

Adult and Young Carers' Surveys 2018

Summary report of responses March 2018

Carers' Surveys 2018

Cumbria County Council wanted to know more about the support that carers receive and how it could be improved. The council were seeking the views and opinions of adult and young carers living in Cumbria about:

- The support they received from their local Carer's organisation
- How this support to their caring role could be improved

In Cumbria the local carer's organisations are:

- Carlisle Carers
- Eden Carers
- Furness Carers
- South Lakeland Carers
- West Cumbria Carers

However, many people in Cumbria currently provide help and support to family and loved ones but might not think of themselves as carers or be formally recognised. This group may not be aware of the support available and it was important that they completed a survey too.

All of the local carer's organisations were involved in the development of an Adult Carers' Survey for those carers who are aged 18 and over or a Young Carers' Survey for people aged 5-18 years.

The period of consultation commenced on 8 January 2018 and ended on 22 January 2018 and surveys could be completed anonymously either online or a paper copy could be returned Freepost in the envelope provided. Hard copy surveys were distributed via local carers' organisations and staff actively promoted the survey and encouraged the involvement of all stakeholders. This included arranging for older young carers to support younger young carers to take part. The Carers' Survey 2018 was also promoted via a media release along with messages to council staff.

A small number of hard copy responses have been received after the closing date; these late responses were entered and considered as part of this report.

A total of 299 responses were received in relation to the Adult Carers' Survey and 68 young carers (5-18 years) completed the Young Carers' Survey.

The information has been used to inform the development of the All Age Carers' Services specification.

Cumbria County Council would like to thank local carers' organisations for their valuable contribution in the development and implementation of this survey.

A summary of responses to Adult Carers' Survey is included from page 3 of this document.

A summary of responses to Young Carers' Survey is included from page 10 of this document.

Summary of responses to Adult Carers' Survey

Who responded? (Questions 1-4)

Most responders were adult carers, 56% aged between 25 and 64 years, 43% aged 65 years and over. 1% of responders were young adult carers aged between 16 and 25 years.

Responders live in the following areas (based on nearest town answer)	Number of responses
Allerdale (including Cockermouth, Keswick, Maryport, Silloth, Wigton, Workington)	29
Barrow (including Barrow, Dalton in Furness)	51
Carlisle (including Brampton, Carlisle, Longtown)	69
Copeland (including Egremont, Millom, Whitehaven)	14
Eden (including Alston, Appleby, Kirkby Stephen, Penrith)	51
South Lakeland (Including Ambleside, Arnside, Grange over Sands, Holmrook, Kendal, Kirkby Lonsdale, Milnthorpe, Sedburgh, Ulverston, Windermere)	62

Some responders opted to not disclose their location.

76% of responders were female, 23% male and less than 1% preferred not to say.

Most responders care for their husband/wife (51%), a further 24% care for mother/father, and 20% care for their son/daughter. Other responses included those caring for brothers, sisters, grandparents, step parents, in-laws, aunts, uncles, cousins, friends and partners.

Those that they care for (Questions 5-6)

63% of those cared for are aged 65 years and over, 31% aged 18 to 64 years and 6% aged under 18 years old.

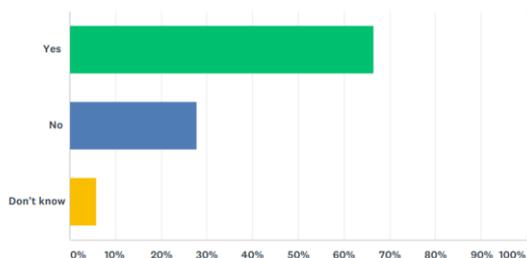
Those that they care for is someone with a (more than one category may apply):

- Physical disability 58%
- Long term illness 35%
- Dementia 29%
- Mental health issue 24%
- Life limiting condition 18%
- Learning disability 15%

Other answers included caring for those with substance misuse problems, autism, communication difficulties, cancer, heart conditions, old age, schizophrenia, blind, ASD, mobility problems, Parkinson disease, ADHD, MS, speech difficulties, OCD, Asperger's.

