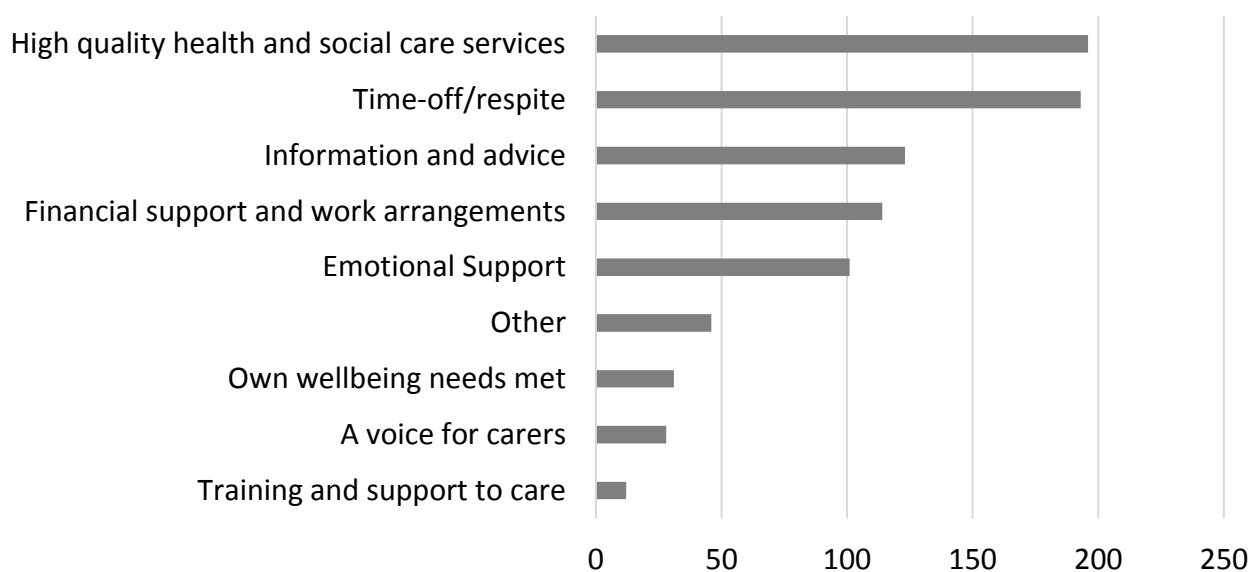
Enquiries about Severe Disability Benefit and Carer's Allowance can be made by calling the Benefits team at Social Security (01481 732596). https://gov.gg/carebenefits

Citizen's Advice Guernsey (01481 242266) and Health Connections (01481 707470) can also provide information.

Priorities

"What are the top three things that matter to you as a carer in terms of support for carers?"

(148 responses)

High quality health and social care services

Time-off/respite

Information and advice

Financial support and work arrangements

Emotional Support

Other

Own wellbeing needs met

A voice for carers

Training and support to care

0   50   100   150   200   250

(Weighted score according to ranking)

For this question respondents were given three ranked free-text boxes in order to write what was of concern to them in terms of support to carers. To analyse this the answers

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were categorised into nine categories based on the Kings Fund "Carers Compass."[3] Each answer was then weighted depending on whether it was listed first, second or third.

Priorities

Overall, after analysing the responses from the survey, 94 respondents referred to high quality health and social care services (36 ranking this first) closely followed by 90 referring to time off/respite (35 ranking this first). This corresponds with feedback that was received at the Carers Engagement Event, in which attendees described a desire to have access to good services and respite which was both relevant to the person accessing it, and which had enough availability and flexibility to meet needs. Information and advice was ranked in the top three by 62 respondents (with 19 placing it as their number one priority).

What was described

High quality health and social care services

Within this category ideas such as easily accessible and available services were mentioned, as well as having daily assistance with personal care and practical support at home from health and social care professionals. Others expressed the importance of knowing that the person that they care for is provided with the best life possible. It was hoped services would be reliable, consistent, safe, and proactive. Continuity of staff and having a named contact to talk to was desired. Good access to equipment (such as hoists, wheelchairs, and other required equipment and independence aids) was raised by a number of people. The importance of support in a crisis was mentioned as well as knowing that there would be good services to support the person being cared for in future if the carer was no longer able to provide care. The importance of good communication between services was also highlighted.

Time off/respite

In most cases respondents straightforwardly stated that they wanted time off. A few were more explicit saying that they wanted a short-break service (sitting service) to allow them to go shopping or attend an appointment; or that they wanted longer reliable breaks or holidays. Some mentioned non-traditional forms of respite moving away from bed-based care.

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[3] The "Carers Compass" is included in the Carers Action Plan which can be found at https://gov.gg/carersactionplan

Information and advice

Most respondents mentioned the general matter of information and communication to support the role of carers. However, some comments further reaffirmed ideas about having one point of contact for information and making access to information easier. Others wanted to better understand who to contact depending on what they needed. A phone line available 24/7 was mentioned as well as the importance of GPs as information providers.

Financial support and work arrangements

For the most part respondents simply stated that they wanted financial support. A couple mentioned flexible working, the high cost of medical care, and a desire for non-means tested benefits.

Emotional support

In this category there were a number of people who said that they wanted to be listened to or have someone to talk to. Some said that they did not want to feel alone. Peer support and counselling were mentioned. Being understood and having contact with sympathetic professionals was also important.

Other

The other category added two clear ideas. Firstly, there was a shared idea of providing transport or specialist transport for both carers and those cared for such as transport for appointments to the doctor. Secondly, respondents also highlighted the importance of family in terms of support for carers.

Own wellbeing needs met

Keeping life as normal as possible, keeping on top of the housework and maintaining the carer's own health were all mentioned here.

A voice for carers

The importance of a community of carers, a forum to discuss issues important to carers and recognition were mentioned.

Training and support

A few respondents mentioned a desire for training and support to care from third sector groups.
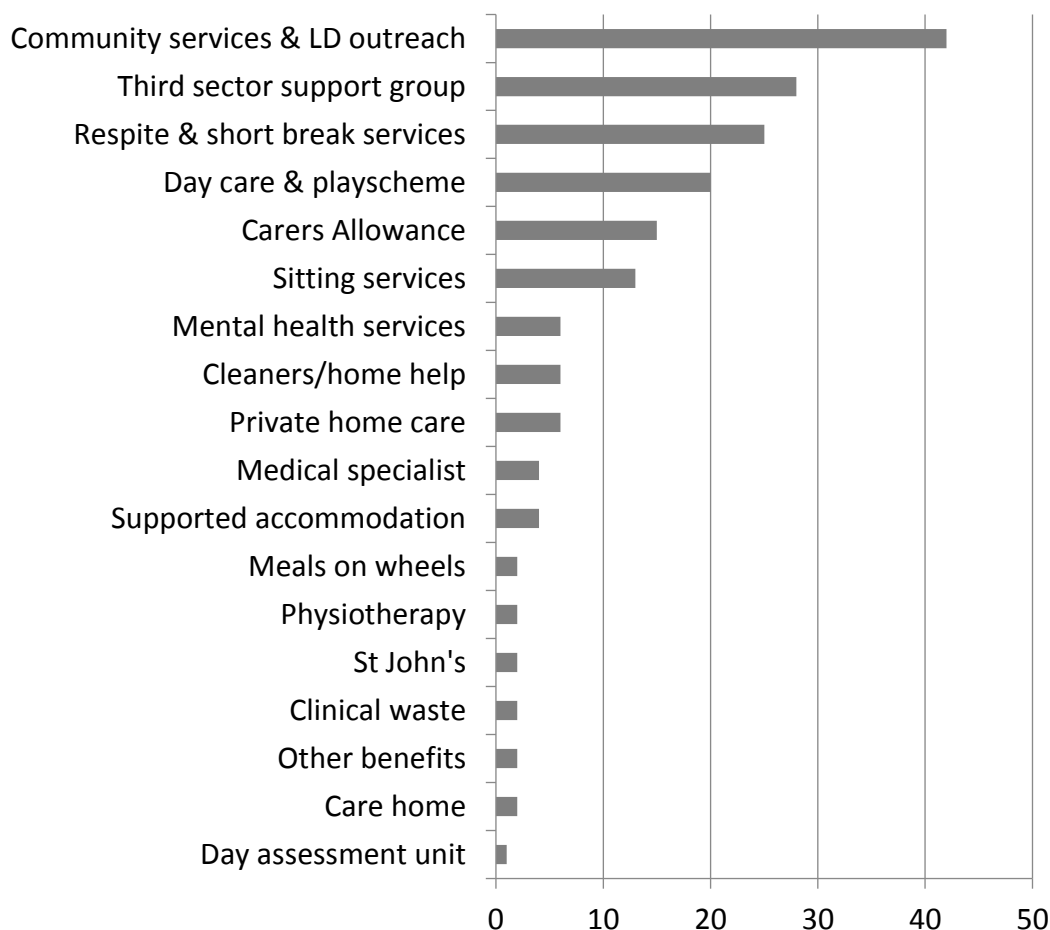
Differences by age

When broken down by age we can see that there are some significant differences with working age respondents giving more weight to the need for time off and financial support/work arrangements (which was lowest priority for older respondents), whereas respondents past State Pension Age giving a higher priority to high quality services and information and advice.

Priority ranking of topics by age group		
	18-64	**65+**
Time-off/respite	1st	3rd
Financial support and work arrangements	2nd	9th
Information and advice	3rd	2nd
High quality health and social care services	4th	1st
Emotional Support	5th	4th
Training and support to care	6th	5th
A voice for carers	7th	8th
Own wellbeing needs met	8th	7th
Other	9th	6th

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"What services and support do you currently access as a carer? What works well, what doesn't?"

(150 responses)

The following services were explicitly mentioned:[4]

Service	Count
Community services & LD outreach	42
Third sector support group	28
Respite & short break services	25
Day care & playscheme	20
Carers Allowance	15
Sitting services	13
Mental health services	6
Cleaners/home help	6
Private home care	6
Medical specialist	4
Supported accommodation	4
Meals on wheels	2
Physiotherapy	2
St John's	2
Clinical waste	2
Other benefits	2
Care home	2
Day assessment unit	1

Particularly positive comments:

At the Carers Engagement Event held in February 2018 some participants fed back that the support from services was largely positive once you were in the service, but that accessing the services you needed could be challenging.

A couple of people commented that they valued the community services support that they received. There were some positive comments about the front-line staff that people interacted with. There was positive feedback about some of the third sector support groups

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[4] This does not necessarily reflect the number of service users in each service, only what was important to survey respondents to include.

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that people engaged with. A couple of people mentioned the palliative care staff as particularly important. Some people commented that they valued the Willows Day Centre service and Jubilee House. During focus group sessions we also received positive feedback on the Rapid Response Team which provides short-term crisis support to adults in the community.

Concerns raised:

Some concerns were raised about out of hours support; about access to and joined up working within mental health support; about access to transport; about the availability of services and respite at the desired times; about the timing of community care visits. Some concern was raised about the short-break service (sitting service) not providing what was desired. There was mention of concern about some of the buildings feeling 'institutionalised'.

