Carers – Isolation & Loneliness

July 2019

Disclaimer

This report is based on conversations or responses freely given by members of the public. Where possible quotations are used to illustrate individual or collectively important experiences.

Engagement officers collect responses verbatim and we also present these in our final report as an appendix. This is important in showing the accuracy of our analysis, and so that further work can be done by anyone wishing to do so.

A full explanation of the guiding principles and framework for how we do engagement and analysis can be found online on our website www.healthwatchbolton.co.uk.

Please note that this report relates to findings observed and contributed by members of the public in relation to the specific project as set out in the methodology section of the report.

Our report is not a representative portrayal of the experiences of all service users and staff, only an analysis of what was contributed by members of the public, service users, patients and staff within the project context as described.

Background to the project

• This project fits with our priority 'carers' which was voted the 3rd most important area for 2018-2019 by our members and the public.

• Following on from the Bolton Carers Strategy which was implemented last year, and our previous scoping project on carers 'What makes a carer friendly community?', this project aims to further explore some of the main difficulties people highlighted. The three main difficulties established from the scoping project were loneliness, isolation, and respite. This project will focus on loneliness and isolation, specifically how an individual's mental health and well-being are impacted by caring.

• In October Bolton Council sent out the governments statutory carers survey to approximately 1500 carers across the borough of Bolton. Only one question in this survey related to loneliness and isolation (Q.11). As such our research project aims to further strengthen the results from this survey, which will be released in spring 2019.

• This project is intended to inform voluntary and statutory sector professionals in terms of how they currently and potentially can help individuals tackle these difficulties.

• We will seek to further explore the difficulties highlighted in our initial carer report, what if any initiatives are in place to support people, the knowledge they have of existing services, and ideas for further interventional support.

Key findings

- Isolation and respite are two interconnected areas affecting people with caring responsibilities.

- In this report we have found isolation to be related to a lack of free time, uneven availability of support, a lack of money as a result of being a carer, and difficulties in reaching the location where support might be delivered.

- One solution to isolation is promotion of groups or clubs that could encourage socialising and sharing of experiences.

- People told us about a wide range of interests they had and how at times these had to be given up, or were not possible due to being a carer.

- Some actions that could be taken to improve this were improving awareness, making the groups accessible, improving access to respite, and allowing those being cared for to attend groups.

Methodology

We collected people's views on being a carer in Bolton. The work was done between October 2018-February 2019.

People were mainly engaged through a survey, this was promoted through our membership, website and social media channels, via a snowball method and at relevant events. Bolton council sent out an email with a link to the survey to approximately 1500 carers across the borough of Bolton, all of whom the council provide a service to.

There were also contributions from visitors to our 'get ready for winter' event stall.

A set of focus groups were held with a local carers group to capture their views.

Survey Questions

1 – What does the term 'lonely or isolated' mean to you?

2 – Do you ever feel lonely or isolated as a result of your caring/supportive responsibilities?

3 – Is there anything that would help you to feel less lonely or isolated?

4 – Do you use any support services (these can be from different organisations including both voluntary and statutory groups, private agencies and social services). Please advise – support break, PA, lunch club, meal services, alarm systems, day centre.

5 – Do you access any local groups/club (these do not have to be carer specific) if so please tell us which.

6 – Is there anything which prevents you from attending groups/clubs?

7 – What would make local groups/clubs more 'carer friendly'?

8 – What kinds of groups/clubs would interest you?

9 – If you were to attend a group/club/activity would you prefer to…

10 – What's the best way for groups/clubs/support and services to tell you about what they offer?

Demographic questions

11 – Age
12 – Gender
13 – Ethnicity

A total of 28 people responded to the survey. The respondents demographic information can be seen on this page.

There were 155 comments collected as part of this work.

Age:
Respondents were aged 35-44 (8), 45-54 (7), 55-64 (12), 65-74 (1).

The majority of participants came from the 55-64 age group (12).