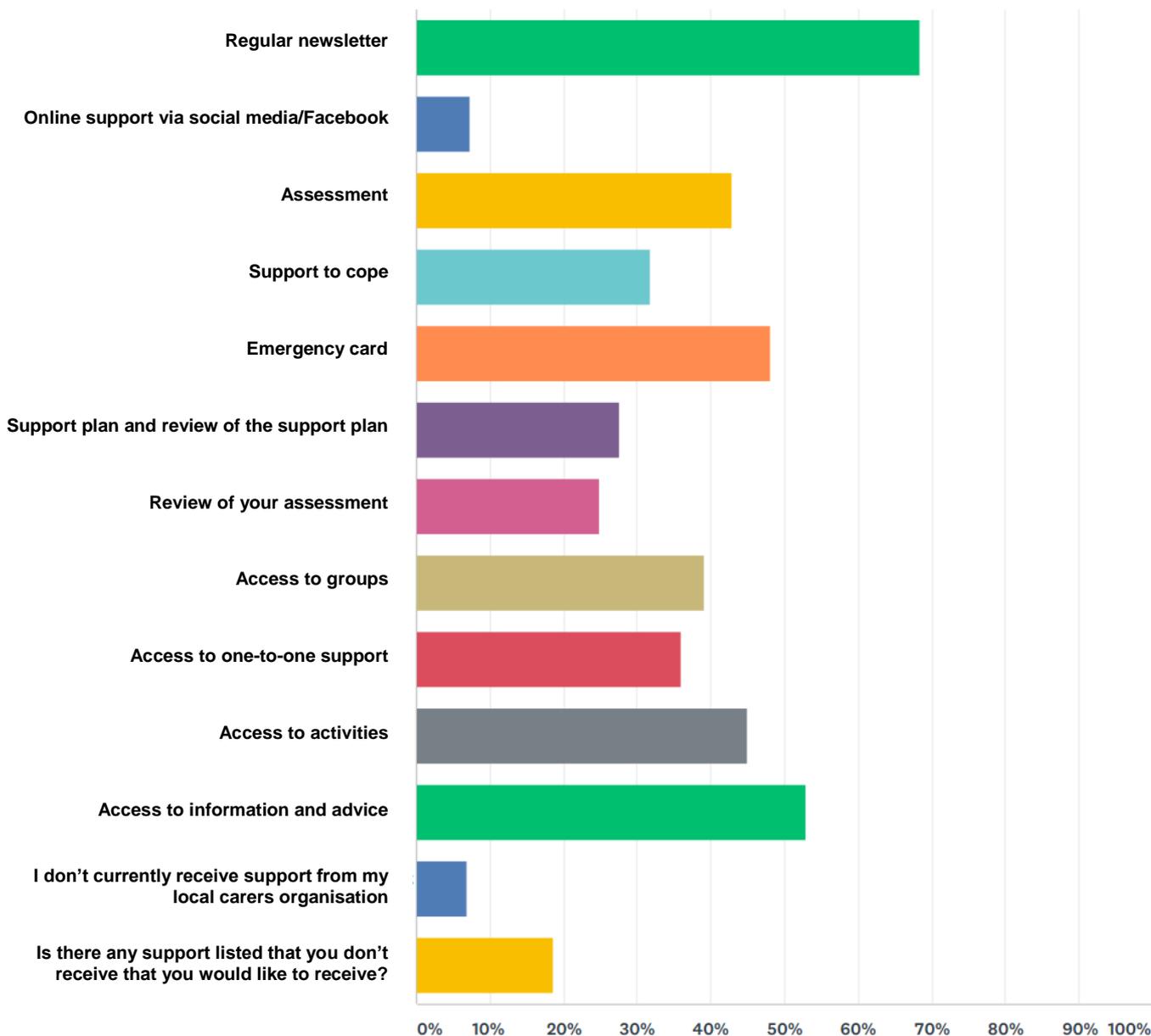
Support they currently receive

Have you had a carer's assessment in the last year? (Questions 7-8)



66% have received a carer's assessment in the last year and 48% have received a written copy of their assessment (Q8). A further 6% are unsure if they have and 28% have not received an assessment

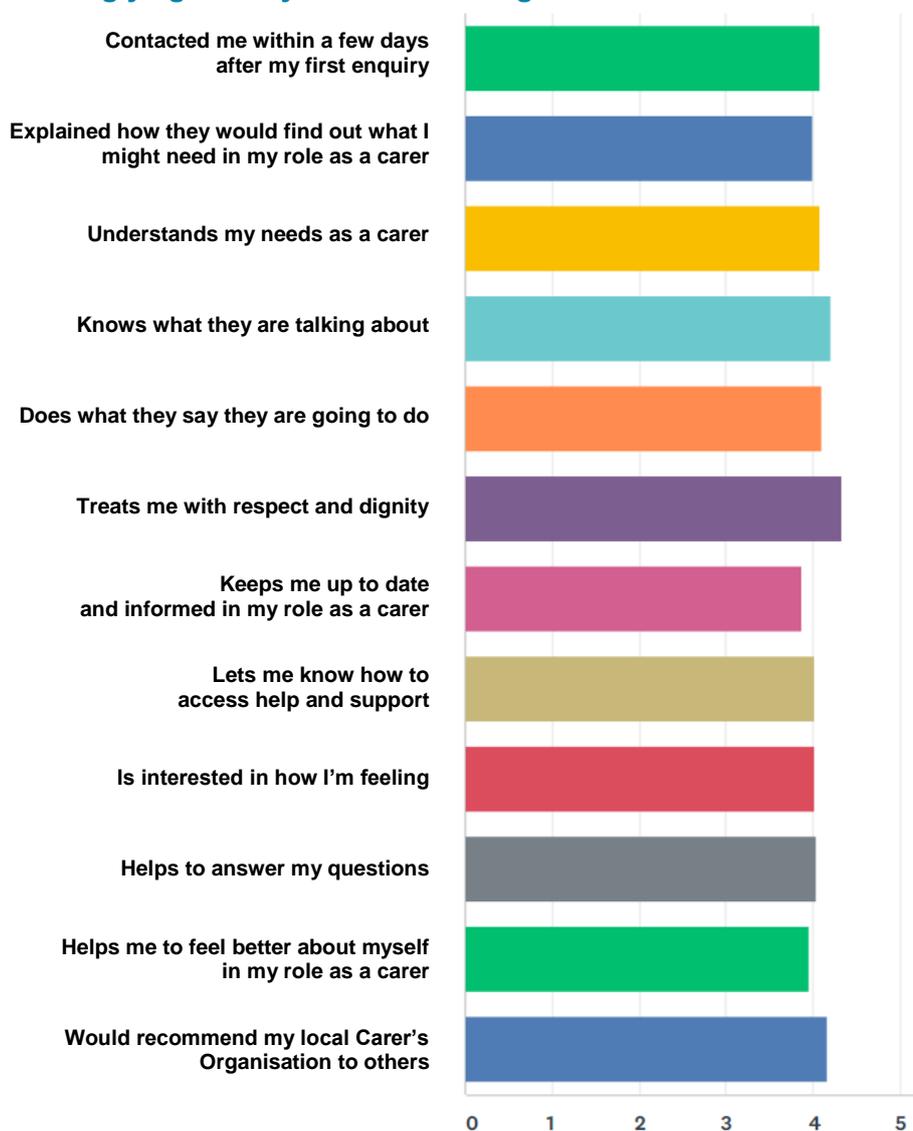
Question 9 What support have you continued to receive from your local carer's organisation?