There was also concern about a gap in services between day care and employment services to provide meaningful activity for disabled adults. Access to childcare for disabled children was also a concern. Some people had felt that there was difficulty accessing Mental Health Services. Access to travel grants for people accompanying people traveling to medical appointments in Southampton was also of concern to some. Some felt that there was demand for further supported or retirement housing on the island which facilitates people to live independently. Particular concerns were raised at the Carers Engagement event about GPs not signposting people to available support services.

Other comments received:

Information about services - It was clear from several of the responses that they felt that they either did not know what services or benefits they were entitled to, or that finding this out had been a struggle. There was demand for more proactive delivery of information to people needing support. Not only on diagnosis, but also when people were moving from one service to another.

Sense of abandonment – some carers felt that there was not sufficient follow up contact from services after someone had been diagnosed. They wanted regular contact to check in with how things were going.

Rights based culture – some carers felt that services were difficult to access and that they were treated as if they should be grateful for what they could get rather than being treated as service users who were entitled to support.

Continuity of services – Several people commented that continuity of support was important – both in terms of when and where support was received and in terms of the staff delivering it. Relationships with care staff were key. This was particularly important for service users who experienced confusion or anxiety.

Who is not accessing services

Fourteen survey respondents suggested that they did not access any services and four that they only accessed Carer's Allowance. Seven of these cared 35-70 hours a week and six more than 70 hours a week. Within these, some were Alderney residents, several were carers of older people; and several were carers of younger people with autism or communication impairments.

"What top three things would you like to see included in a Carers Action Plan?"

(136 responses)

(Weighted score according to ranking)
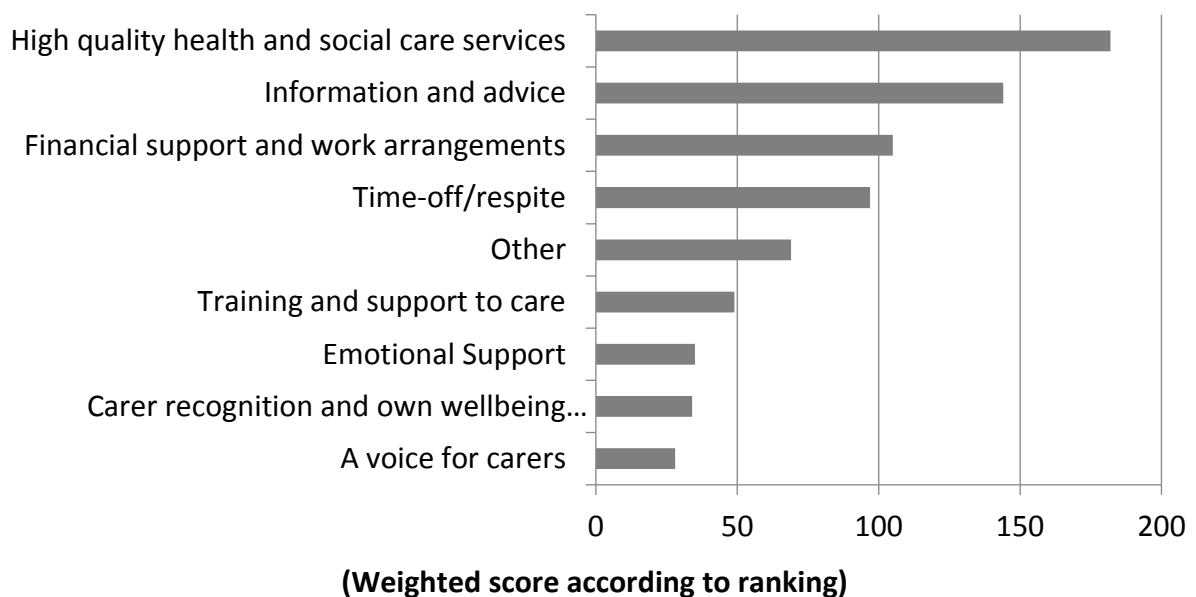
In a similar way to a previous question on support for carers, respondents to this question were also given three ranked free-text boxes to describe what three things they wanted to see in the Carers Action Plan. The answers to this were categorised into nine categories based on the Kings Fund "Carers Compass". Each answer was then weighted dependent on whether it was ranked first, second or third.

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Priorities

Interestingly, the priorities were ordered slightly differently for this question, though the top four responses remained the same. The top three responses were actions around high quality health and social care services (78 responses, 41 ranking this first); information and advice (65 responses, 32 ranking this first) and financial support and work arrangements (54 responses, 32 ranking this first).

Suggested actions

High quality health and social care services

Those who chose high quality services mentioned continuity of services, having more professional carers to help people stay in their own homes and providing social activities and drop in services. An annual or routine assessment of needs and a plan for services was important. Some requested cleaning services at home. More specialist nurses were suggested. Having options about what services to access was felt to be important. Having a legally binding level of service provision was also mentioned. A desire for new services providing emergency support for Mental Health services at night time outside A&E and providing a sheltered workshop for disabled adults were suggested. Innovative cross-sector working and good communication between services was desired.

Information and advice

Respondents who chose information and advice commented on having a helpline to answer concerns or for emergencies, and also a list/booklet of what help is available from who and where. More information on legal rights was felt to be needed. Having somewhere to call out of hours for advice was important to some.

Financial support and work arrangements

In the third rank of priority, respondents mentioned that within the Action Plan they would like to see financial support regarding medical costs, carers allowance to be higher/easier to access and more affordable housing for people needing care. There was also mention of statutory leave for carers and flexible scheduling to allow carers to balance responsibilities.

Time-off/respite

Increased availability of respite was desired, with choice about when to have time off. Respite provided at home (rather than in a care home) was suggested. Emergency respite in crisis was mentioned by a few.

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Other

The other category mentioned ideas such as transport issues, including issues with bus services and unresponsive taxis. Also mentioned was the need for a long term strategy looking towards the future and being aware of the ageing population. Some respondents did not feel comfortable with the term 'carer'. Another respondent felt there should be gender specific support for male carers. Additionally, respondents commented on including in the Plan investment in employment opportunities for people with learning disabilities and a need for additional support from external agencies in Alderney.

Training and support to care

A tailored support programme for carers and training options for both carers and others in the community about carer's issues, hidden disabilities and mental health issues were all mentioned. Support for carers to assist the people that they support to live as independently as possible was suggested. Training on using a mobile phone, computer or tablet were mentioned.

Emotional support

Better access to peer support groups was suggested as well as access to psychological, mental health and counselling services. Online support groups were suggested. A service where individuals volunteer to phone lonely people free of charge was mentioned.

Carer recognition and own wellbeing

Carer's assessments were mentioned. Better visibility and understanding of carers was considered desirable. More activities and support groups were thought to be a possibility; one suggestion was to have these organized on a parish basis. It was also noted that it should be a choice for carers what level of care they provided. Challenging carers 'I can cope' mentality was considered important. Regular support groups and social activities were important to some.

A voice for carers

A voice for carers, acknowledgement of their importance, easier routes to making contact with other carers and legal rights to protect carers from discrimination were mentioned[5].

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[5] It should be noted that it is intended that carers will be covered by the discrimination legislation which the Committee *for* Employment & Social Security are developing.

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Broken down by age

Similarly to the previous question, we can see that working age respondents gave significantly more weight to suggestions relating to financial support or work arrangements. Respondents past State Pension Age gave a higher priority to training provision. Otherwise there was broad agreement.

Priority ranking of topics by age group		
	18-64	**65+**
High quality health and social care services	1st	1st
Information and advice	2nd	2nd
Financial support and work arrangements	3rd	8th
Time-off/respite	4th	3rd
Other	5th	4th/5th
Emotional Support	6th	6th
A voice for carers	7th/8th	7th
Training and support to care	7th/8th	4th/5th
Own wellbeing needs met	9th	9th

Information, advice and training

"What are your preferred ways of accessing information? (select all that apply)"
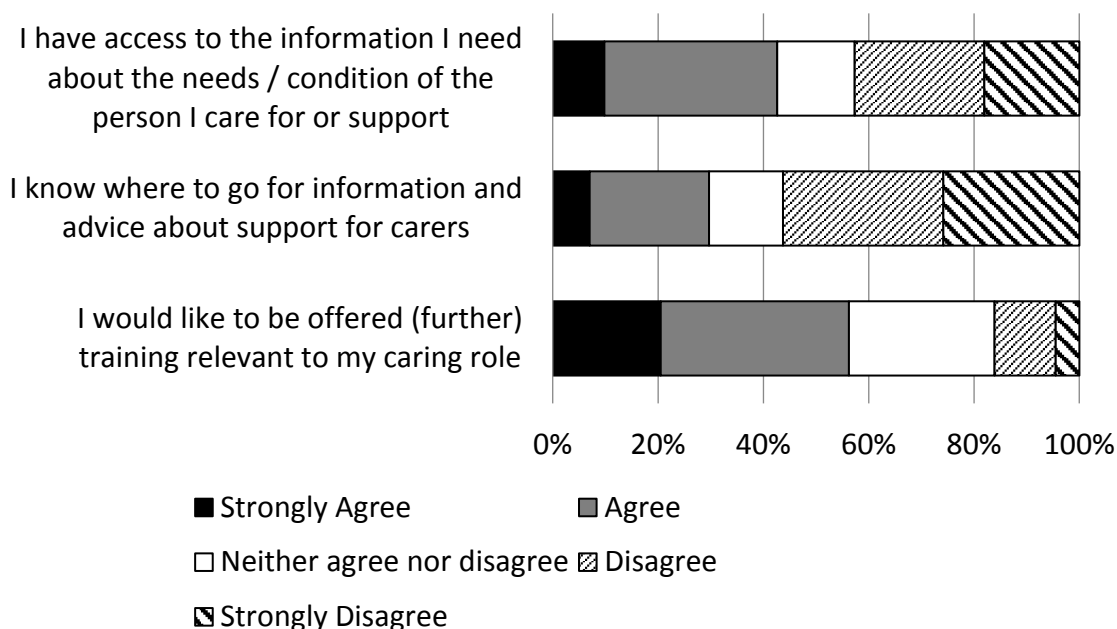
(145 responses)
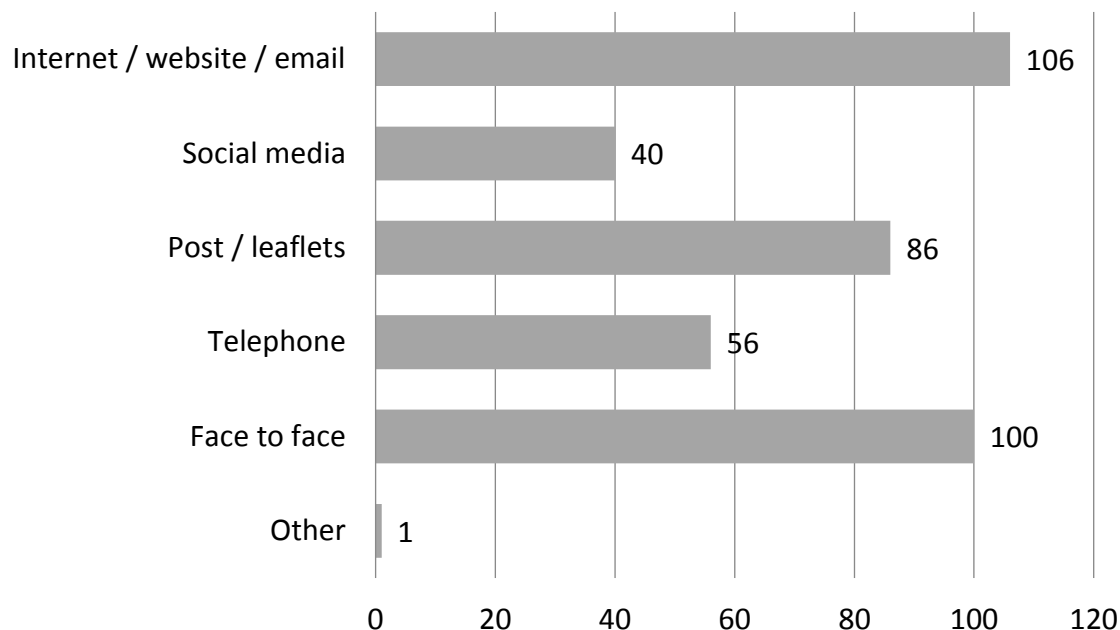
A range of formats for receiving information by carers was clearly desired with online, face to face and leaflets/information provided through the post all desired. This suggests that those services and charities that work with carers will need to provide any information aimed at carers in a range of formats.

