



Report Title:	Carers report group work - loneliness and isolation
Organisation:	
Date(s):	Get ready for winter 25.10.18 / Tonge Moor groups 22.01.19
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Acknowledgements

Healthwatch Bolton would like to thank those that took part for sharing their views and experiences.

Disclaimer

This report relates verbatim comments gathered during the time of our visit. All comments recorded by Healthwatch Bolton have been added to Healthwatch Bolton's databank of patient comment.

Background

Loneliness and isolation were key concerns found in our initial report on carer experiences - 'what makes a carer friendly community?' To follow up on these two areas a survey was conducted to gather more information, the findings will appear in a separate full report.

As a companion to the ongoing work we also gathered people's views on loneliness and isolation at two events during the past year. At the annual 'get ready for winter' day Healthwatch Bolton asked local people for their views. We also visited a carer group in Tongue Moor to gather people's views. Comments from these two groups feature in this snapshot.

Strategic drivers

- This project fits with our priority 'carers' which was voted the 3rd most important area for 2018-2019 by our members and the public.
- This project is intended to inform voluntary and statutory sector professionals in terms of how they currently and potentially can help individuals tackle difficulties related to caring.

- 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.

Who we spoke to

Get ready for winter event - general comment collected from members of the public.

Tonge Moor groups - we held two focus groups and spoke to ten people.

Method

A total of 94 comments were gathered for this research. Engagement officers also made a number of additional observations and summaries when working with groups.

Get ready for winter event - a series of three questions were asked:

1. What does lonely mean to you?
2. Can you name any groups/clubs in Bolton?
3. Can you name any carers groups/clubs in Bolton?

Tonge Moor groups - eight questions were asked:

1. Length of time caring and for what reason
2. What do loneliness & isolation mean to you?
3. How has life changed for you, what things did you used to do that you aren't able to anymore due to your caring responsibility?
4. How does this make you feel?
5. What kinds of activities would you like to do?
6. How would you best like to access these activities? Alone, with the person you care for, or with the person you care for but with them being looked after in a different room?
7. What do you think of the sit-in service being offered by Bolton Carers?
8. How should groups inform them of activities/services?

Topics/Themes

- Loneliness • Isolation • Solutions • Groups/clubs

The Comments

People's responses have been grouped under several headings to make the findings easier to understand. Only a selection of the comments have been included, in order to represent a variety of views.

Loneliness and isolation

We asked people to share their opinions of loneliness and isolation. They felt the lack of contact with other people was a key part of being lonely or isolated.

"Lonely means being by yourself."

"Having no friends."

"Lonely means I feel left out."

"Alone looking at four walls all day. No-one to talk to or see for days or weeks."

Loneliness was also heightened at certain times of the day or around meaningful events. (Engagement officer observation)

The group said they have feelings of loneliness at least 2/3 times a week. It can be worse during certain times e.g. Christmas, a person's birthday but in general the feelings of loneliness are there all the time. (Engagement officer observation)

One person in the group said they felt isolated on a daily basis whilst 4 others said they feel it mostly at the weekends. One person said she tried not to think about it. If she does she feels isolated so she tries to keep her mind occupied with other things. (Engagement officer observation)

Effects

People were affected by a lack of free time, this could mean loss of friends and made it harder over time to remain socially active.

"Don't have time to do normal socialising."

"My life revolves around caring now."

"I started caring because I wanted to but now I do it because I feel like there is no alternative."

"Any change of routine can be difficult especially for those with dementia. This means it is difficult for the carer to get involved in things within the community."

"Those with mental health are hard, you never know what they are going to be like on a day to day basis so I can't commit to going to groups or sessions as I may not be able to."

Activities

We also asked people what activities they would like to do:

- Arts & Crafts
- Film club
- Gym Volunteer
- Go back to work

There were some suggestions about what could be done to support carers:

"Local carers groups which offer trips out. It's nice to be able to go out somewhere with other like-minded people, it also gives you something to look forward to. As it's with other carers they know and

understand the importance of all the planning involved in being able to do things like this so trips are organised with that in mind i.e. shorter more local trips, rally around to offer carer support etc.”

“Just getting out anywhere. Sometimes I literally just have to walk down my street as I need to get out of the house. Or I will go to the local shop to buy something as it means I get to see and speak to someone else but it doesn’t take too long.”