Ethnicity:
26 people identified as 'White British', 1 person identified as 'Any mixed', 1 person identified as 'Other'.
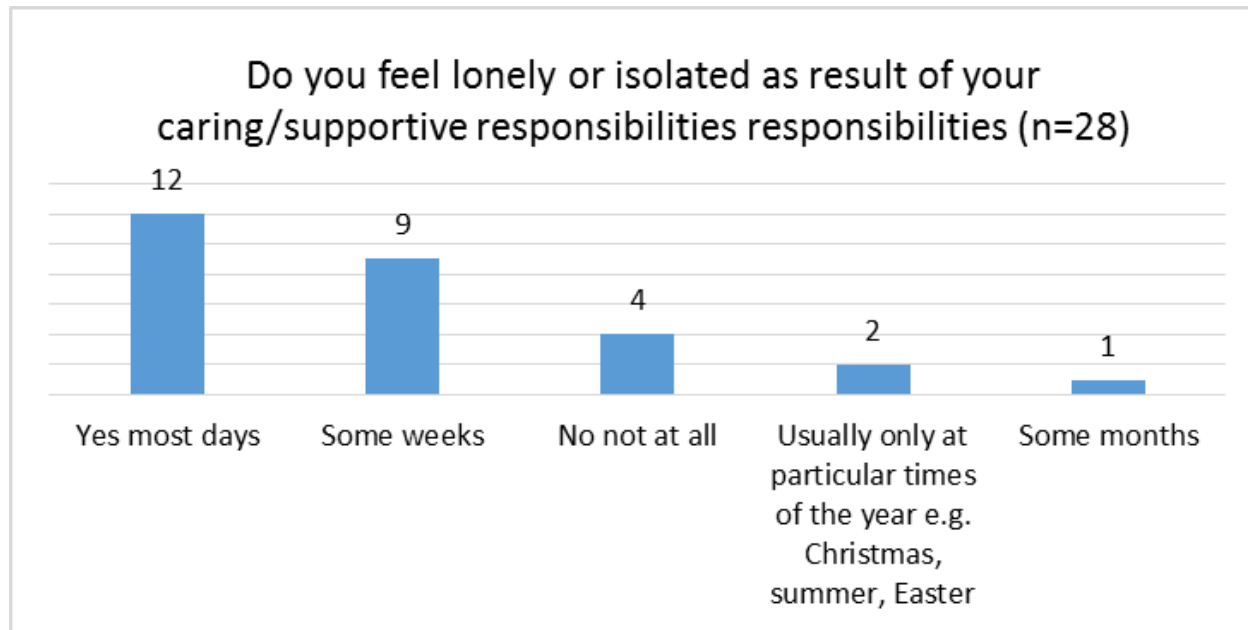
Diversity
LGBT: 22 said 'no' when asked.
Armed forces: 23 said 'no' when asked 1 said 'yes'.
Disabled: 22 said 'no' when asked 3 said 'yes'.

We asked people to state whether they felt lonely or isolated, and when this was likely to be.

A large number of those asked stated 'yes most days' (12 of 28 people).

Do you feel lonely or isolated as result of your caring/supportive responsibilities responsibilities (n=28)

Time of year is important for some in feelings of isolation:
"Christmas"
"Winter time"
"Christmas is the worst. I no longer speak to my family."

The sense of responsibility can also weigh on people's shoulders:
"When the mental and physical demands become overwhelming is when the reality hits how isolating a carers life is."

Getting out and about also a factor:
"Usually when the weather is bad and unable to travel. My husband no longer drives so we are reliant on public transport but I have had lots of issues…"

Defining loneliness

People said loneliness was related to the inability to socialise due to the care responsibilities they had.

There was also concern that others did not understand what caring meant.

"Not able to do the things that I want to do due to my caring situation."

"Desiring the company of friends, but having nobody to call upon."

"Feeling that no one understands what I am going through in my caring role."

"Being unable to get around, to choose when and where I go. Having no one to talk too, laugh or break up a day by chatting about news, TV or just the time of day. Being aware of if I fall will some one find me."

"Isolated, not having my hair cut."