While paper responses to the survey were received, as the vast majority of responses were web based one might assume that respondents comfortable with using the internet would be slightly over-represented compared to the total population of carers on the island.

"How do you feel about the information, advice and training you receive at the moment?"

(138 responses)

I have access to the information I need about the needs / condition of the person I care for or support

I know where to go for information and advice about support for carers

I would like to be offered (further) training relevant to my caring role

0%   20%   40%   60%   80%   100%

■ Strongly Agree   ■ Agree

□ Neither agree nor disagree ▨ Disagree

◧ Strongly Disagree

(The responses of people who selected "not applicable" were not included in graph or figures below)

There was an even divide amongst respondents who felt they had access to the information that they need about the condition of the person they care for (43%) and those who did not (also 43%). Respondents who were supporting a person with a Learning Disability were somewhat more likely to say that they had the information that they needed about the condition of the person they support (58% agreeing or strongly agreeing) with people who were supporting someone with a mental health condition or dementia less likely to say they had the information they needed (36% and 35% agreeing or strongly agreeing respectively).

More than half (56%) said that they did not know where to go for information and advice about support for carers. This was common across all groups. However, people who support family members or friends with a mental health condition were slightly more likely to say that they did not know where to go for information or advice about support for carers (61% disagreeing or strongly disagreeing).

More than half (56%) would like further training relevant to their caring role. The lowest demand for further training was from people who support someone with physical impairments (where 49% agreed or strongly agreed that they would like to be offered

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further training), the highest demand was from people who support someone with a mental health condition (where 71% agreed or strongly agreed that they would like to be offered further training).

"What training and information would you find most helpful and when and how would you like to receive it?"

The majority of respondents to this question felt that further training would be helpful.

Peer-to-peer
A number of people highlighted the value of peer-to-peer learning opportunities between carers, both in support groups or in online forums.

Training topics
Respondents and participants in discussion sessions and the event identified that training would be valued in the following topic areas:
- Condition specific information (about the progression of the condition of the person being supported (where relevant), symptoms, medication)
- How carers can facilitate supporting people to find ways to be independent and maintain their own health
- Carers rights and entitlements and understanding service provision and benefits
- Training about how to cope with end of life where caring for someone terminally ill
- Coping mechanisms for difficult situations, managing relationships, stress and anger management
- Restraining and making yourself safe (where appropriate, i.e. if person was confused and could be aggressive)
- Communication methods such as sign language and PECS (where relevant)
- Mental/emotional wellbeing and relaxation skills; as well as skills to cope with loss
- Financial advice
- Legal advice
- First aid
- Manual handling

Others suggested that the content of the training should be similar to that provided to staff who were starting to work in a care home. It was also noted that it would be helpful if the training covered the most up to date advice and techniques available for carers.

How to deliver training and practicalities

Whilst on the whole small group courses provided on-island seemed to be described more frequently as a solution, some people expressed a preference for online training. Some requested one-to-one training in their own home. Others identified off-island courses which they felt it would be helpful to attend on the specifics of a condition. Specialist nurses were identified as a valuable resource for information about particular conditions.

Some carers found it easier to attend courses during the day, others in the evening. Some carers would not be able to leave the person they support to attend a course unless replacement care was provided. Funding for training was important. One respondent reported having spent significant amounts of money on obtaining training for themselves in the absence of any provision. Whatever training was provided there was a desire for clear information about it.

At the carers event it was suggested that a "personal action plan" should be arranged for carers when they become a carer, outlining the training sessions they should undertake.

Information

"The biggest frustration has been the lack of information. When my husband was first diagnosed we walked out of the surgery and just felt abandoned to his fate."

The following points were made about information. Respondents wanted:

- to be proactively given information at diagnosis and transition points.

- to have a phone number to call in minor emergencies for advice when you aren't sure what to do (this was wanted 24/7).

- to have information provided through a range of mediums:

  o a comprehensive website explaining service provision (an information app was also suggested)

  o a phone number to call

  o leaflets (with links to the website)

- a single point of contact who you could get to know to ask for advice or a named contact to call within services rather than calling a department or service area.

- a one-stop shop where there were multiple services on one site as a place to go for help.

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- GPs to be recognised as an important point of contact and respondents wanted GPs to provide information to carers.

- to have somewhere you could seek information confidentially without the person you were supporting over-hearing what you were saying.

- more proactive advertising of signpost.gg: some carers were unaware of it at present.

- transparent information on the ethos of services, how they were run, eligibility criteria, how they were allocated, who made decisions, and how to complain.

Topics where information was particularly requested included benefit entitlement, understanding what services were available, and legal advice. Guardianship and the potential to use legal aid to fund access to guardianship was particularly mentioned. There was a need for parents to be made aware of this before their children reached the age of 18.

Other points made

High staff turnover meant that professionals who were new to the island did not always know where to signpost people in terms of the services and support that is available in the Bailiwick of Guernsey.

In some cases it was felt that someone who has the experience of being a carer will be better able to understand what information a person will require at any point in the caring journey than a professional without this experience. It was suggested that current or recent carers could be involved in providing information and support.

Some felt that the information on signpost.gg was currently incomplete and further information needed to be added.

Work and finances

"In addition to your caring role, which of the following applies to you? (select more than one if necessary)"
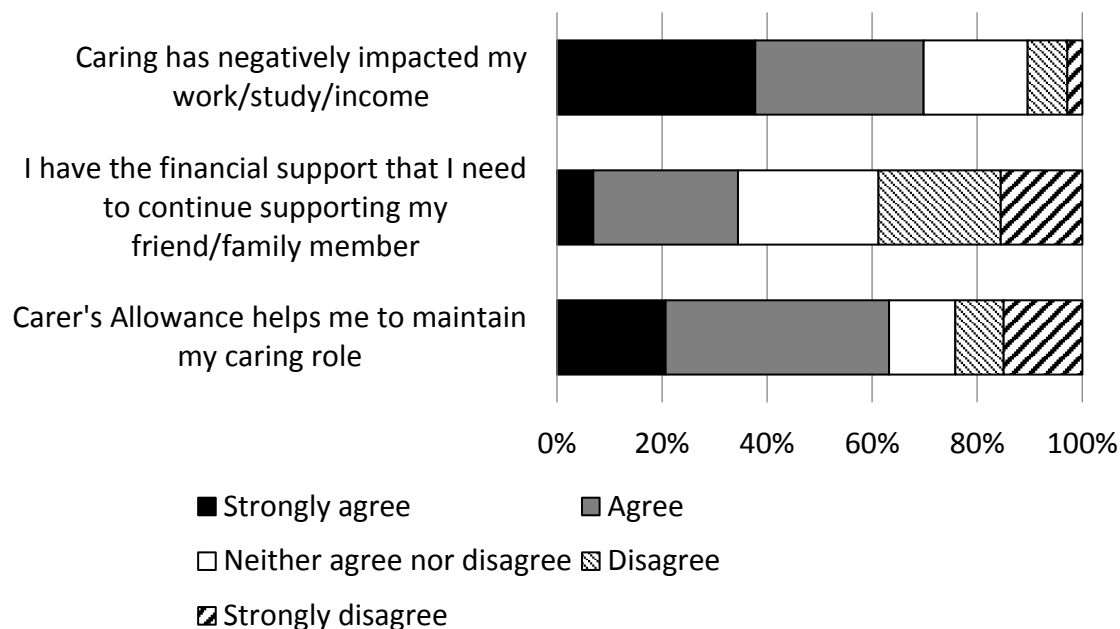
(137 responses)

In the 'Other' category some commented that they had to give up work to care. In the 55-64 age group in some cases this was described as early retirement to be a carer. A couple of people volunteered and a few were also foster carers.

"How do you feel about work/study and your financial situation?"

(132 responses)

Chart categories (top to bottom): Caring has negatively impacted my work/study/income; I have the financial support that I need to continue supporting my friend/family member; Carer's Allowance helps me to maintain my caring role. X-axis: 0% to 100%.

Legend: ■ Strongly agree ▨ Agree □ Neither agree nor disagree ▨ Disagree ▨ Strongly disagree

(The responses of people who selected "not applicable" were not included in graph or figures below)

70% of respondents felt that caring had negatively impacted their work, study or income.

Whilst 34% of respondents felt that they had the financial support that they needed to continue in their caring role, 39% felt that they did not. There were significant differences between age groups: under 54s were twice as likely as over 65s to disagree or strongly disagree – i.e. saying that they did not have the financial support that they needed to continue supporting their friend/family member (56% of under 54s disagreed or strongly disagreed compared to 32% of 55-65 year olds and 23% of over 65s).

63% of those who responded to this question felt that Carer's Allowance contributed to their maintaining their caring role.

"Would you like to say more about what support would help you balance your work and care responsibilities?"

Caring as work

Some respondents felt that there was a need for recognition of caring as work and that financial support and respite provision should reflect this. Respondents highlighted that they wanted a full range of employment options to be available for the person they supported and themselves. Some respondents noted that they would like to work part time but were currently unable to. Some respondents mentioned having given up work and retired early to care.

Flexible working

Some respondents to this question outlined how necessary the support of employers was to carers including the importance of allowing flexible work to enable carers to balance their work and caring responsibilities. Others noted that they had changed their working patterns or moved to a job where they could undertake shift work to fit around their caring responsibilities. The desire for a legal right to request flexible working was mentioned.[6]

Good service provision

Provision of community services and day centres were vital in providing meaningful daily activity for those being supported so that the carer was free to work during the daytime. Community services support at the right times of day was needed. It was suggested that having a social worker allocated on diagnosis could help to get in place the support needed.

Some parents of adults with disabilities noted that they felt they had had to give up work when their son or daughter left school as they did not have access to an equivalent adult service or work opportunity which provided a reliable time at which the carer could be available to work.

Childcare and day care in the school holidays was a problem for some working parents of disabled children.

A number of people mentioned the potential of personal budgets to allow people to purchase support at the times needed so that they could go to work.

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[6] The States of Deliberation agreed to the principle of developing a legal right to request flexible working in February 2018 as part of *Longer Working Lives* Policy letter.

