

Adult Carers

Exploring their views & experiences of Health & Social Care
Provision in Blackburn with Darwen

November 2016

Disclaimer

Please note this report relates to the findings from 83 Adult Carers. Our report therefore is not a representative portrayal of the experience & views of all Adult Carers in Blackburn with Darwen, only an account of what was represented at the time.

Acknowledgements

Healthwatch Blackburn with Darwen would like to thank the following organisations, groups & volunteers for their involvement & support with the project:

- Barbara Castle Way Health Centre
- Blackburn with Darwen Carers Service
- Darwen Health Centre
- Memory Café, Revidge Fold
- Senior Social, The Old Function Room, Darwen
- Shine, Ivy Street Community Centre
- Sliding Doors
- YSYC

Adult Carers Task Group Members, Angie Allen, Diane Adams, Lori Homayon Jones, Richard Moorby & Karl Riding.

Thank you to Karl Riding for kindly providing illustrations for this report.

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Introduction

Healthwatch Blackburn with Darwen decided to explore the views & experiences of Adult Carers in Blackburn with Darwen. According to Carers UK 1 in 8 adults care for family & friends on an unpaid basis, with 6000 more people becoming Carers every day.

Why Adult Carers?

In the 2011 Census there were 5,430,016 Carers in England, this accounting to an 11% increase since the 2001 Census.

It is estimated that there will be 9 million Carers in the UK by 2037.

Local Statistics

In the 2011 Census there were 15,756 self-identifying Carers in the borough, over 4000 of these people provided more than 50 hours of care per week.

Research Methods

Task Group

A task group was formed prior to the launch of the project, this was made up of volunteers with both an interest or lived experience of being a Carer. The task group met monthly throughout the project to ensure everything was going to plan, review engagement activity & findings. They also actively attended events, promoted the project & acted as both facilitators & researchers throughout the project.

Questionnaire

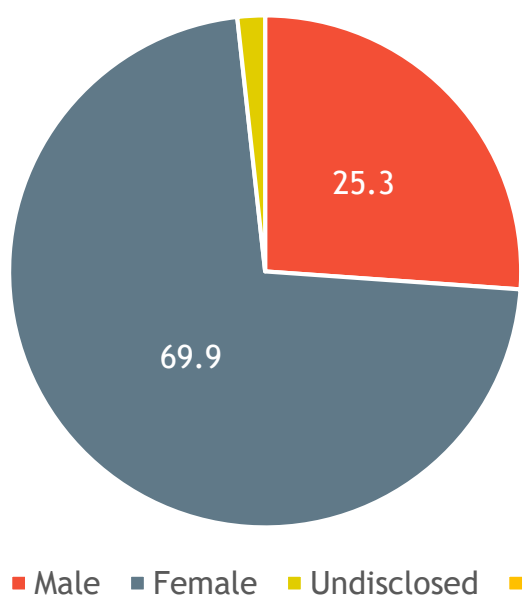
Volunteers helped to devise the questionnaire, this was used to gather feedback face to face whilst also be sent out electronically & by post by both Healthwatch BwD & Partner Organisations.

The use of language was important to ensure we engaged with as many residents as possible. Rather than asking if someone was a carer we asked if they lived with and/or supported someone with a Physical or Mental Health Condition or Substance Misuse Issue.

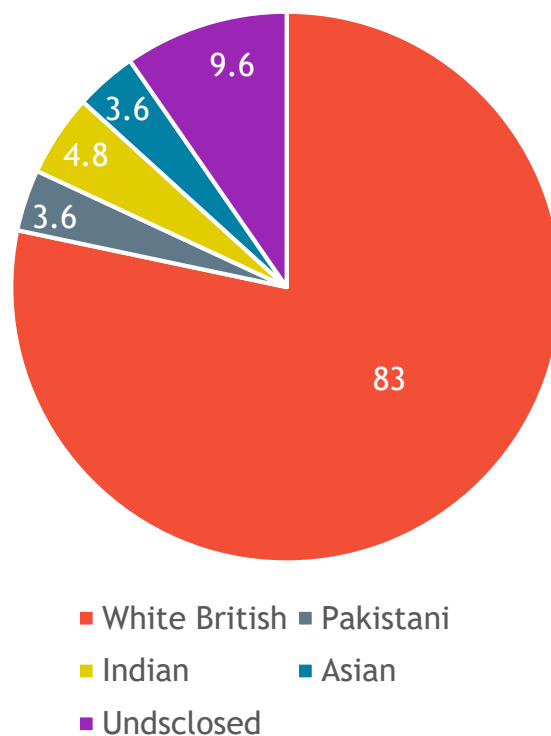
Who we spoke to?