Themes raised in response to support that they would like to receive

- Difficulty in accessing activities, whether due to lack of support with transport, difficulty getting into car and some activities not open to both the carer and individual. Several would like more networking opportunities with others, such as local café meetings.
- Better access to information and advice including support about benefits and carers rights, some don't receive newsletters and online newsletters were suggested. Some are unaware of current support available, other would like to be able to phone someone to answer questions.
- The need for a break in providing care with some form of respite.
- Inconsistency around Carers Assessments – some report not being offered an assessment, some elect not to go through the process, others go through the process but do not get a copy of the assessment.
- Some report receiving no help or support at all and a monthly carer's allowance was suggested.
- Additional support for those with mental health problems.

Question 10 Thinking about the support you receive from your local carer's organisation, how would you score the support on a scale of 1 to 5, with 1 being that you strongly disagree and 5 that you strongly agree? My local carer's organisation....



The majority of themes raised in response to this were positive including:

- Highly rating the current service provided describing it as first class, wonderful, excellent, impressive, reassuring, caring, helpful and professionally run. Support workers are excellent, approachable, know their role and respond promptly face to face and via phone providing rapid response and continuous help and support.
- Support provided is seen as essential and a vital link for help and information.
- Help received has allowed people to help others.

Comments were received about feeling supported but felt the service could be more proactive. Some thought it was difficult to comment/not yet applicable as support is in progress at the moment whilst others want to retain privacy and prefer not to receive support.

Negative responses included:

- Feeling of isolation with little support with solving problems.
- Not much activity for older carers and activities too far away with limited transport.
- Poor service including lack of assessments and advice has been viewed as negative
- Level of support seen to be getting worse.

Question 11 Please tell us one thing, if anything, which has changed for you because of attending your local carer's organisation. If nothing has changed why do you think this is?

Responses highlighted the following:

- Better able to cope with the demands, relieve pressure, reduce stress and isolation and have more 'me' time for activities including massages and aromatherapy.
- More networking opportunities and getting to know other carers and support with transport.
- Receive respite and able to provide help to others.
- Increased confidence in the caring role with awareness of support available for carer and those they care for including counselling opportunities.
- More secure future with peace of mind and reassurance that help is available should people need it and pre preparing emergency cards.
- Help with paperwork and applying for funding, allowances and grants.
- Some felt there is good support over the phone, but need more home visits, others felt that nothing has changed and in some cases things have got worse.
- For some the problems are seen to be too complex and time consuming to address and others have not yet used the services fully.

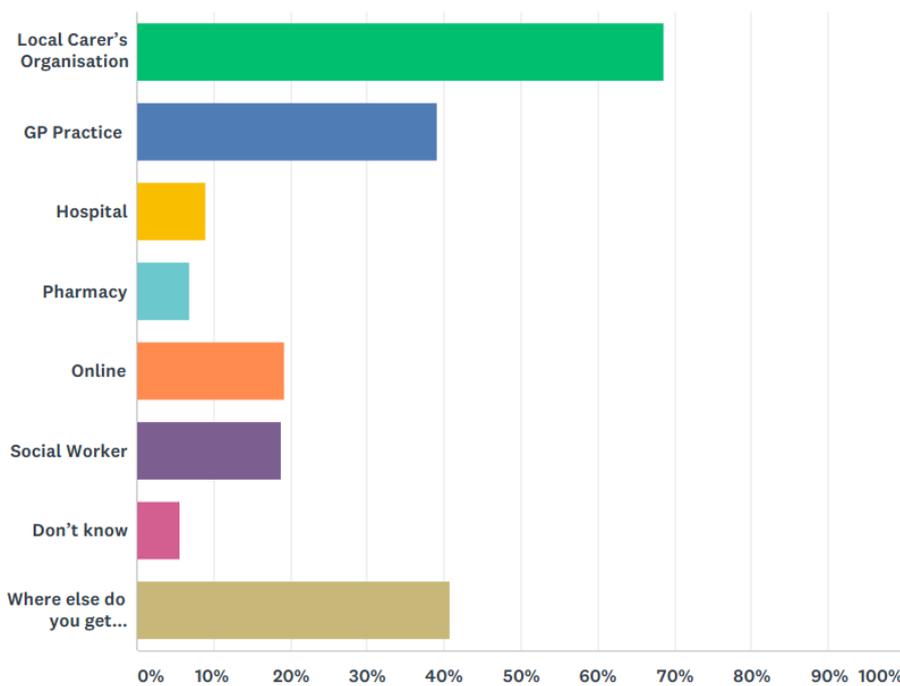
Question 12 Thinking about your needs as a carer, please tell us one thing that would help you in your caring role.

Many of those who responded are pleased with the service that they receive and are keen to see the level of support continued. Suggestions for additional help include:

- Respite and short breaks.
- More aromatherapy, massages, exercise opportunities, reflexology, yoga.
- Networking opportunities with other carers, regular focused advice sessions and access to counselling. Training and information days, with sessions closer to home.
- Support with transport in general and blue badge applications.
- Better signposting and information including clarity of local offer support identifying who best to contact with a central information store.

- Practical help with day to day tasks such as shopping, housework and meals.
- More financial support, including support with benefits and increased allowances with applications processed more promptly.
- Home adaptations and improved access to technology.
- More contact with reliable, knowledgeable, dedicated social workers and more frequent contact - weekly visits, throughout the year, more proactive regular support.
- Reduced bureaucracy - easier access to statutory provision and improved service from departments providing assistance with teams who have a better understanding of the needs of carers. Improved communication between organisations and simpler procedures.
- Support keeping work skills up to date.
- Help in emergency and faster response to crisis.
- Better service provision in the county.