"I'm a different person now lost my sparkle emotionally exhausted don't enjoy going away."
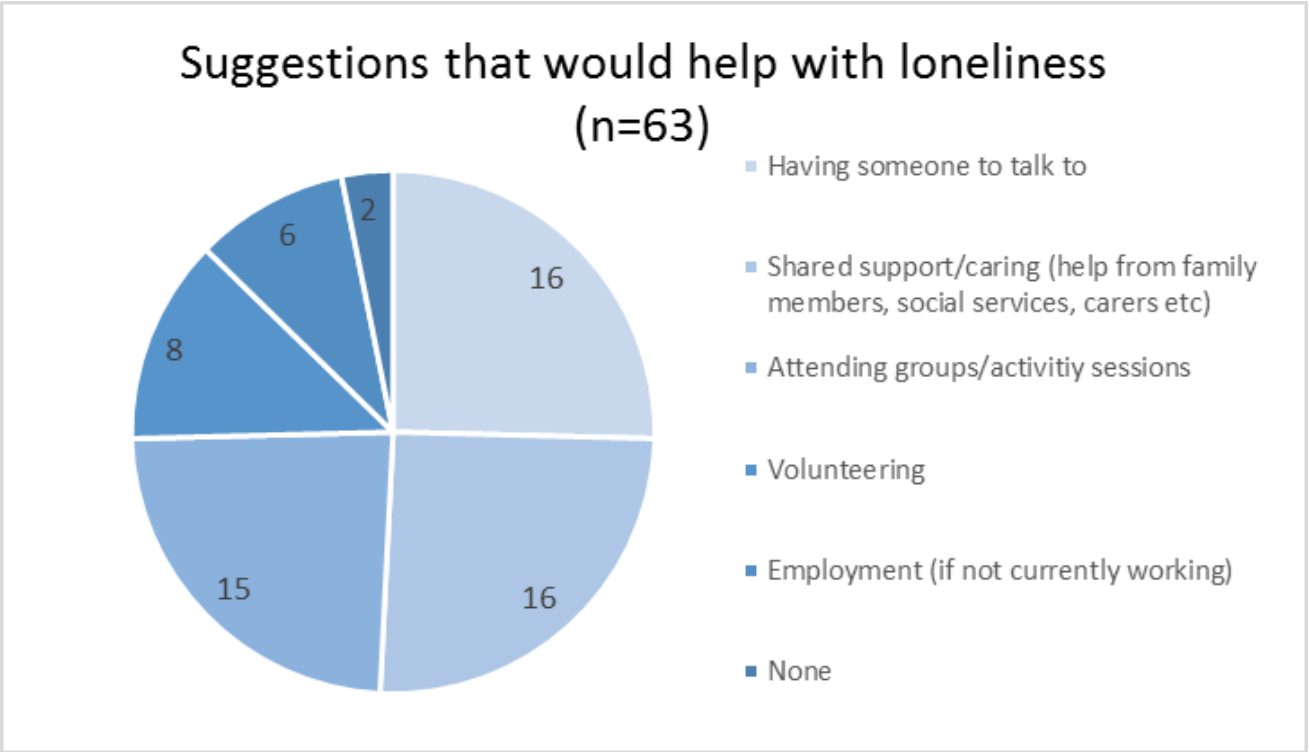
"It's put a massive strain on our family life. The people who understand are carers themselves."

"I don't have a social life as I'm too exhausted to go out. I'm also financially poorer having given up work to care for my kids."

Effect on life

There were significant effects on people emotionally and socially which contributed to feelings of isolation.

Suggestions that would help with loneliness (n=63)

- Having someone to talk to — 16
- Shared support/caring (help from family members, social services, carers etc) — 16
- Attending groups/activitiy sessions — 15
- Volunteering — 8
- Employment (if not currently working) — 6
- None — 2

Additional comments taken from people stating 'anything else' (11):

Neighbour and friend support – "Feeling that neighbours or family genuinely want to help. Or that a friend is really happy to listen."

Continuity in classes needed – "I've found that taking classes concerning interests I already have helps as I immediately have something in common with others. However, I have found that some networks vanish once the class closes down. Finding a 'replacement' class at a time and place that suits can be really difficult."

Respite care – "No family available to support and low level of respite. More respite would be wonderful and good quality home care."