Carers Action Plan: Summary of Carers Views

Time off

Where carers needed to use their annual leave to provide cover to care they often did not have any time off to recuperate. Statutory carers leave was mentioned.

Financial issues

Other comments highlighted the struggle of staying in work but not qualifying for the carer's allowance which means that there was less time for caring or personal responsibilities.

Some respondents noted that they had significant issues with obtaining affordable accommodation, health care and transport when income was lost due to needing to give up work to care.

Access to relevant services

Transport was highlighted as important. Both access to transport and discount on taxis or off-island travel were desired. Transport for those attending appointments or services was suggested to free up more time for carers (who currently took responsibility for providing transport). Needing to provide transport to and from day services and appointments could significantly disrupt a carers ability to work.

It was also suggested that businesses should be providing useful services to make life easier, such as online food shopping.

Understanding employers and colleagues

Supportive and understanding employers and colleagues were important as well as general awareness where the whole community is engaged.

"Do you have any comments on the current system of Carer's Allowance?"

On the whole respondents seemed to be divided between those who were positive about the existing system and those who felt that the eligibility criteria for the Allowance should be broadened and the amount paid weekly should be increased.

Of the positive comments, individuals described that Carer's Allowance enabled them to provide care and support and they appreciated receiving it. The use of a weekly payment was valued.

Carers Action Plan: Summary of Carers Views

Of those who wanted to change the Allowance the following points were made:

Allowance was too low

The Allowance (in 2018: £84.06 per week) was considered not to be high enough. Arguments tended to focus on five points:

- That it was not comparable to (lost) earnings for 35 hours work

- That it was not comparable to the cost of replacement care

- That it was lower than Severe Disability Benefit, but it was not clear why this was the case.

- That it was not sufficient to cover the costs of living (doctor's bills and taxis being noted as particularly an issue)

- Needing to seek top up from Supplementary Benefit led to intrusive questions for means testing and could mean a work-requirement was imposed and some carers felt this was inappropriate.

Eligibility criteria

Several people felt that the bar for 'severely disabled' was too high[7] or excluded people who still needed support. Some respondents said they had had to give up work to support someone but had been told that that individual did not count as 'severely disabled'. Others were caring for more than one person simultaneously, none of whom qualified as 'severely disabled' which meant that they could not access Carer's Allowance. It was suggested that there should be different levels of claim possible for Severe Disability Benefit, reflecting the fact that the costs of supporting some people were significantly higher than the costs of supporting others.

Some felt that the Allowance should be proportionate to the number of hours support a person provided, and felt that 35 hours was too high a bar to receive support.

A few respondents felt that the income threshold was unfair (members of households with an income of more than £97,000 were not eligible for Carer's Allowance in 2018).

A comment was made that people who undertook caring under the age of 18 might also incur expenses and an allowance should also be made available to Young Carers.

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[7] In order to claim Carer's Allowance you must be supporting someone who is claiming Severe Disability Benefit.

Carers Action Plan: Summary of Carers Views

Not being able to combine Sickness Benefit and Carers Allowance could be problematic as it meant lost earnings.

There was a suggestion that you should be able to get more than one Carer's Allowance if you supported multiple people in receipt of Severe Disability Benefit.

It was also mentioned that when a person who was being supported went into a care home the carer felt that they continued to provide care and support by arranging doctor's appointments, visiting and paying for necessary items (such as incontinence pads). It was queried whether Carer's Allowance should stop when someone went into a care home.

Reluctance or difficulty claiming

Several respondents noted that they feel they only found out about Carer's Allowance by chance or through friends and were not made aware they were entitled to it. Several carers felt that the forms were too complex and that they needed assistance completing them.

Frequency of renewal of Carer's Allowance was felt to be too high (e.g. annually) and this was felt to be unnecessary and time consuming by some claimants. Some individuals expressed a reluctance to claim Carer's Allowance.

A few specific cases of poor communication with benefits staff were raised.

Other points

It was suggested that there could be better communication with Carer's Allowance claimants about wider carers issues and other forms of support available.

"If you are in receipt of Carer's Allowance, what does it enable you to do?"

Many respondents used Carer's Allowance to cover their general living costs or replacement for earnings, allowing them to reduce time at work. Some spent the Allowance on items for the person being supported. Replacement care, home help and gardening were also mentioned by several respondents.

It was noted that if you claimed Carer's Allowance your Social Security Contribution was paid towards your State Pension and other contributory benefits.

Number of people who mentioned this
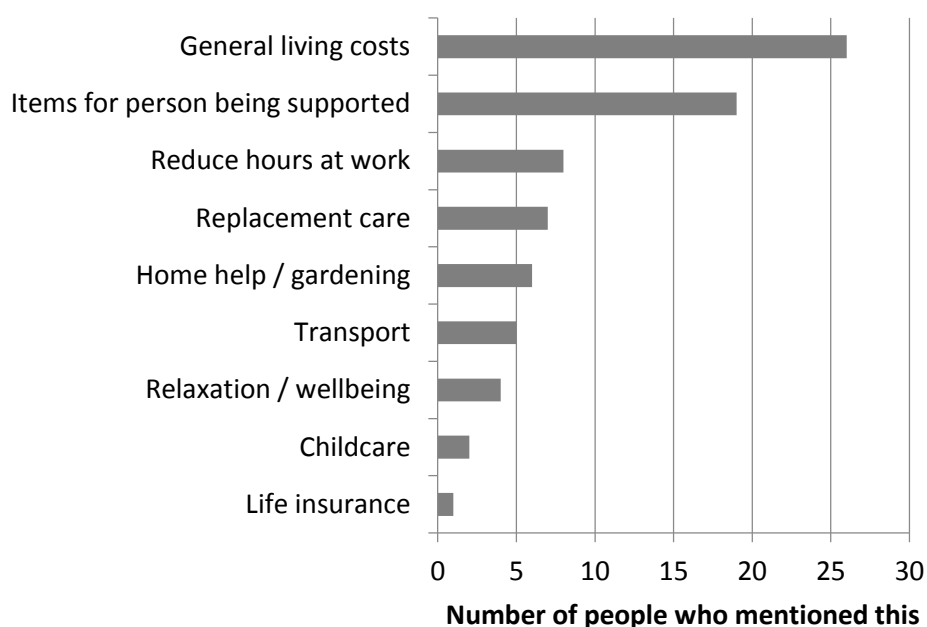
Under General living costs people mentioned rent, utility bills, food, petrol, health insurance, and clothing.
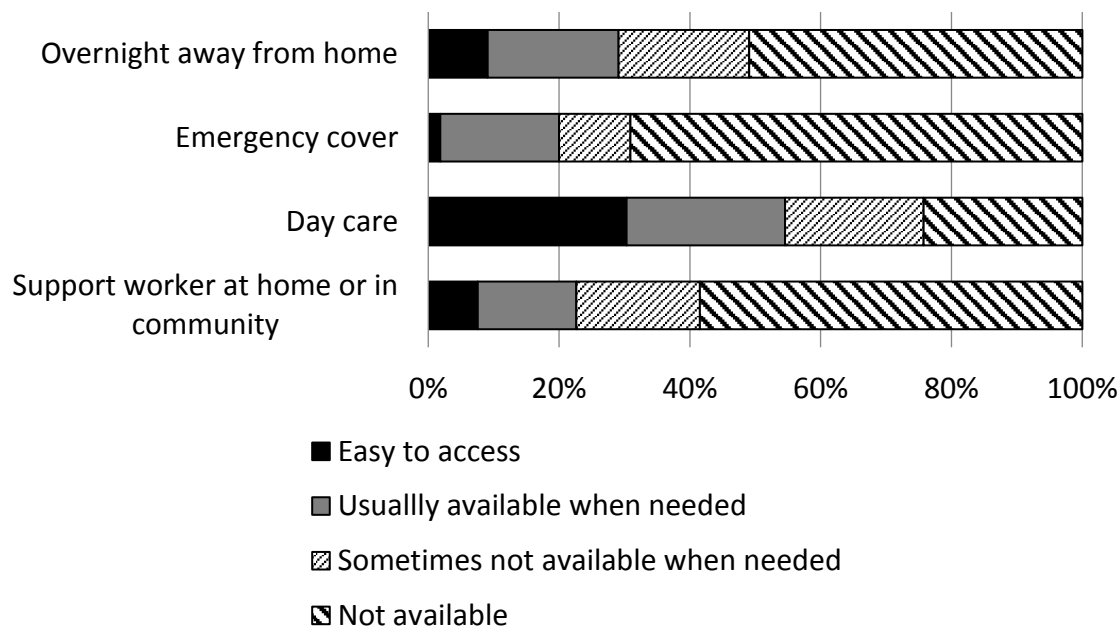
Items for the person being supported included equipment such as wheelchairs and independence aids, incontinence pads, additional laundry or heating costs associated with care needs, doctors bills, special dietary foods, activities and hobbies for the individual, and occasional treats. Transport costs were largely relating to the need for taxis.

Replacement care was sometimes to support people to go shopping or undertake activities of personal interest, or to enable them to work part time.

Carers Action Plan: Summary of Carers Views

Time off and services

"To what extent have you found the following types of short-break service easy to access?"

(123 responses, 66 excluding 'not applicable')

Overnight away from home
Emergency cover
Day care
Support worker at home or in community

0%   20%   40%   60%   80%   100%

■ Easy to access
■ Usuallly available when needed
▨ Sometimes not available when needed
◩ Not available

There was some variation depending on who the carer was supporting. There were challenges and room for improvement in all groups; however, carers of under 18s, people with autism and people with mental health conditions scored lower in all categories. Carers of people with dementia scored higher in most categories.

Most of the comments on this question were from respondents who had either not been offered any support or were not aware of the options listed. There were some comments about availability and supply: one respondent commented that their respite was cancelled at the last minute; others that there were not enough beds available. One commented that the day care available was not suitable for the person that they cared for. Another that the process for booking through a social worker was difficult.