In total 83 residents shared their views & experiences with us.

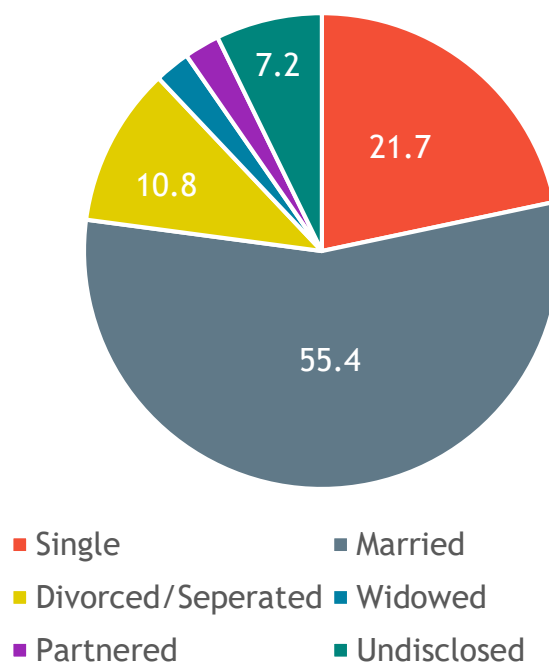
Gender



Ethnicity



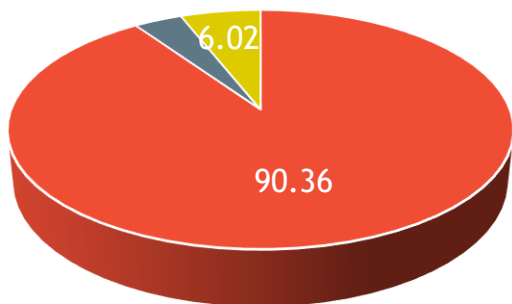
Marital Status



*Please note any figures presented in this report are % values unless otherwise stated.

Research Findings

Do you live with and/or support someone with a Physical and/or Mental Health Condition or Substance Misuse Issue?



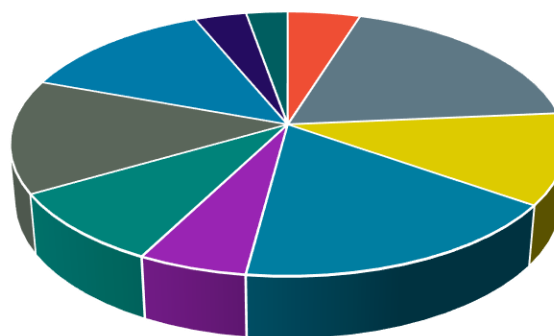
■ Yes ■ No ■ Some of the time

'All my adult life & solely for the last seven years' Single Female 45-54

'Over the last few years my husband has developed dementia'

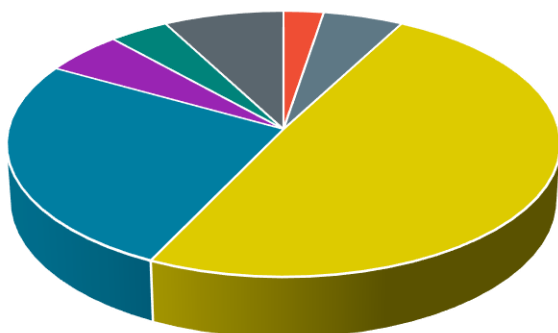
'Five years, gradually gone worse'

What tasks do you carry out in order to support this person?



■ Financial
 ■ Cooking
 ■ Cleaning
 ■ Personal Care
 ■ Washing/Laundry
 ■ Shopping
 ■ All needs
 ■ Medication
 ■ Remind me about things
 ■ Daily Living Tasks

How long have you lived with and/or supported this person?



■ Up to 12 months ■ 1-2 years
 ■ 2-10 years ■ 10-20 years
 ■ 20-30 years ■ 30-40 years
 ■ 40 years +

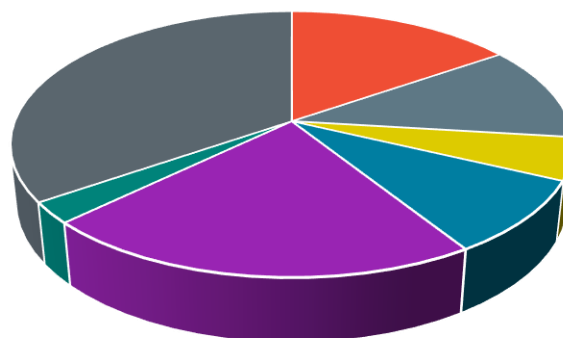


'I am there day & night. I do everything, wash, clean, cook'
Married Female 64+

'Following him round, he gets muddled up doing things' Married
Female 64+

'Monitor his drinking' Married Female
55-64

What support and/or equipment do you use in order to support this person?