People wanted contact with others as a means of sharing experiences, relief from their responsibilities and asking for support.

Not being left alone or feeling unsupported would go some way to reducing or removing isolation.

We also explored what 'talking' to someone might mean:

Face to face – 17 responses   Group setting – 13 responses   Online – 7 responses

Comments from those that stated 'other':

If face to face, suggestion this should be done in a friendly informal way "Face to face, but would feel like It was a very formal situation. Not someone who is a friend or genuine. Almost like a job."

Recognising not everyone can use online easily "Any option would be great however I'm not great online I need help."

Total responses 50 •Not applicable – 9 responses •Other – 4 responses

Suggestions for help – groups – Analysis

We collected a number of examples of activities people liked:

- Sport/outdoor activity
- Craftwork
- Volunteering
- Art
- Singing
- Socialising
- Reading
- Learning/informing self
- Writing
- Theatre or shows
- Therapies (beauty, massage, mind/body)
- Cooking/baking
- Shopping
- Sport (watching)
- Quizzes
- Conferences/fairs/conventions
- Music (listening or playing)
- Culture/heritage sites
- DIY

Roughly half of people said they were not attending local groups:

13 - People accessed local groups/clubs
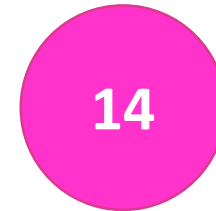
14 - People did not access local groups/clubs

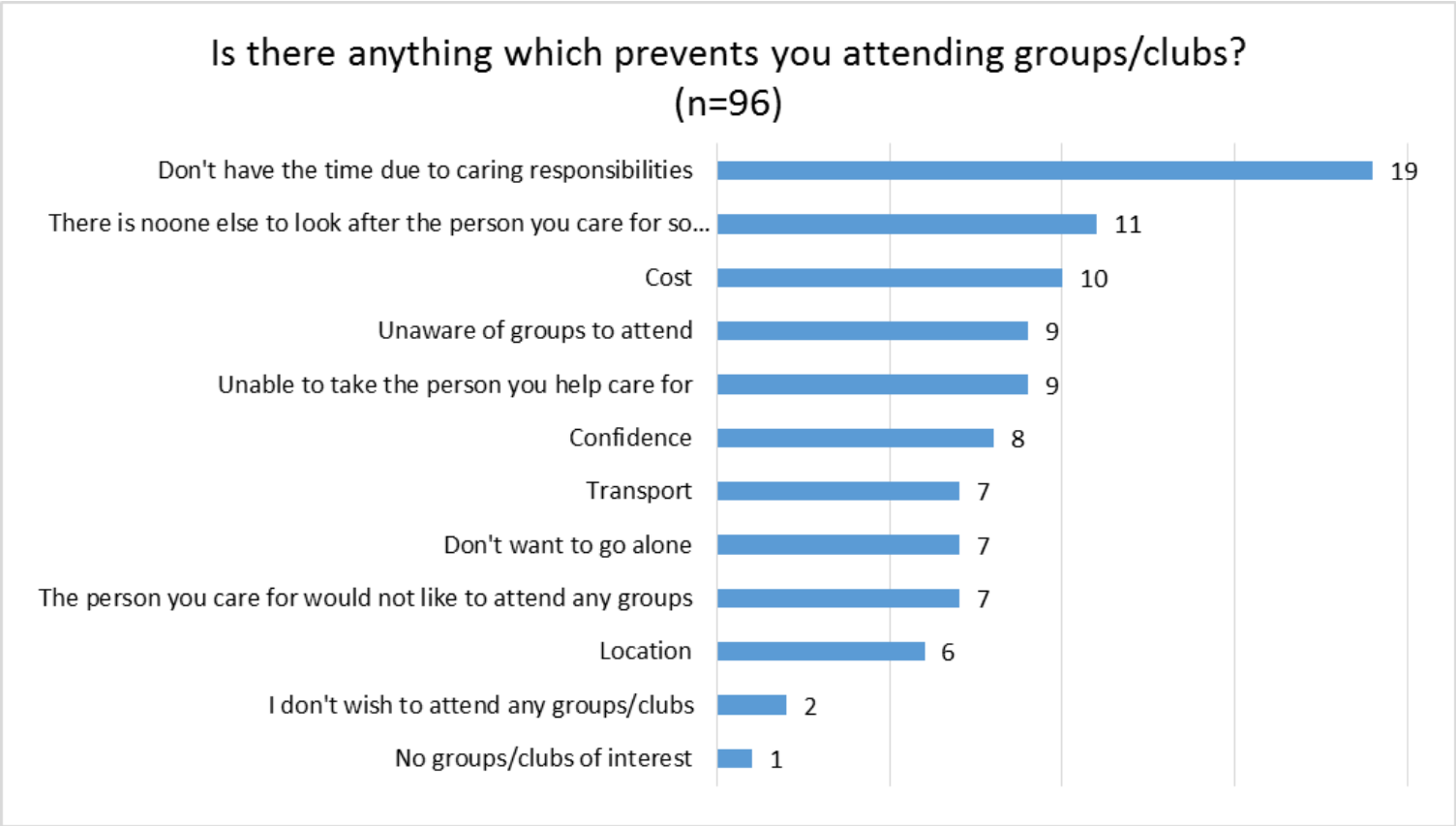Exploring the challenges to attending groups and getting support from others:

Is there anything which prevents you attending groups/clubs? (n=96)

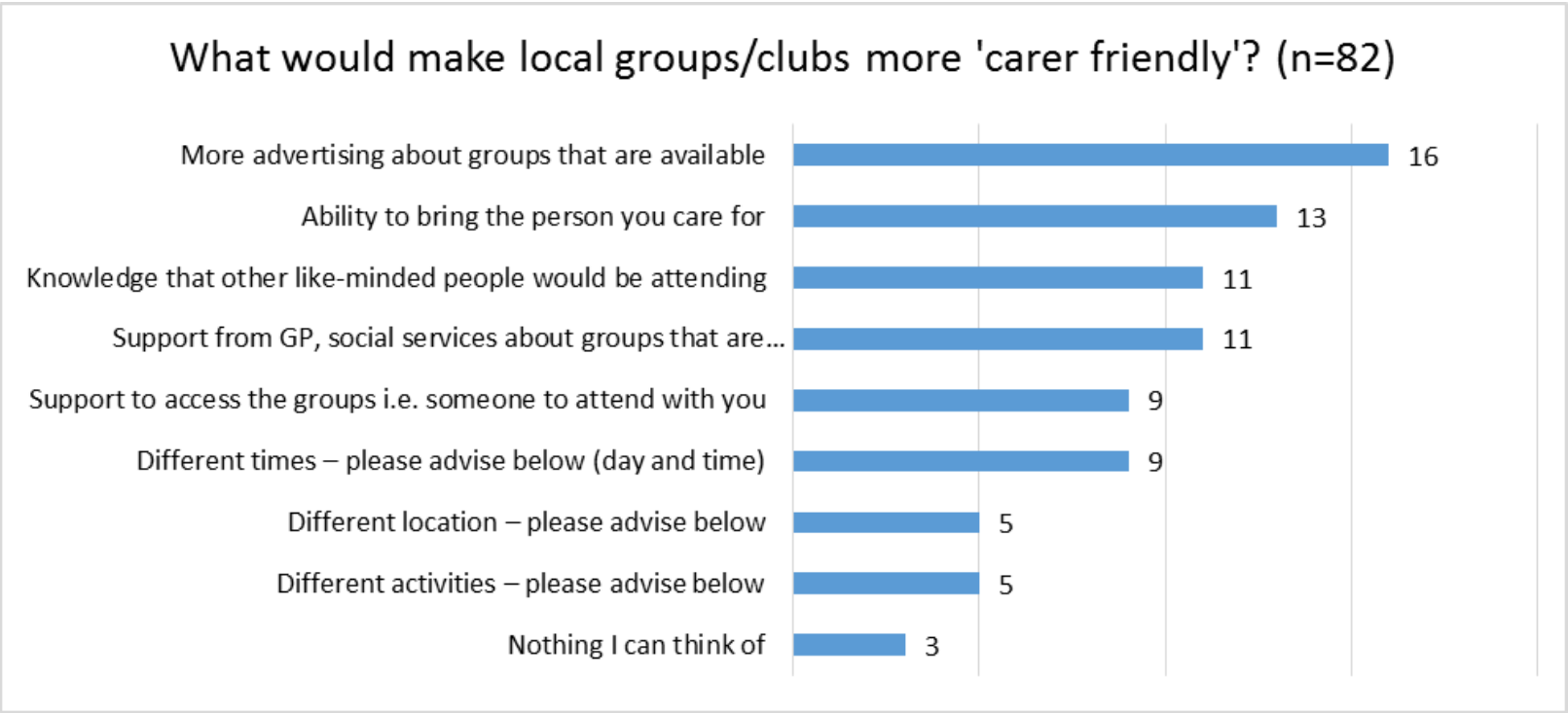| Category	Value
Don't have the time due to caring responsibilities	19
There is noone else to look after the person you care for so…	11
Cost	10
Unaware of groups to attend	9
Unable to take the person you help care for	9
Confidence	8
Transport	7
Don't want to go alone	7
The person you care for would not like to attend any groups	7
Location	6
I don't wish to attend any groups/clubs	2
No groups/clubs of interest	1