"If you do not use short-break/respite services at all, please tell us why? (tick all that apply)"
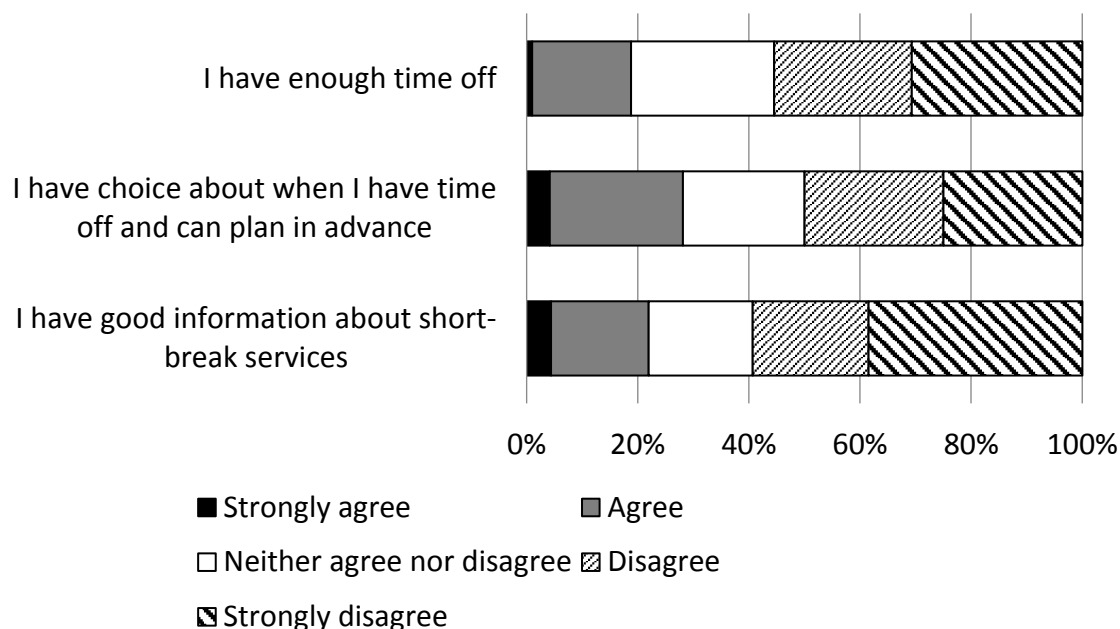
(109 responses)
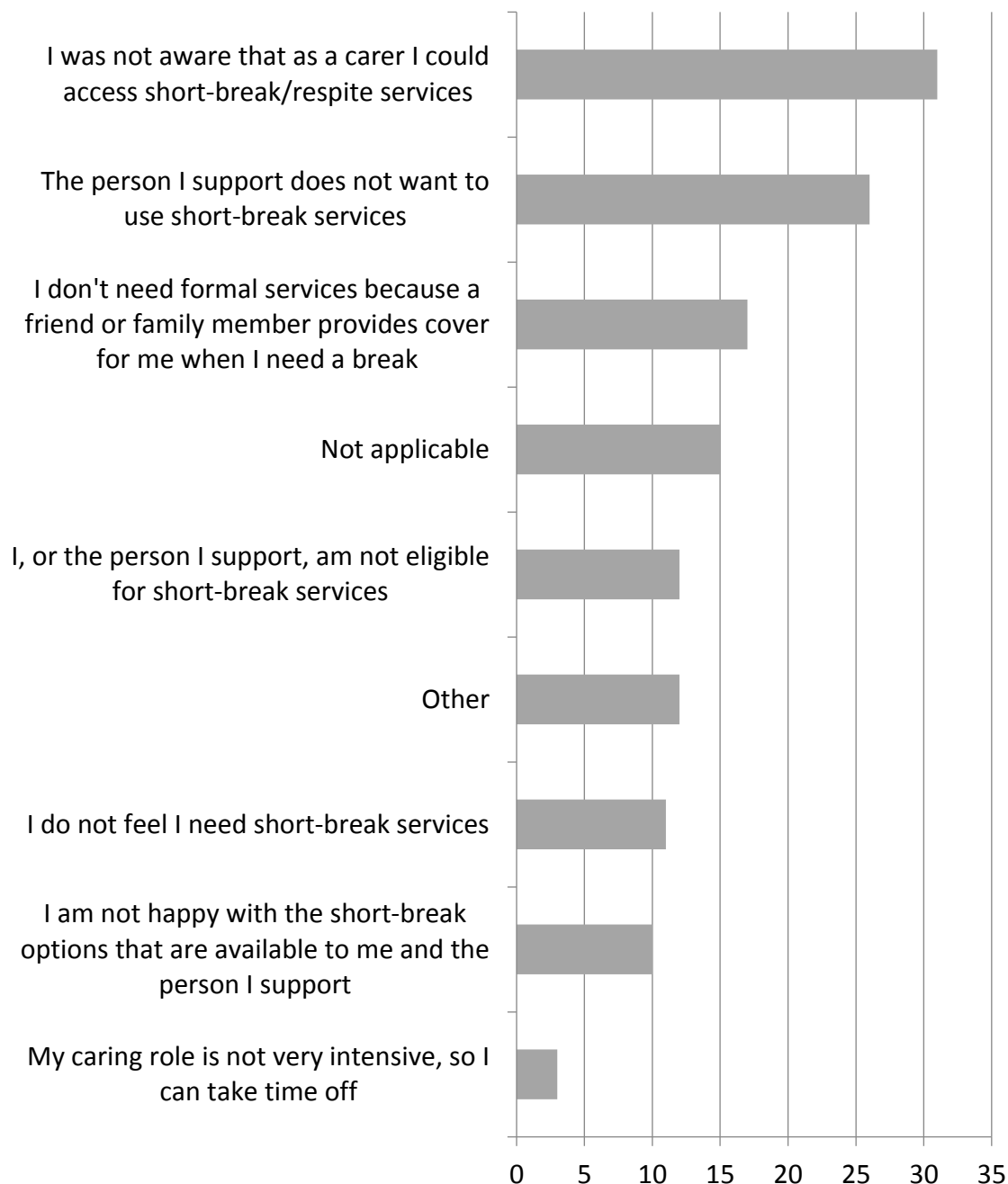
The most common reasons cited for not accessing respite services were that the respondent was unaware of what was available and that the person being supported did not want to use the services available.

Respondents who replied 'other' outlined the following additional reasons:
- Linguistic and cultural differences which would make the service provided inappropriate for the individual
- Not being eligible for Long-term Care Benefit
- Not meeting the eligibility criteria for the services available
- Not being able to access services when needed or at short notice
- That accessing respite services or obtaining a Needs Assessment Panel certificate was inaccessible to the carer without support to navigate the process which was not available.
- That the person didn't know who to contact to access support
- That couples who both had different support needs couldn't be provided for in the same respite service.
- That a relationship with the person providing support was important and necessary
- The required services were not available in Alderney
- That there was too much paperwork needed to access services

"Thinking about whether services meet your need for time off…"

(125 responses)

(Graphs and figures below exclude responses where "not applicable" was selected)

The majority of respondents felt that they did not have enough time off (55%), did not have choice about when they could have time off (50%) and did not have good information about short-break services (59%). Some respondents felt that they did have sufficient time off (19%), had choice about when to have time off (28%) and had good information (22%).

Whilst there was some variation depending on the condition of the person being supported, those who agreed or strongly agreed that they had enough time off was no higher than 20% in any group. Carers of people with dementia were more likely to say that they found it hard to plan time off in advance (66% disagreed that they had choice about when they could have time off); carers of people with Learning Disabilities seemed to be most likely to report that they had choice about when to have time off and could plan in advance but even within this group 42% disagreed or strongly disagreed that they had choice about when to have time off. People supporting someone with a learning disability or autism were more likely than those with a physical impairment, dementia or a mental health condition to say that they had good information about short-break services (38% and 29% agreeing or strongly agreeing respectively compared to 20% for people with physical impairments, 21% for people with a mental health condition and 13% for people with dementia). Even in the

group most likely to respond positively less than half of the group felt they had good information.

"Please tell us more about your experience of accessing time off. What would meet your needs?"

A key message was that respite needed to be relevant to a person's needs and with flexible options in how and when it was delivered.

Information and eligibility

Responses were often characterised by some uncertainty about what people were entitled to or whether they would be able to get support to do what they wanted or needed (whether this was to go on holiday for a couple of weeks, go out in the evening or go out to do the shopping). A number of people expressed desire for access to respite, or for more respite. Specific comments were made about the lack of information or not being aware respite was available or how to access it.

It was felt that there needed to be a transparent system for assessing who got respite and how much.

There were also some specific comments:

- In some cases people had felt they needed respite but been told that they were not eligible for respite or that they would be eligible but none of the services could provide suitable support for the particular needs of the person they cared for.

- There was some confusion about whether people living in extra-care developments were eligible for respite provision[8].

- Some people had lived in Guernsey long-term but were caring for parents that had come over from the UK and were not eligible for respite via Long-term Care Benefit.

- Some of the terminology was confusing (e.g. 'EMI'[9])

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[8] In certain circumstances people who are carers who are living in extra-care housing with a person whose care needs otherwise exceed the service provided by the scheme are eligible for respite, but this would not apply to all extra-care residents.
[9] Elderly Mentally Infirm, a rate of payment of Long-term Care Benefit to care homes primarily used for people with dementia.

Carers Action Plan: Summary of Carers Views

Quality and relevance of services

In a number of cases people highlighted that they couldn't access respite because the person that they supported did not like the services available or did not like being away from home or being away from their usual carer. In some cases this was related to specific conditions (e.g. dementia) where it was easier to provide support in an environment and with people whom the person was familiar than to access bed-based respite provision in a care home.

Respondents highlighted the need for respite and short break services (like other services) to be reliable, and for people to be able to trust the service and the staff.

There were some positive comments from people who had accessed services and found them useful. Particularly in relation to the Willows and Russell's day care services which were valued for their holistic approach and the fact that staff had a sense of humour and attendees had fun. Humour and fun were considered important parts of providing care.

Some of the provision (the Croft was mentioned in particular) was felt to feel 'institutionalised' (this was referring to building design more than staff). It was also suggested that the location of the Croft could be improved to reduce transport needs (i.e. if it was co-located with Le Rondin or Le Murier).

There was positive feedback about the Learning Disability service 'drop ins' and also the Children's Services family carer support system.

The need for meaningful activity for the supported individual in day care and other forms of respite was raised

Some carers had some concerns about some private care staff's English language skills and were not confident in their understanding of medication instructions.

Emergency respite

Some of the carers consulted had not managed to access last-minute support when they were unwell, even if they had asked for it. In some cases planned respite was also cancelled even where this was for the carer to attend hospital appointments themselves.

Booking and assessments

Some carers found that they had difficulties booking, or the booking process had been stressful and time-consuming. A central point of access for respite care was suggested.

In some cases, needing to fill in separate forms to access each service when the person you supported accessed multiple services was a frustration.

Carers Action Plan: Summary of Carers Views

There was also difficulty with pre-booking respite for planned breaks or holidays for some individuals. There were cases where booked respite had been cancelled at the last minute and also cases where a booking had been sought months in advance but was not confirmed until the day before the scheduled departure of the carer.

The care home assessment process through the Needs Assessment Panel could feel long, though there was positive feedback about the staff that supported people through the process.

Availability at times needed

There were some general comments about the lack of availability of respite when it is wanted or needed, or lack of flexibility in being able to meet a person's needs. When support was available – some people wanted support at particular times but found that there wasn't availability at these times (evening, daytime, weekends).

It was queried whether a pre-bookable bed (like the EMI respite bed currently available at Green Acres) could be available in a residential care home.

There were also some specific challenges for working carers with day centre hours being shorter than working hours and it was also noted that the provision of respite cover during the school holidays was limited and this could impact parents ability to work as they could not purchase a service from a private provider if the needs of their children were too complex for mainstream provision. A similar issue was faced for parents of pre-school children with additional support needs, as they may not be accepted by private nurseries but there was not an alternative provision.

Short-break service (sitting service)

There were a number of points made about the short-break service. There were several people who felt that the two hour period offered was not sufficient. There were also questions raised about the fact that sitters could not always provide the personal care or support that the carer themselves would provide which made carers reluctant to leave the person they supported with a sitter.

Amount needed

Some people felt that the amount of respite care that they were eligible for was too short. There were some concerns that the 28 day limit on respite care paid for from the Long-term Care Insurance Fund was too short in some cases and that provision should be based on

needs. There were some questions on how this was calculated and whether it should be 28 nights rather than 28 days. It was also noted that there was a need to plan for increased demand for respite care in future.