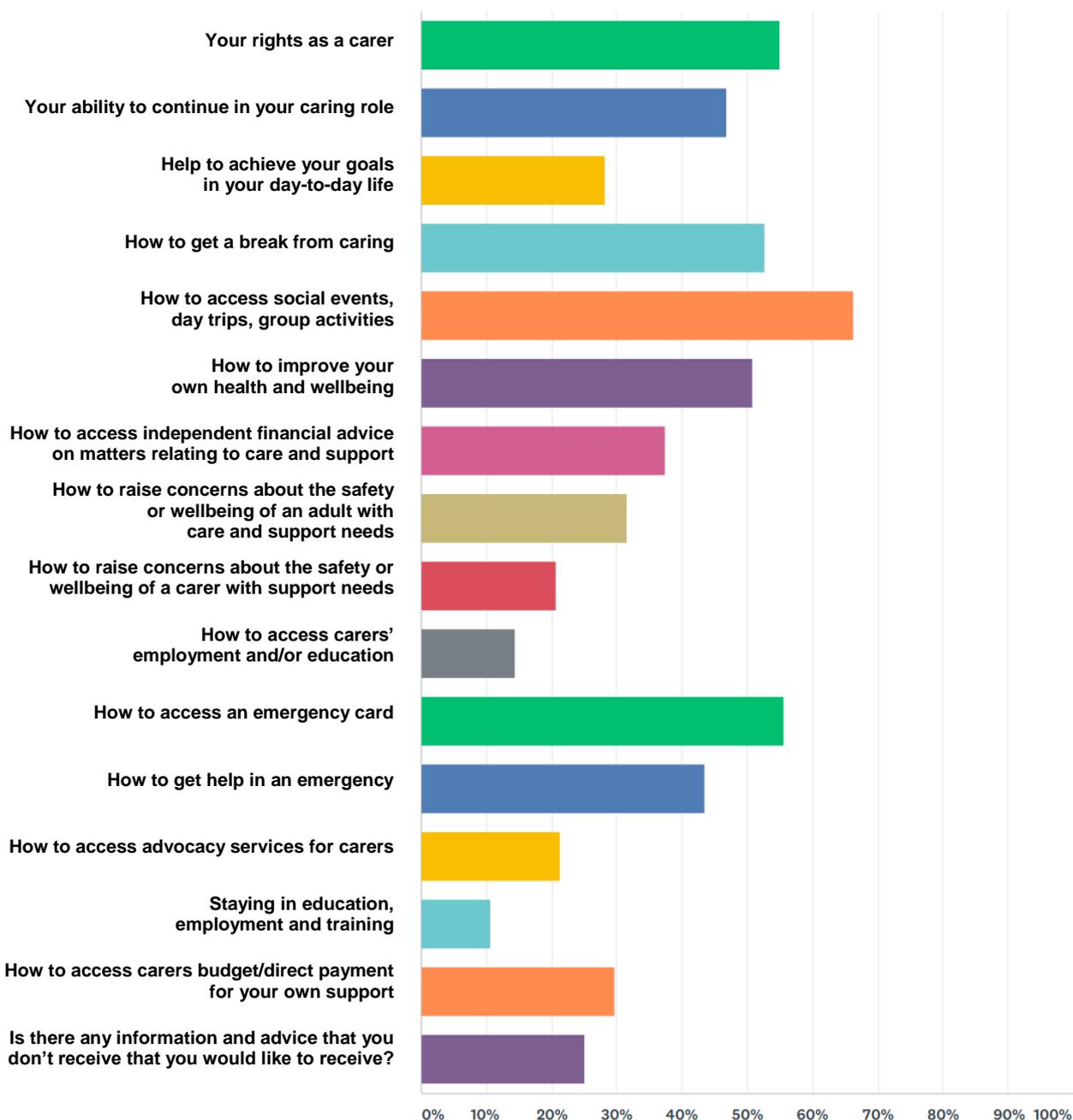
Question 13 Where do you get information and advice about support for you in your caring role?



Where else do you get information and advice?

- Parent network and support groups including network days and conferences
- Charities and support organisations such as Age UK, Age Concern and Alzheimer's Society
- District nurses and occupational therapists
- Friends and family
- Radio
- Newsletters
- Social media support groups
- Notice boards and leaflets
- Libraries

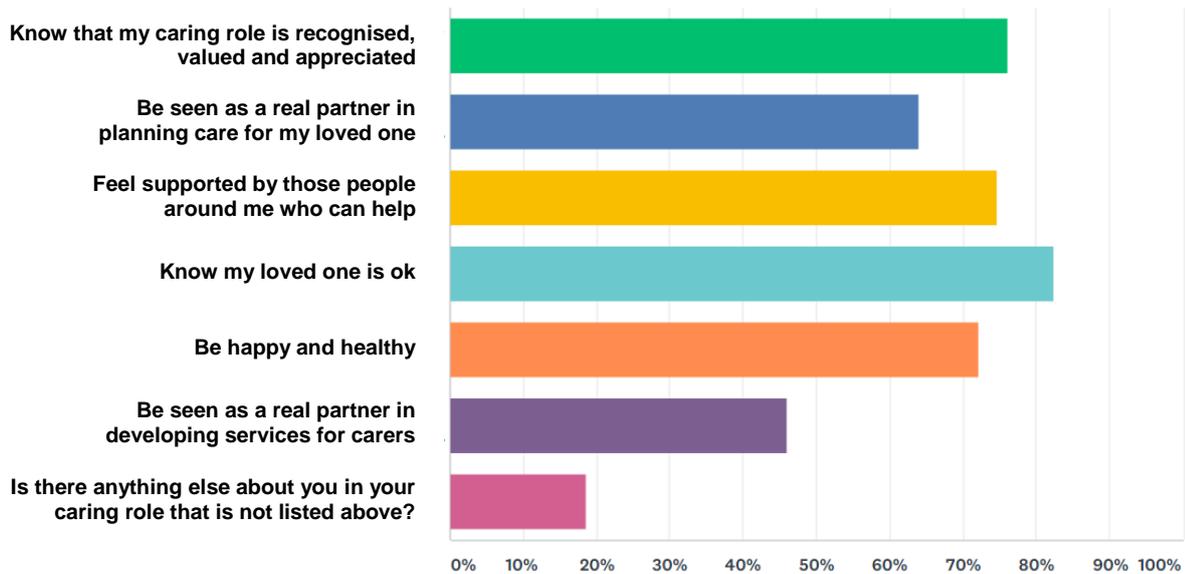
**Question 14 What information and advice have you received to support you in your caring role?
(tick all that apply to you)**



Is there any information and advice listed that you don't receive that you would like to receive?