Other:

"In my own case, caring responsibilities interfere only when a minimum regular attendance is demanded as I can't guarantee I'll make any given session or (in academic settings) work placements required."

"Son currently in an ATU 140 miles from home so can access, but not appropriate to take him to places with me all time and he struggles to go and really doesn't want to be hanging out with his mother no more than brother would."

"I've seen groups going on and would love to attend however firstly the family members I care for are housebound 99% of the time in the last 5 years I can count on one hand the amount of times both of the members of family I care have been well enough to get out, however because it takes a lot of there strength and energy to get dressed and ready to go out even with my support so the amount of times we've made it out is then halved."

"I work full time as well as being a career. Lots of the groups I've seen are during weekdays when I am at work."

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Exploring how to improve groups/clubs for carers:

What would make local groups/clubs more 'carer friendly'? (n=82)

Category	Value
More advertising about groups that are available	16
Ability to bring the person you care for	13
Knowledge that other like-minded people would be attending	11
Support from GP, social services about groups that are...	11
Support to access the groups i.e. someone to attend with you	9
Different times – please advise below (day and time)	9
Different location – please advise below	5
Different activities – please advise below	5
Nothing I can think of	3

Time

"I would like to try more academic courses. While I appreciate WHY there are minimum attendance requirements and placements etc., it would be great if there was more flexibility to make this possible for carers. Especially those of us who also work and would struggle to make placements, lectures and other activities".

"Morning groups, so I would be in time to pick my children up from school."

"Weekend groups, evening groups."