Access

Within our focus groups we had some useful comments on the challenges of accessing groups with those being cared for:

Three said ‘alone’ as it provides a respite from caring (worried that if cared for in another room they would still be relied upon), however after discussion with others in the group they decided that if this wasn’t to be the case they would change their minds and like for them to come with them?
(Engagement officer observation)

All six eventually decided they would like to attend with the cared for person being supported by someone else. It allows the carer to still get a break, it’s a treat for the cared for, it gets both people out of the house. (Engagement officer observation)

All four said they would like to go to some alone as it provides them a break from their caring responsibility. (Engagement officer observation)

Informing

We also wanted to explore how people could be better informed about existing groups and activities. Four suggestions emerged:

- Telephone
- Email
- Through GP
- Newsletter

Within the focus groups people did not feel they had enough information from those they came into contact with. There was some lack of awareness on the benefits of officially registering as a carer with a local GP. (Engagement officer observation)

This group in particular talked about the lack of information they received from their GP and the council. There was also a lot of confusion around the reason as to why you should be registered with certain people i.e. the council and many thought that if you were registered with Bolton Carers this meant you were registered with the council and anyone who needed to know, because they are associated with the council and use Bolton council colours and designs. (Engagement officer observation)

As with the other group this group talked about the lack of information they received from their GP and the council and carers services in general. They also didn’t understand why you would need to be registered with certain people and didn’t see what the benefit of this was and who was supposed to inform you of things like this. (Engagement officer observation)

Sit-in service

We found lack of awareness about Bolton’s sit-in service from those in the groups:

All 6 had never heard of the service but worried about how much time they would be allowed, how often they could use it and for how long (i.e. could you only use it for a period of six months then they say someone else needs to have a turn now) and worries about who the person sitting in would be. If it was someone who was trained to support a person with the specific difficulty required, they matched people on personalities and interests and they were allowed to meet with them a few times and it was the same person each time all six of them said it would be a good thing. (Engagement officer observation)

All four said they didn't like this idea. They said mainly this was because the cared for person wouldn't want someone new that they didn't know suddenly coming into their house to look after them. This was especially the views of those who looked after people with dementia, learning disabilities and severe mental health issues. (Engagement officer observation)

Groups

We gathered a list of groups people mentioned they were aware of. Increasing awareness of what is available could help improve the support people are getting and reduce isolation and loneliness.

General groups:	Carer based groups:
<ul style="list-style-type: none"> • Social services • Dance clubs • Harmony youth club • Brownies • Gymnastics • Swimming • West Houghton OAP's • Castle Hill Youth Club • Mental health clubs • Rainbows • Youth Club • Dramatic action (volunteering) • Brazley community centre • Day services • Age concern • The 'Friendly Hour' at St Catherine's Church Farnworth • UCAN 	<ul style="list-style-type: none"> • Bolton carers • Thicketford House carers group • Thicketford Road • Carers and Stroke Association Bolton

Conclusions

This report should ideally be read alongside the companion piece, which summarises the results of our survey into loneliness and isolation amongst carers.

The pressures of being a carer can restrict free time and the chances to socialise. A lack of free time reduces access to respite from a caring role. People may lose support networks due to lack of contact.

If possible there should be improved awareness – through GP and other medical services – of existing local groups and access to respite.

Telephone, email, magazine were supported as ways of communicating with people.

There was also desire to make use of GPs to spread information.

Get ready for winter	Responses
1. What does lonely mean to you? (How does it make you feel, how would you stop someone from feeling lonely)	25
2. Can you name any clubs/groups in Bolton	18
3. Can you name any carers groups/clubs in Bolton	5
TOTAL	48

Tonge Moor groups	Responses
Length of time caring and for what reason: (many of these carers care for more than one person e.g. both parents, parent and partner, child and parent)	10
What does loneliness & isolation mean to you	2
How has life changed for you, what things did you used to do that you aren't able to anymore due to your caring responsibility	28
How does this make you feel?	6
What kinds of activities would you like to do?	-
How would you best like to access these activities? Alone, with the person you care for, with the person you care for but with them being looked after in a different room?	Summary given by engagement officer
What do you think of the sit in service being offered by Bolton Carers?	Summary given by engagement officer
How should groups inform them of activities/services?	Summary given by engagement officer
TOTAL	46