- How to get respite
- Access to financial support
- How to get an emergency card
- Access to advocacy
- Access to education and training
- How to raise concerns about safety and wellbeing
- How to reduce loneliness and isolation
- Information about plans for mental health services
- Advice and assistance with the new regulations

Question 15 How much do you think the following statements are true about you in your caring role? (tick all that apply to you)I want to...



Is there anything else about you in your caring role that is not listed above?

- Be visible
- Make decisions for my own wellbeing
- Access practical help and respite
- Know there is support in place for the future
- Understanding how to deal with issues related care and medication
- Be involved with co-production as part of the solution

Question 16 Do you have any other suggestions to improve the support you receive from your local carer's organisation?

Positive comments about the current service provided – suggestions for improvements include:

- More respite
- Specialist support for people with mental health problems
- Help knowing where to go at what time and clarity around who to contact
- A fairer funding model and reasonably priced care
- More activities for older carers and practical networking/information training days
- More frequent proactive contact from support organisations and support for carers that are quietly independent and don't want to ask for help
- Increase visibility of carers organisations

Question 17 Please tell us if you have any needs of your own

- Respite and 'time for me'
- Help with organisation, cooking and household tasks
- Guidance of where to find additional help
- Access to counselling and legal advice
- Reduce loneliness and isolation
- Massage therapy to help cope with lifting and handling

Summary of responses to Young Carers' Survey

Who responded? (Questions 1-3)

- 68 young carers across the county completed the survey.
- 49% of responders were aged 5-11 yrs. and 51% were aged 12-18 yrs.

Responders live in the following areas (based on nearest town answer)	Number of responses
Allerdale (including Cockermouth, Keswick, Maryport, Silloth, Wigton, Workington)	12
Barrow (including Barrow, Dalton in Furness)	8
Carlisle (including Brampton, Carlisle, Longtown)	6
Copeland (including Egremont, Millom, Whitehaven)	12
Eden (including Alston, Appleby, Kirkby Stephen, Penrith)	21
South Lakeland (Including Ambleside, Arnside, Grange over Sands, Holmrook, Kendal, Kirkby Lonsdale, Milnthorpe, Sedburgh, Ulverston, Windermere)	4
5 respondents skipped this question	Total 63

58% of responders were female and 42% male.

Those that they care for (Questions 4-7)

Most responders care for their mother/father 63%, a further 40% care for brothers/sisters and 3% care for grandparents. Other responses included those caring for a son/daughter or child/children with disability with some responders caring for more than one person.

4% of those cared for are aged 65 years and over, 58% aged 18 to 64 years and 38% aged under 18 years old.

Those that they care for is someone with a (more than one category may apply):

- Physical disability 46%
- Mental health issue 38%
- Learning disability 33%
- Long term illness 23%
- Dementia 5%
- Substance Misuse 5%

Other answers included caring for those with Autism, Asperger's or Diabetes.

The amount of time spent caring each day is:

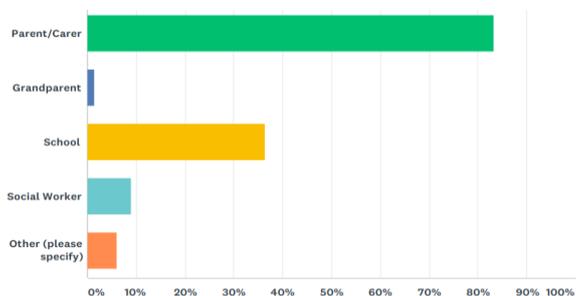
- Less than 1hour 10%
- 1-2 hours 30%
- More than 2 hours 18%
- Some time, but I do not do this every day 42%

Support they currently receive

Have you had a carer's assessment in the last year? (Questions 8 -10)

- 39% received a carer's assessment in the last year and 32% didn't know.
- 9% received a written copy of their assessment, 39% had not received anything and 52% didn't know.

Those who were involved when responders first met with their local carer's organisation were:

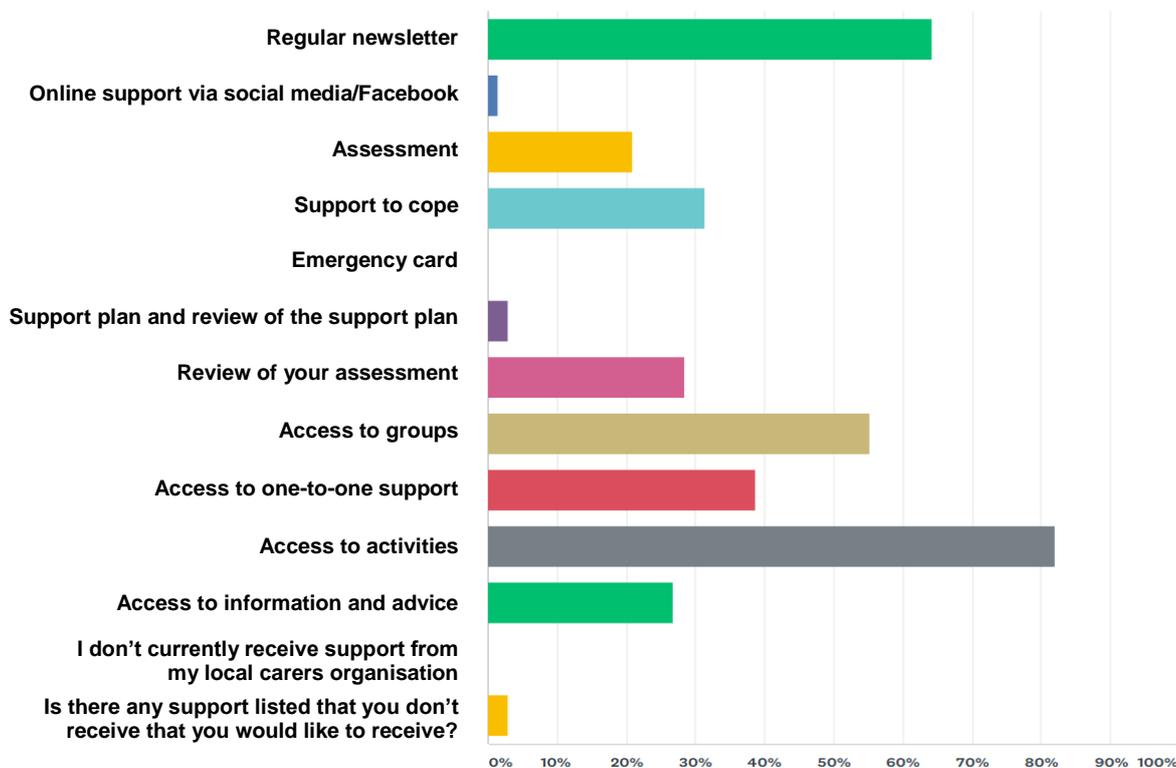


Other responses included: older sister, Police and CAMHS.

Question 11 If you are aged 14 or above and you have had a chat with your local carer's organisation about the support you can receive when you turn 16 or 18, were you asked whether you want to:

ANSWER CHOICES	RESPONSES	Count
Continue providing care as a young adult carer	36.84%	7
Change your caring role	0.00%	0
I have not had a chat about this	63.16%	12
TOTAL		19

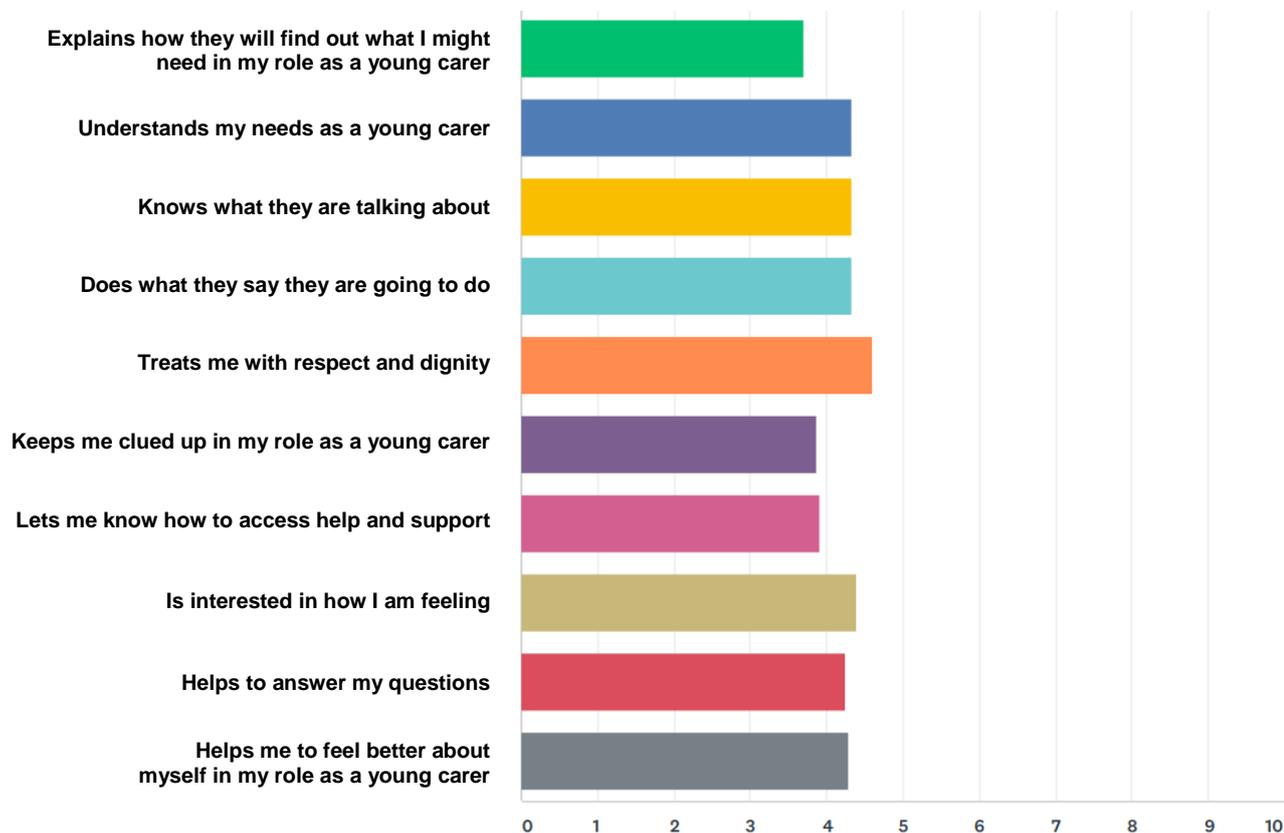
Question 12 What support have you continued to receive from your local carer's organisation?



Is there any support listed that you don't receive that you would like to receive?

1 responder - more one to one support.

Question 13 Thinking about the support you receive from your local carer's organisation, how would you score the support on a scale of 1 to 5, with 1 being that you strongly disagree and 5 that you strongly agree? My local carer's organisation....



No comments were submitted from respondents who scored 1 in any of the statements above.

Comments from responders who scored 5 in any of the statements above highly rated the current service provided describing it as: really good, great, really helpful, they take care of us, treat us with respect, brilliant, very understanding, kind, helpful, the best, they always know what they are talking about.

Question 14 Please tell us one thing, if anything, which has changed for you because of attending your local carer's organisation.

Responses highlighted the following:

- Feeling happier - less stressed, more/independent/confident/comfortable in role/patient
- Time out from caring responsibilities to attend activities/days out
- Making new friends
- Not feeling alone in their role having someone to talk to and support them
- Engaging with young people who are in a similar situation

If nothing has changed why do you think this is?