- Wheelchair
- Walking Stick/Frame
- Stair Lift
- Hand/grab rails
- Bath/Shower Chair
- Personal Alarms
- None

'he sleeps downstairs, we have an outside toilet' Married Female 45-54

What support and/or equipment do you need in order to support this person?

Participants mentioned a wide range of support & equipment,

- Better Mental Health Assessment 1.2%
- Verbal Skills 2.4%
- Stair lift/walking aids 3.6%
- Respite 3.6%
- Sensory aids/training 3.6%

- Training & knowledge of what's available 7.2%
- Showering facilities 4.8%
- Support with employment 1.2%
- None 27.7%

'Good training from health and social care staff on how to communicate with hard of hearing/deaf people. Also how to change batteries, switch hearing aids off and on. Shouting at a deaf person or telling them to turn up deaf aid is not helpful' Single Female 55-64

'He used to have Creative Support but since a hospital admission he lost the support, they took his budget off him' Married Female 55-64

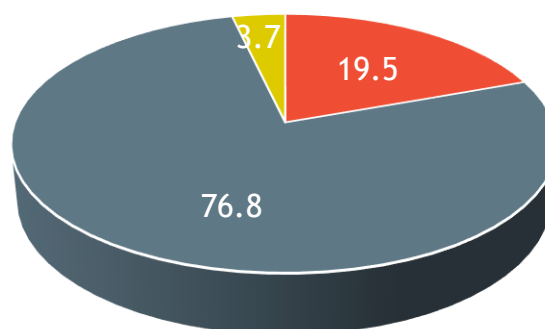
'A day off once a month from having to nag him to come to the machine and use it correctly till he's had the full benefit then use his flutter correctly to clear phlegm, would be a life saver'

'Support getting my daughter into employment, she has learning difficulties, sorting out about her future if anything happens to me' Widowed Female 55-64

'I don't know what I would like, we just look after her' Married Female 65+

'Having someone to ask 'am I doing this right?' Married Male 45-54

Have you been offered and/or attended any training to help carry out your caring role?

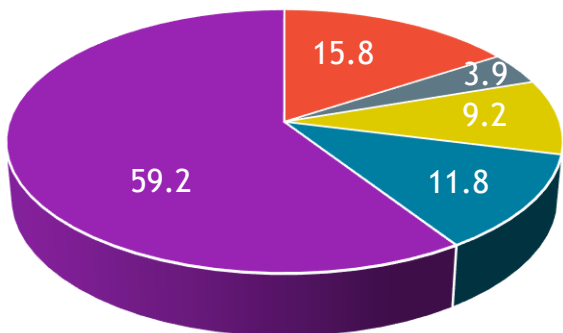


■ Yes ■ No ■ Unsure ■

If you attended training how would you rate it?

- Very Good 38.1%
- Good 38.1%
- Okay 23.8%

Does the person you live with and/or support need specialist carers (e.g. overnight)?

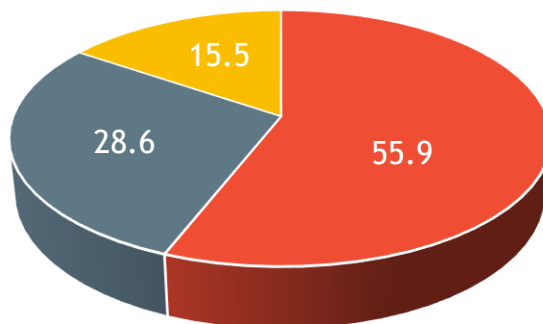


- All of the time
- Most of the time
- Some of the time
- Rarely
- Never

'family do it. If my daughters and I weren't there it would be difficult.'
Married Male 45-54

'all the time, the carers were coming in at the wrong time'

Are you aware of local services that can support your health & wellbeing?



- Yes
- No
- Unsure

'yes but we don't fit any bracket'

If so what services have you accessed?