Factors impacting on need for respite provision

Family support and community organisations

Some people relied significantly on family support to step in to cover for them if they needed help. Others valued activities organized by third sector groups as providing desired activity for the person they cared for and time off for themselves.

Personal budgets

Personal budgets were mentioned as something which might help carers and disabled people to arrange care to suit their needs better, which might reduce the need for short-break services.

Transport

Transport was quite a significant issue for some people, who suggested that they would find it easier to go on holiday and leave the island or avoid taking time out of work if the person they supported could get transport to their appointments, events or services without depending on them.

Getting transport for a person to and from day care and getting transport for a carer who could not drive to go out when alternative care was available were also challenges for some.

"Thinking about health and social care services for the person you care for or support: what is your experience of interacting with services? What are your views on the quality of services provided?"

There were a few people who said that they had had no interaction with services and in some cases there were concerns that the cared for person was not willing to accept help from professionals.

A number of positive comments were received and the following services were particularly mentioned: Community Nursing and the Rapid Response team; medical staff; the Croft; Recovery & wellbeing; Disability Services; palliative care; the Willows day centre; hospital staff; occupational therapy and physiotherapy. It was also commented that the restructuring of Community Services so that they were not attached to GP practices was positive. However there was also some dissatisfaction with services in some areas.

Information, communication and planning

Some people described communication failures – particularly difficulty calling and speaking to the relevant person; waiting a long time for someone to call you back; a number of people said that they felt like it was a fight to access services. There was a desire for more information about services, their structure and ethos.

Good communication about what the person being supported had been doing whilst using a service could be key, particularly where the individual had a communication impairment as carers wanted to know what the person they support had done whilst in the care of a service and couldn't always speak to the person about their day.

Needing information about what would happen in the future was important to carers. They wanted to know that there would be sufficient service support to allow them to plan their lives (how many hours they would be able to work for coming years, for example). This was true for children moving into adult services, for people caring for people with deteriorating conditions, and for older carers who wanted to be sure that the person that they were supporting would be left in good circumstances if they died.

A clear plan of how a person's needs would be met was also desired and some felt was not clear at present. There were concerns about the transparency of decision making about an individual's care with some carers feeling that they were not included appropriately.

Carers Action Plan: Summary of Carers Views

Systemic issues

Lack of availability of services was an issue for some (with some comments that services were good when you got them but that they were turned down because of lack of availability).

There was felt to be a lack of out of hours support for some: as one respondent summarised *"how many carers long for 9.01 on a Monday morning to get help?"*

Some felt that there were gaps in services. In a few cases this made it feel much less like an individual had a choice about whether or not they would be a carer; they felt there were not appropriate alternative services available to support the person they cared for. In particular concerns were raised about lack of school-holiday provision; a gap between the services the Guernsey Employment Trust offered and the day centre services offered at St Martin's Community Centre; and a concern about a gap for children who parents feel are not best suited to special education or main stream school.

Lack of specialist support on the island was mentioned as something which affects the service that some people receive. In some cases there were concerns about waiting times to access services or receive specialist appointments.

The cost of accessing medical services and seeing a GP was felt to be a significant issue. Drop in centres for primary care were also suggested. Transport to use services or get to appointments was a challenge for some.

It was felt that community services may offer support at times when they have availability but there wouldn't necessarily be alternatives if this time was not suited to the individual. Some respondents believed that current community services were adversely affected by insufficient resources.

Some concerns were raised about the ability to find support in crisis situations. Participants were aware of situations where carers had had to call the police for support and this did not seem appropriate to them.

Relationships with staff

Continuity of staff was important. An annual review or regular contact with staff was suggested. Where applicable it was suggested that this should involve all the agencies involved in supporting a person. Whilst this was desired, it was not felt that this was put into practice effectively in all cases at present.

Staff availability or a sense that staff were under time-pressure and had priorities other than the people they were with was a concern to some. It was felt that there was a need for person-focused care and that in some cases staff were focused on paperwork and processes rather than people. *"…they don't have time to care. It always seems to be a process…"*

Carers Action Plan: Summary of Carers Views

It was felt some medical staff were not able to deal appropriately with people with dementia or learning disabilities.

It was felt that the way that staff framed questions to carers was important. It was suggested that asking a carer 'Can you cope?' would tend to lead the carer to be defensive, whereas telling a carer 'There is help available if you need it' might be more productive.

Some carers felt like getting the support that they needed depended on knowing the right people to call.

Consistency and lack of rights based culture

It was felt that the current system was not consistent or rights based and some carers felt like there was an expectation that they should be grateful for whatever support they received rather than having an entitlement to a certain standard of support. Due to lack of clear entitlement to a level of service, you could be unsure what to expect and this could increase anxiety and make it harder to plan.

"It has felt like a constant battle to get even the most basic needs met, I have been made to feel guilty and ungrateful for any support given"

Range of options

It was also noted that services needed to be appropriate to individual service users. Some service users did not enjoy group contexts (e.g. in day care) or particular activities – but still needed to be supported.

Crisis support

Some carers noted that they had been through very stressful times when they or the person they were caring for was unwell and it was difficult to access extra support at these times of crisis/emergency/ill health.

Carers highlighted that services should proactively identify situations which could escalate and provide support and intervention early on rather than allow situations which could lead to carers breaking down and being unable to continue in their role.

Changes in care and transitions

Lack of joined up working (between medical staff and care staff – especially at hospital discharge; between health and education; between mental and physical care services; between States and third sector support; transition between children and adult services; communication between different community service teams; the same information

Carers Action Plan: Summary of Carers Views

submitted to multiple services in assessments for different benefits or services and a general lack of signposting to other services). Whilst in some cases a Team Around the Child approach was being trialed to improve this, not all respondents were happy with how this was working at present.

There were also some concerns about the fact that when a change in care was needed (if a new form of care was needed or an increased amount of care) it was often assumed that the carer would provide this with no discussion about whether there were other options or what impact this would have on the carer's life.
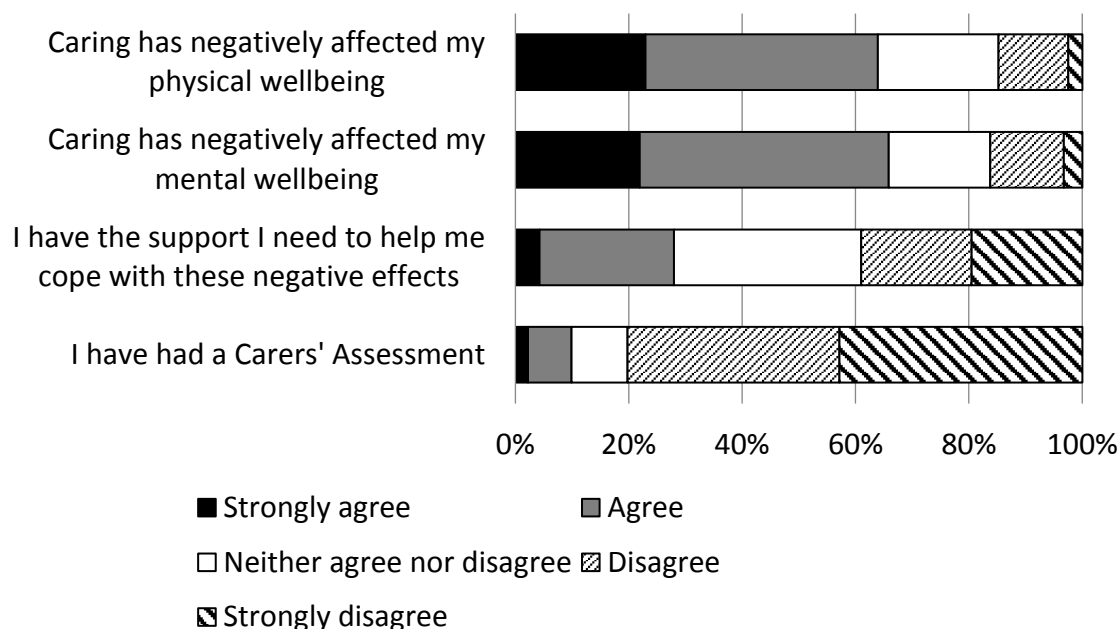
Complaints

Some carers felt that they were unaware of how to complain or who to complain to if they were not satisfied with the service. There were also concerns about raising complaints given the degree of dependence upon a good relationship with a service for support.

Wellbeing

"How do you feel about your own wellbeing?"

(131 responses)

Strongly agree
Agree
Neither agree nor disagree
Disagree
Strongly disagree

(Graphs and figures below exclude responses where "not applicable" was selected)

The majority of respondents felt that their physical wellbeing (62%) and/or mental wellbeing (64%) had been negatively affected. Some were receiving support which helped them to cope with these negative effects (26%). Note that if we compare these figures to those published by Carers UK in their 2018 "State of Caring" report in the UK 61% of carers said they had suffered physical ill health as a result of caring and 72% of carers said that they had suffered mental ill health as a result of caring[10].

Only 8% of respondents in the survey of carers in the Bailiwick of Guernsey reported that they had received a Carer's Assessment.

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[10] Carers UK (2018) "State of Caring" p.6. Available at: https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2018-2 [accessed 11th December 2018].

Carers Action Plan: Summary of Carers Views

"What impact has caring had on your wellbeing? What further support would you find helpful?"

Whilst a few respondents mentioned positive impacts, including caring being a rewarding activity and opportunities for learning, many people felt that there were negative impacts on their wellbeing.

Negative impacts

Many respondents experienced sleep disturbance or a lack of sleep, tiredness and stress.

Whilst some respondents experienced physical health issues (including high blood pressure, weight loss and musculoskeletal injuries from lifting people), there were frequent mentions of feelings and social situations that carers struggled with. These included: a sense of grief or loss (for a person or for a previous lifestyle or life plan); feeling abandoned or that people weren't interested in their wellbeing; feeling guilty; feeling trapped; feeling angry or a sense that they were being treated unfairly due to a lack of support or options; anxiety; worry; depression; feeling down; and irritability. Loss of ability to act spontaneously was mentioned due to needing to plan for someone else to be available to support the cared for individual. Social isolation and loneliness was an issue for a number of people. There was a mention of the impact that caring had on family life, on family roles (i.e. being primarily a spouse or parent rather than being a carer; as well as impacts on children of adults needing support, and siblings of disabled children; and sometimes tensions between adult family members on who was providing more support to an older parent); there were negative impacts on sex life and relationships between couples. Some felt that caring had an impact on their sense of self and independence through loss of a social life or work. Some mentioned a sense that most people did not understand what they were going through.

Finances were mentioned by some respondents as a source of stress and lack of money was described as a barrier to being able to go out.

People receiving support

Some people reported that they felt well supported. In some cases this was support from other family members. Peer support from other carers could be invaluable. Some people had attended a mindfulness course which they found helped. Others felt that the respite or time-off that they did receive was what helped them to manage. Some noted that they used activities like going for a walk to help them to maintain their wellbeing. Beau Sejour was mentioned as a useful resource, as were talking therapies.

Carers Action Plan: Summary of Carers Views

What respondents felt was needed

The following were suggested:

- Proactive support to meet your needs and to prevent a crisis.