Responses highlighted the following:

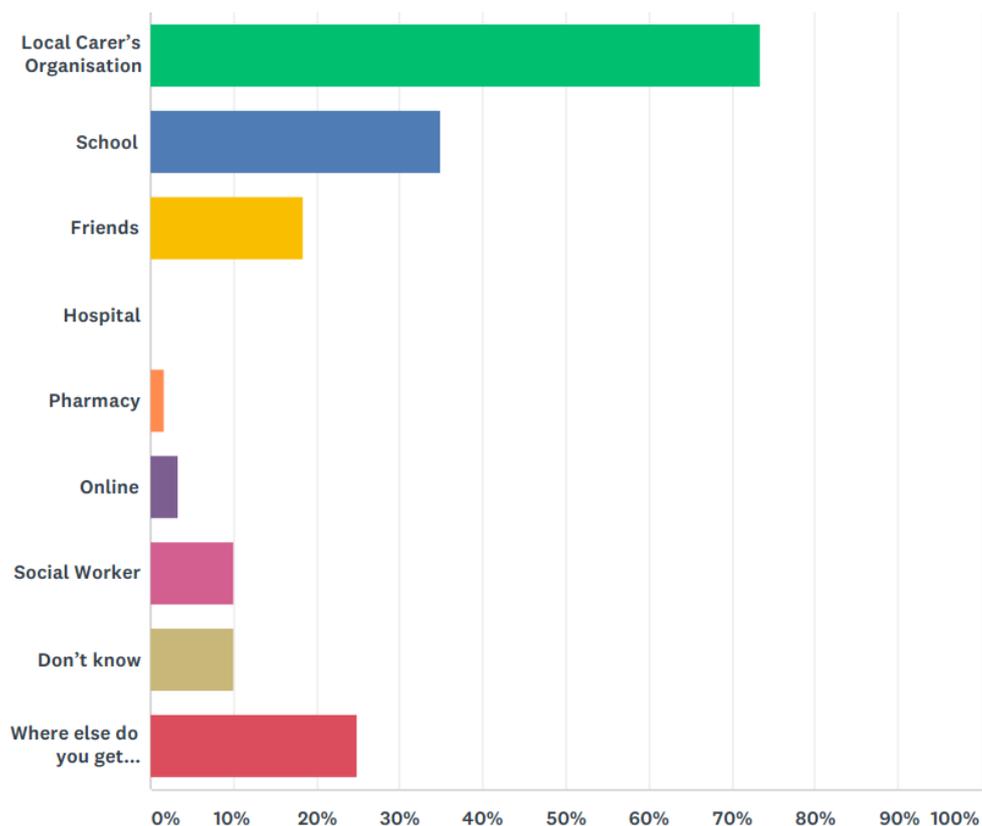
- No longer a group to attend,
- Once getting older hardly anything to attend (groups),
- Lack of support because they only care on the weekend now and holiday times,
- More emotional support needed.

Question 15 Thinking about your needs as a carer, please tell us one thing that would help you in your caring role.

Responses highlighted the following:

- Continue to have someone to talk to
- Continue to see the same support worker
- Training/education in relation to specific caring role
- Attending activities
- More time out
- More money
- Having someone to help when tired
- Empathy from other people

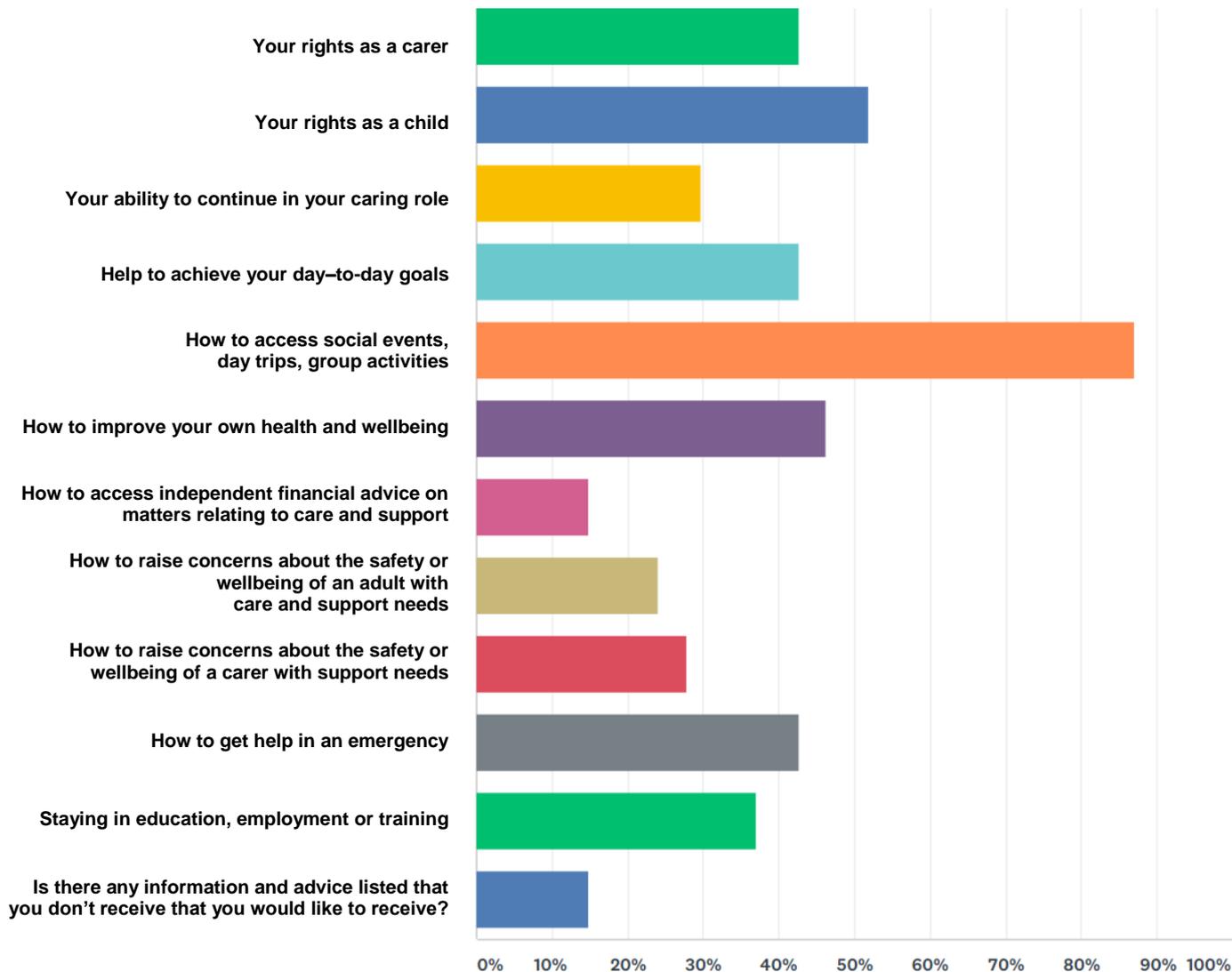
Question 16 Where do you get information and advice about support for you in your caring role?