Carers Service 29

Social Services 7

'I have a cleaner and good neighbours'

'we go to the dementia café once a month' Single Male 45-54

'we manage on our own' Married Female 64+

What was your experience of these services?

65.1% of participants said their experience was good or very good

The experience of other participants was very mixed, recurring themes were the length of time involved & poor communication.

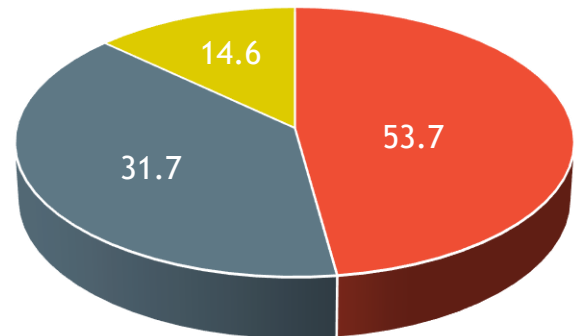


'Social services are very drawn out, took 12 months to get what we needed' Married male 64+

'Carers Service, fantastic, I don't know where I would have been without them'

'seem to be going round in circles' Married Female 25-34

Do you know where to get information that can support you?



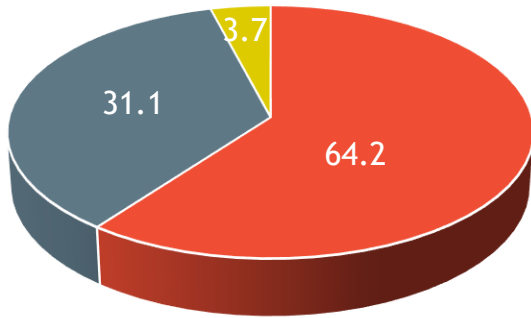
■ Yes ■ No ■ Unsure

'I recommend YSYC, I attend regularly' Married Female 55-64

'Yes although we don't always fit the criteria, get passed pillar to post' Married Female 45-54

'Unsure, when you do something all the time you just continue doing it'

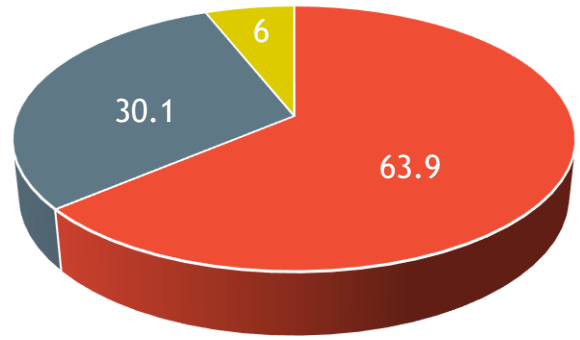
Do you know where to get information that can support the person you live with and/or support?



■ Yes ■ No ■ Unsure

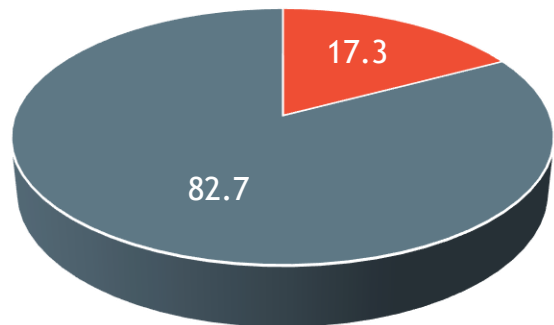
'Yes but the local authority support for mobility training is based on the assumption that the person is not working and can access services during working day'

Do you know about respite Care?



■ Yes ■ No ■ Unsure

Have you used respite care?

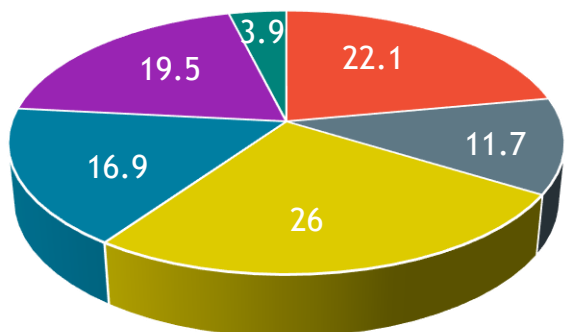


■ Yes ■ No

'No because we are told it's not available for mental health' Married Female 55-64



Do you feel valued as a carer by Health & Social Care Services?