- Financial support

- Information on what support was available

- Someone to talk to (even if there was a wider family around people often felt they had to keep a 'brave face' for family and friends and wanted someone else to talk to)

- Emotional support

- Access to free alternative therapy

- Someone to listen to you and help co-ordinate care

- Peer support

- Respite that the supported individual enjoys and which gets them out the house

- Out of hours support to call in a crisis

- A place to go to discuss the mental health needs of the person being supported

- Information about what would happen in the future to help reduce anxiety (both at points of transition and if there was a risk the carer would pass away before the person they were supporting)

- Social care support or support from medical professionals was suggested in some cases

- Sufficient social care support to allow you to stay in your own home

- Personal budgets and access to affordable private care provision

- Time off and time for a social life

- The need for support immediately after diagnosis

- Volunteers to support carers
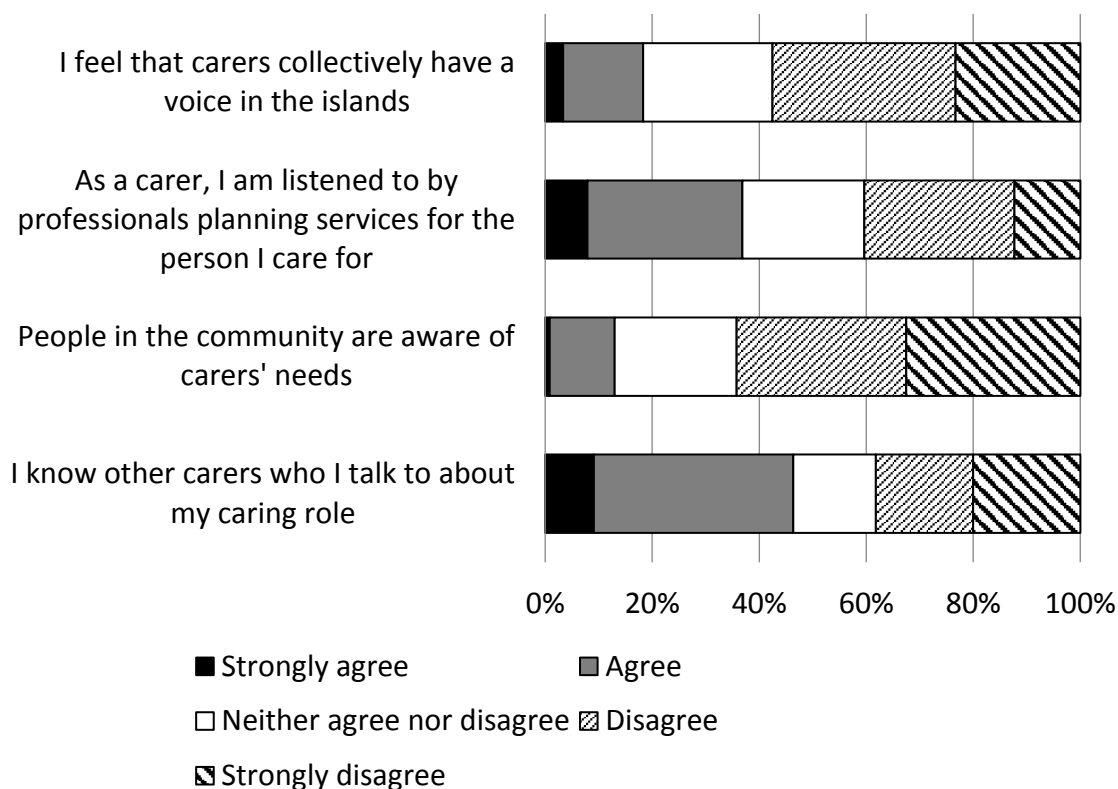

Some carers not willing to accept help

In addition some carers were not identifying as 'carers' or accepting that label (preferring to see themselves as family members), some consultees were concerned that many carers were reluctant to ask for help or resisted help because they preferred to see themselves as independent and managing.

Carers Action Plan: Summary of Carers Views

Recognition of Carers

"How do you feel about your contact with other carers and people's awareness of carers at the moment?"

(129 responses)

Legend:
- ■ Strongly agree
- ▦ Agree
- □ Neither agree nor disagree
- ▨ Disagree
- ▧ Strongly disagree

(Graph and figures exclude responses where 'not applicable' was selected)

The majority of respondents felt that carers did not collectively have a voice in the islands (58%). 64% disagreed that people in the community were aware of carers' needs (rising to 71% for carers of people with physical impairments).

There was a more even divide between respondents who felt professionals listened to them when planning services for the person they cared for (37%) and those who did not (40%).

There was also more of an even divide between respondents who knew other carers to talk to about their caring role (46%) and those who did not (38%). People supporting people with physical impairments or mental health conditions were least likely to know other carers who they could talk to about their caring role.

Carers Action Plan: Summary of Carers Views

Collective voice

It was not felt that carers had a collective voice in Guernsey at present.

Low awareness of carers and experience key to understanding

Many people felt that awareness in the community was low. Some people felt that they had received patronising or inappropriate comments. Many also highlighted that you couldn't really know what it was like to be a carer 24/7 until you had lived through it.

The fact that there was a still a stigma around mental health could make it harder explaining your needs.

Dementia Friendly Guernsey was cited as an example of an awareness raising initiative which had had a positive impact.

Advocacy

A few people mentioned that they felt that advocacy support for carers could be important. Several people suggested that they felt that they had to fight for the support they needed.

Confidentiality

In certain cases carers noted that they felt frustrated that the health professionals of the person that they supported could not share information due to patient confidentiality.

Peer support groups

A number of people were already in touch with peer-support groups and they found this contact valuable. Some wished to be involved but found that the relevant support group always met at a time which they could not attend.

Other respondents said that they were not involved in peer support groups and did not want to be. Some of these said that part of the reason was that they felt that listening to other people's problems wouldn't help their situation and might make them feel low.

Some people said that they received support from family or friends.

A number of respondents said that they had no contact with anyone in a similar situation.

Not feeling valued

Several respondents felt that carers were not valued at present. In some (but not all) cases this was linked to access to financial support. Respect, availability of information and proactive support from health and care professionals were also mentioned as important but lacking. One respondent said in the current system: [Carers] "needs are not seen as anyone's priority."

Do professionals listen to carers?

There were a couple of examples where respondents believed professionals had not listened to carers and had behaved patronisingly or dismissively towards them. Other comments suggested some ambiguity about whether professionals were engaging with carers and understood their issues or not. There was certainly a sense that some carers felt that professionals could be more proactive about engaging with carers and providing carers with information. Some carers expressed an interest in participating in planning service developments.

Identifying as a carer

Some people felt that it took some time to identify as a carer or to recognise that that was what you did, others still felt uncertain about whether they 'counted' as a carer or not:

"I became a carer by accident. I expect most people do. I was in denial that I was a carer for a long time"

Training for other people about Caring

A number of people suggested that we should include sessions on family caring in primary and secondary schools.

The media could also be used to raise awareness of carers and the challenges they face. It was also suggested that other people should be trained about the needs of carers including GPs and care home staff.

Other points raised in consultation

States responsibility

Some carers were concerned that the States would ask too much of carers or the third sector but that it was important that the government showed responsibility in providing adequately for people who needed support.

Front-line staff

There were concerns that front-line staff's working conditions were not sufficiently high and that they were not receiving sufficient time off work.

There were also concerns about housing licenses meaning that good staff were leaving the island when continuity and knowledge of the island's systems was important to service users.

Who to tell if you have a problem

Some felt that there was a lack of clarity about who you would tell if you had a problem that you wanted to be improved. Others mentioned that they didn't know how to make a complaint or what the procedure was. When people had wished to consider making a complaint about a service they had sometimes experienced difficulties doing so.

Carer's assessments

A number of carers expressed support for the idea of having a carer's assessment. Very few carers reported that they had had carer's assessments. If a carers assessment was introduced it was suggested that this should cover emotional, financial and physical wellbeing and should be backed up by action, though it was agreed that there may be an iterative process of using assessments to identify needs and develop services to meet those needs.

Young Carers and siblings

A couple of respondents specifically mentioned Young Carers and the need to ensure that they had sufficient support to engage with their studies. It was also noted that support for carers could help to support siblings also and allow parents to spend more time with their other children. Support for siblings of children with additional needs was also highlighted as important.

Carers Action Plan: Summary of Carers Views

Care Regulation

Private care agencies were not currently registered or accredited by the States. This made some carers reluctant to use them, even if they could afford to do so. Regulation of care agencies was crucial.

Developments of capacity and guardianship law were also important to supporting carers to undertake their role.[11]

Cross jurisdiction caring

It was noted that some carers were caring across different jurisdictions (i.e. caring for someone that lives in the UK, or coming from elsewhere to care for someone in Guernsey). This could complicate support.

Business provision

It was suggested that certain services like online grocery shopping and improved accessible transport could significantly support carers.

End of life

It was noted that carers might need specific support and advocacy when they faced the end of the life of the person that they were supporting. In particular they might require good information and support making decisions about the care for the person that they were supporting at this time.

Other financial issues

Cost of medical appointments

There were a number of comments that the costs of medical appointments, health insurance and ambulance subscriptions were high.

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[11] Both legislation to regulate care agencies and capacity legislation are under development at present.

Carers Action Plan: Summary of Carers Views

Customer service in benefits

It was felt that home appointments for benefits assessments were felt to be useful but not everyone felt able to access them. It was suggested that benefits information could be improved by the use of clear flow charts explaining processes. It was also suggested that there could be a single, named point of contact for carers in Supplementary Benefit. There were concerns about the waiting times in Supplementary Benefit to speak to staff.

Some carers raised specific instances where benefit payments had been stopped when they should not have been. These seemed to be due to communication problems.

There were some particular cases raised around needing to routinely re-apply for some benefits (particularly Severe Disability Benefit) when parents felt that their child's situation would not change and the frequency and length of re-assessment undertaken seemed unnecessary.

Funding for equipment

Whilst there was means-tested support for assistance with purchasing equipment available from Supplementary Benefit, many people also received financial support to purchase equipment from charities. However, it was difficult to know which charities to approach and there was felt to be a lack of clear information available on this at present.

Some carers felt that if a medical professional, occupational therapist or physiotherapist recommended a piece of equipment this should be proactively provided rather than depend on the individual finding the funds to purchase it.

Long-term care benefit

Several people expressed a desire to be able to receive long-term care benefit to help to find ways to meet someone's needs at home rather than moving them to a care home.

Some felt that the apparent disparity between the level of financial support given to people living in care homes compared with those living in the community was unfair and that community service provision was insufficient at present.

Cost of living

Some general comments were made about the cost of living and concerns around getting affordable support for home help and gardening. It was suggested that the tax allowance for dependants could be improved.

Carers Action Plan: Summary of Carers Views

Off-island travel for medical appointments

There were concerns about the arrangements for covering costs for people to travel off-island to accompany someone to a medical appointment in the UK. In some cases carers felt that the travel costs were not covered when they should be, or that there were other problems such as the need for a parent accompanying a child to a medical appointment to support another dependent child who couldn't be taken to the UK also. The age limit on funding for two adults to accompany a child off-island was also questioned.

Travel off-island could also be stressful if needing to arrange transport in the UK and accommodation.