Where else do you get information and advice?

- Parent/Carer
- Newsletter
- Family support

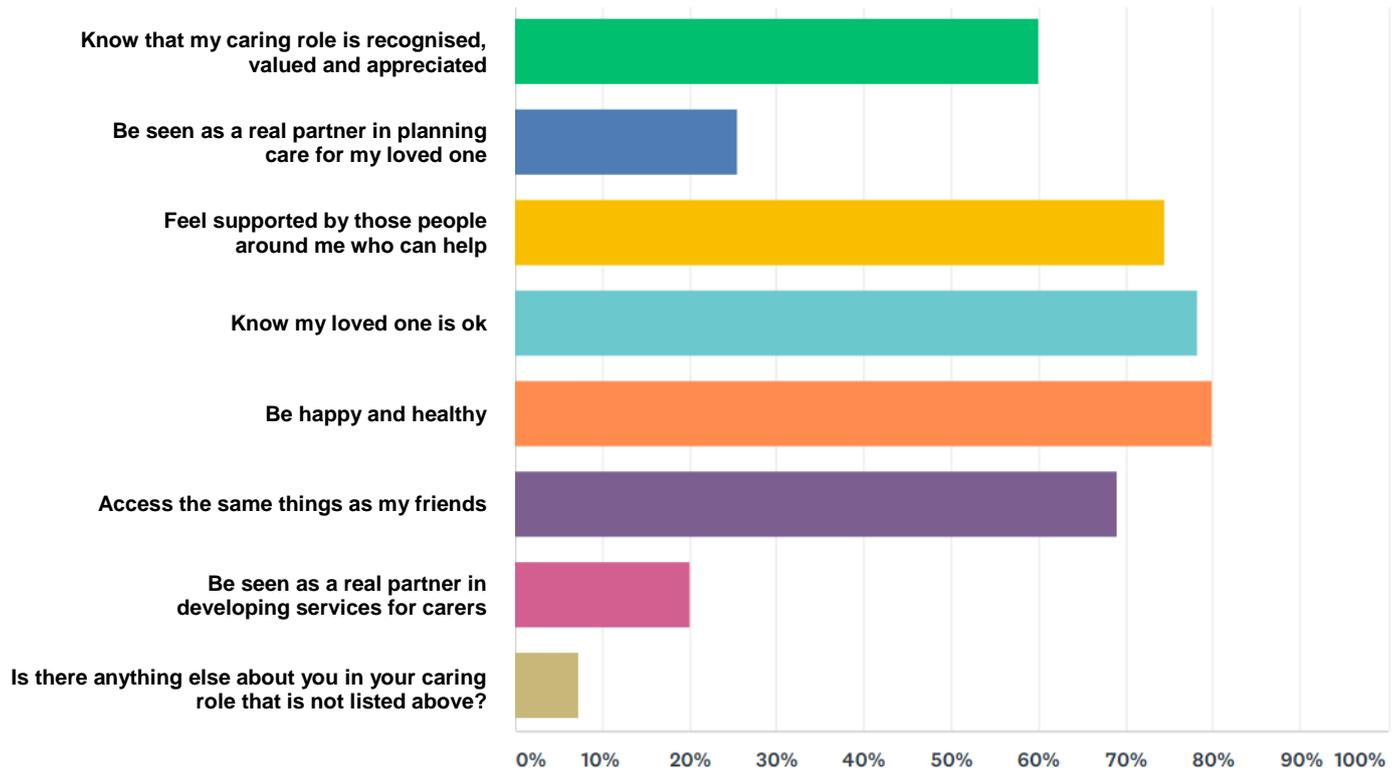
**Question 17 What information and advice have you received to support you in your caring role?
(tick all that apply to you)**



Is there any information and advice listed that you don't receive that you would like to receive?

- How to achieve my day-to-day goals
- Help in an emergency
- Accessing social events
- More advice on specific caring roles e.g. autism
- Benefits/allowances – for the person cared for
- What happens once they have left school and gone on to living away from home.

Question 18 How much do you think the following statements are true about you in your caring role? (tick all that apply to you) I want to...



Is there anything else about you in your caring role that is not listed above?

- Personal problems
- Free time

Question 19 Do you have any other suggestions to improve the support you receive from your local carer’s organisation?

Suggestions for improvements:

- More frequent information in letter form not email
- Information about other facilities/services available to young carers
- Help on how to improve the home environment
- Raise money for more and bigger trips e.g. London or Disneyland
- One to one support
- Tell people and children about young carers
- More funding
- A regular weekly meet.

Question 20 Please tell us if you have any needs of your own.

Responses highlighted the following:

- To get out more
- More one to one time with support worker
- More free time
- More financial help
- Physical and mental health needs
- More support during the hardest times.