Location

"Going to Thicketford suits me, but may be difficult for others. Perhaps move some around Bolton and the area."
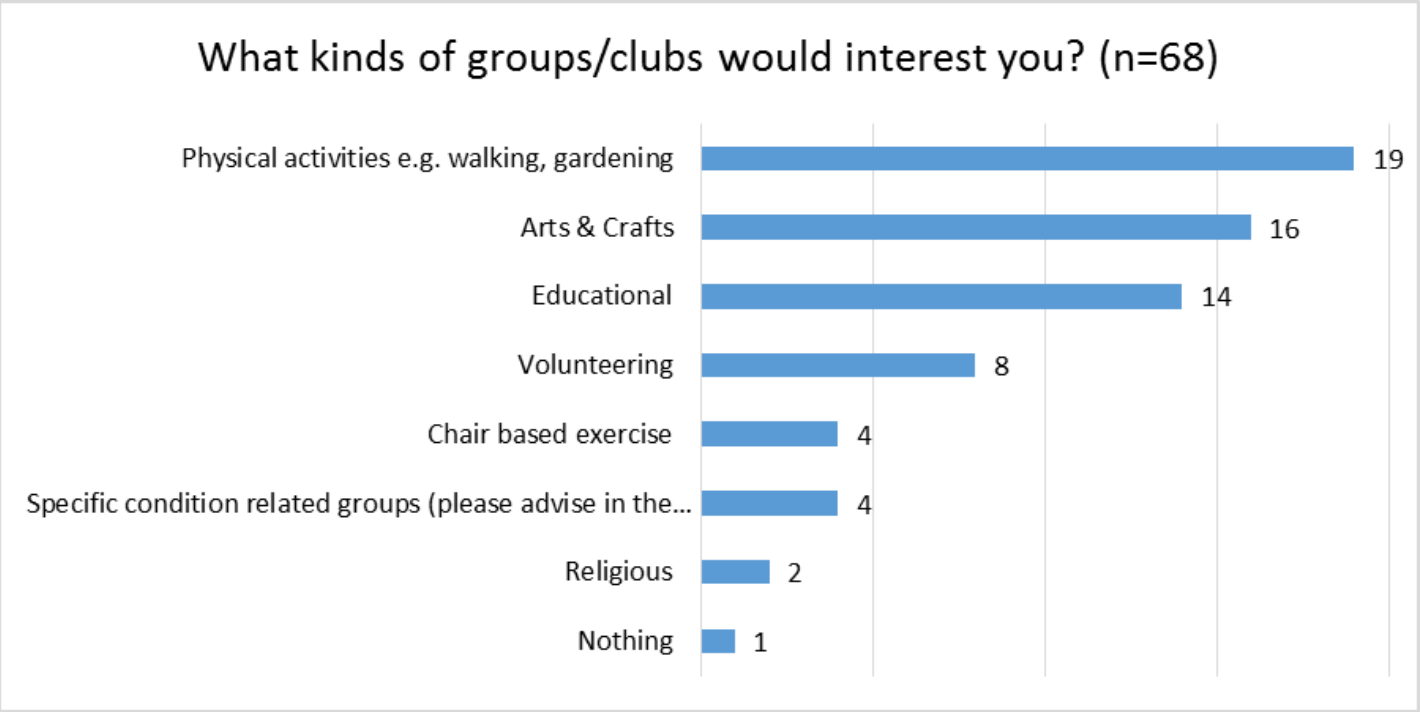
Other

"The groups could try and organise car shares."

"More information on groups is the main thing. No one tells you what is out there so how are we supposed to know where we can go. The GP doesn't tell you. You get a diagnosis and are just left."

Exploring how to improve groups/clubs for carers:

What kinds of groups/clubs would interest you? (n=68)

Category	Value
Physical activities e.g. walking, gardening	19
Arts & Crafts	16
Educational	14
Volunteering	8
Chair based exercise	4
Specific condition related groups (please advise in the…	4
Religious	2
Nothing	1

Specific condition groups mentioned:

"Motor neurone disease."

"Headache/migraine/chronic pain."

"Carers in same position as self."

When we asked how people preferred to attend groups/clubs, the majority preferred either to be separated from the person they care for during activities, or to go alone. This speaks to the need for respite.

We also asked the best method of communication about groups/clubs, the most popular group was email, newsletters, leaflets in GP, leaflets in relevant services and text messages. Newspaper and radio were the least popular.

Conclusions

- Experiences of the caring role have been explored from the carer's point of view. It is clear for many the challenges of loneliness and isolation are related to a lack of support, time away from their caring role and the responsibilities placed on them.

- People were asked to share possible ways to alleviate loneliness and isolation. Many useful suggestions were found, the report shows what activities and which interests people have, it also shows useful groups and clubs people are already engaging with.

- Finally people have given examples of ways communication and attendance could be improved by local groups and clubs. As most people expressed concern about support and having a break from their caring responsibilities, there is potential to improve the situation.

Healthwatch Bolton would like to thank all those that took part in this research or facilitated it to take place.

Possible useful groups mentioned by participants:

- Bolton carers
- Bolton Carers Support
- Wonder women group
- Tonge Moor carers group

- Working Potential Walk & Talk group (Bolton at Home)

- University of the 3rd Age
- Art group organised by Stroke group
- UCAN centres
- Local church

- Stroke support group
- Community choir
- Facebook group