It was queried whether there was an overlap in questions asked around travel grants and around Severe Disability Benefit assessments.

Concerns around supplementary benefit

Parents of disabled adults who relied on benefits for their livelihood were concerned about how to include their child in their will in such a way that the individual would benefit from what was left to them rather than this being deducted from their benefits. Legal advice was desired on managing these issues.
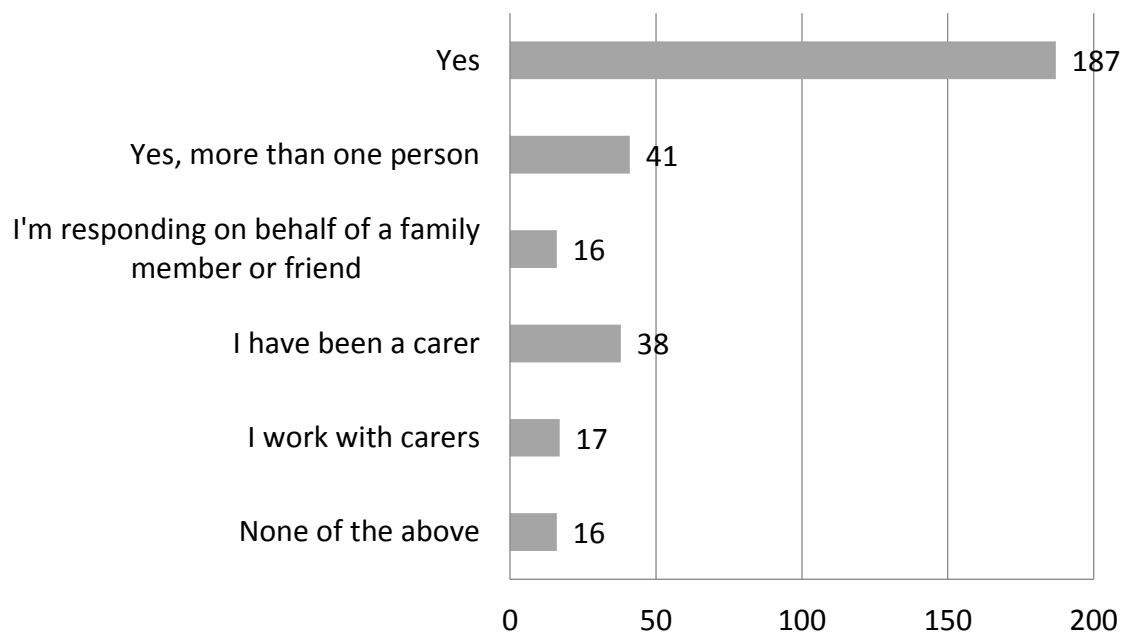
There had been some errors with individuals being charged for A&E attendance when this should have been paid by Supplementary Benefit.

Profile of online respondents

The majority of respondents were currently caring.

 "Do you care for or support a family member or friend who needs ongoing support (unpaid)? *(please select all that apply)"*
(284 responses)

"On average, how many hours a week do you spend on supporting your friend(s) or family member(s)?"

(130 responses)

Category	Responses
0 to 4	2
5 to 9	4
10 to 19	8
20 to 34	9
35 to 70	26
70+	53
varies under 35	10
varies more than 35	11
n/a	5
other	2

Carers Action Plan: Summary of Carers Views
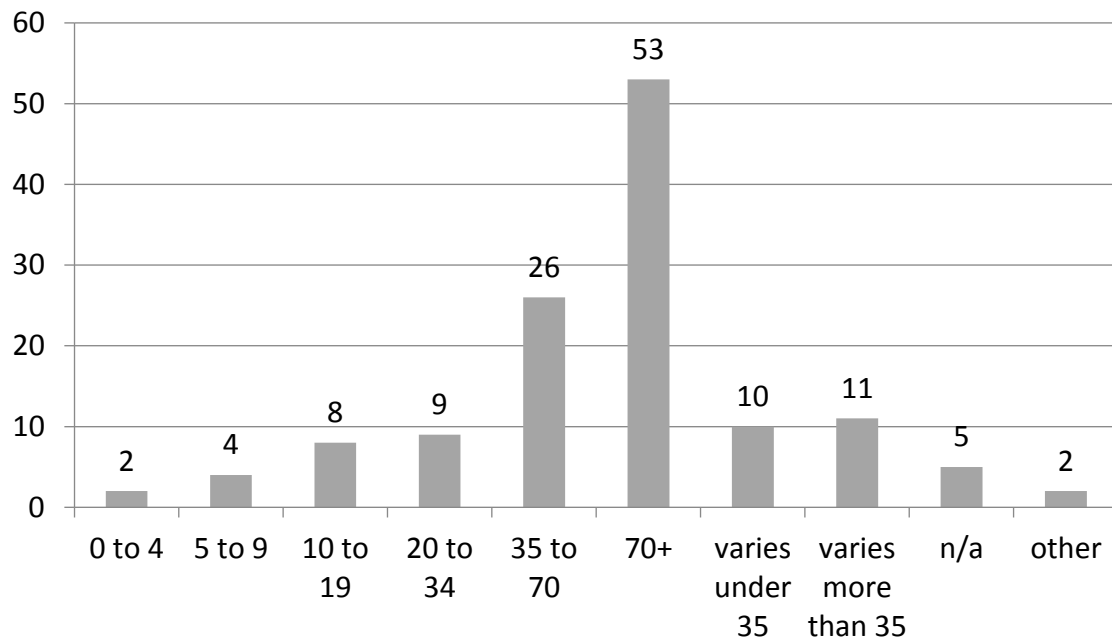
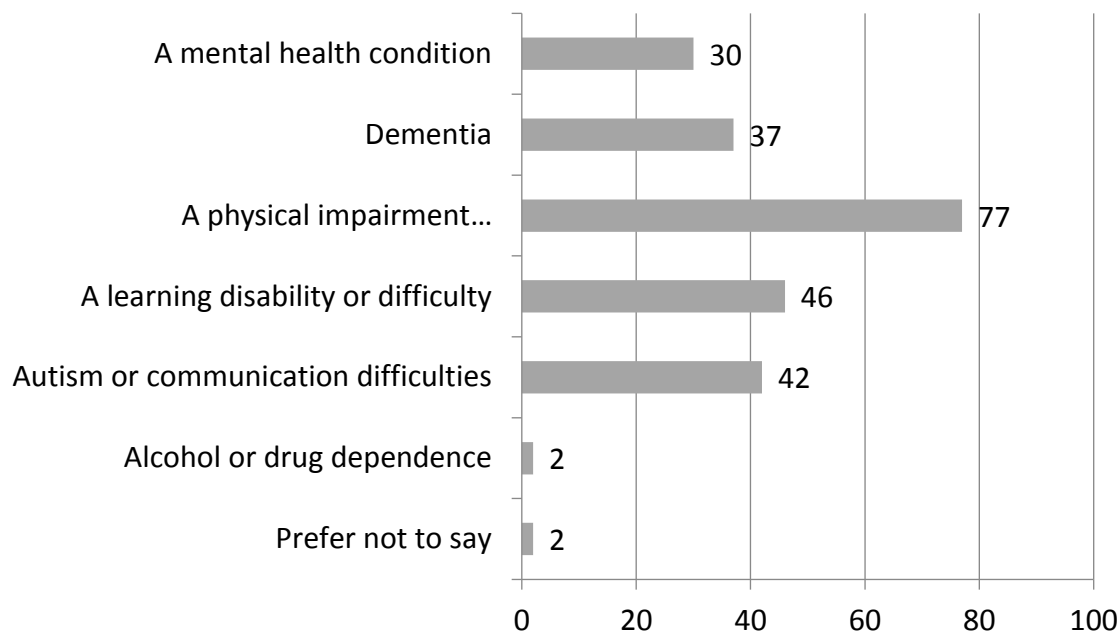# "Does the person/people you care for have…? (select all that are relevant)"

(129 responses)

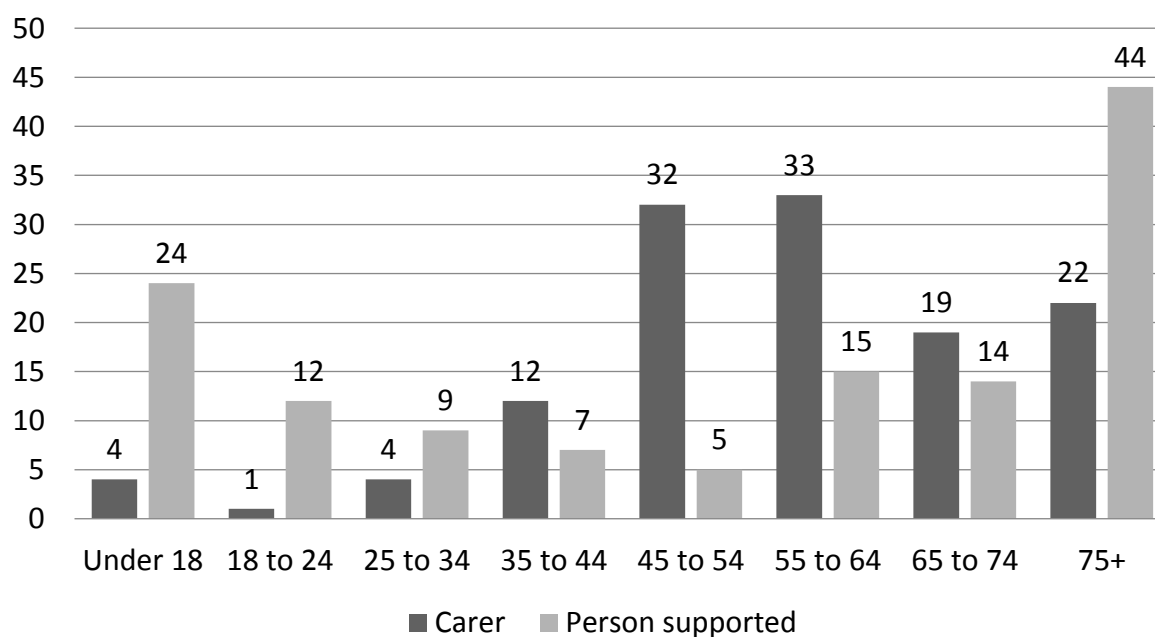| Category	Value
A mental health condition	30
Dementia	37
A physical impairment…	77
A learning disability or difficulty	46
Autism or communication difficulties	42
Alcohol or drug dependence	2
Prefer not to say	2

N.B. Frailty and mobility issues due to old age have been included in 'A physical impairment'

"What age group do you and the person you support fall into?"

(131 responses)

Age group	Carer	Person supported
Under 18	4	24
18 to 24	1	12
25 to 34	4	9
35 to 44	12	7
45 to 54	32	5
55 to 64	33	15
65 to 74	19	14
75+	22	44

■ Carer   ■ Person supported

Carers Action Plan: Summary of Carers Views

"Which island do you and the person you support live on?"

(132 responses)

Legend: ■ Carer ■ Supported Person

Island	Carer	Supported Person
Guernsey	124	119
Alderney	5	6
Herm	0	0
Sark	0	1
Elsewhere	1	2

Carers Action Plan: Summary of Carers Views