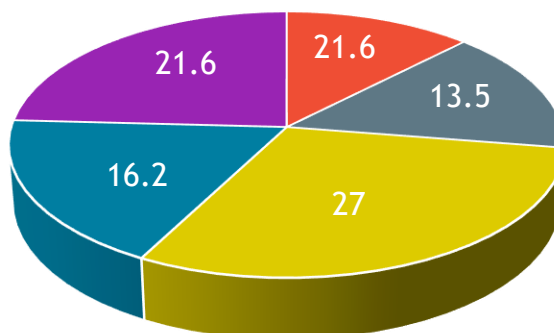
- All of the time
- Most of the time
- Some of the time
- Rarely
- Never
- Unsure

'No not really, went to GP to get info for son, he said he doesn't deal with it' Married Female 64+

'Never, I feel used, like I'm having to do their job for them' Married Female 45-54

'Rarely, social services very poor, rarely get back to you. Aids & Adaptations communicated directly with grandmother who has Alzheimer's and didn't inform family. Grandmother didn't understand phone call regarding referral and case was closed without liaising with family'

Do you feel listened to as a carer by Health & Social Care Services?



- All of the time
- Most of the time
- Some of the time
- Rarely
- Never

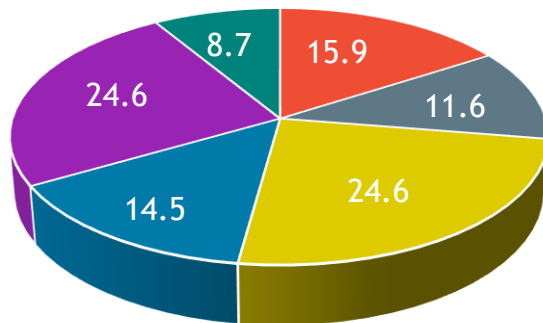
'I gave up years ago trying to have decent conversations with health and social care services' Female 64+

'they don't always appreciate the view of the carer'

'More adult carers support groups needed, on a bad day you have nobody'

'It was quite frustrating dealing with the receptionist, although it was on his records he had dementia I asked the GP surgery not to ring home as my husband couldn't relay messages back to me, it took months to get through to them.'

Does the person you live with and/or support feel listened to by Health & Social Care Services?



- All of the time
- Most of the time
- Some of the time
- Rarely
- Never
- Unsure

'noticed a change, son is now seen as an individual'

'he wouldn't be aware'

'never, he says they are not listening to me mum'

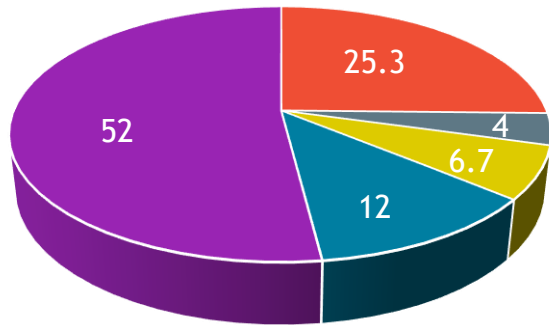
'some of the time, people on the front line are good but you rarely see them'

'has no faith as feels been lied to too many times'

'social workers & care agencies seem to have poor knowledge of Alzheimer's'

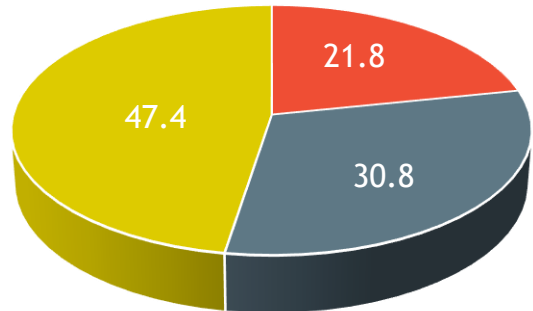


Do GP's ask if you live with and/or support someone?



- All of the time
- Most of the time
- Some of the time
- Rarely
- Never

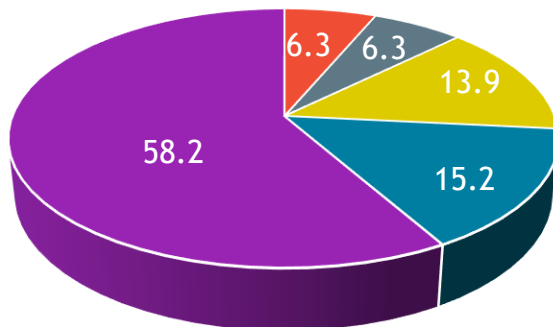
Are there additional services and/or support that would benefit you that are not currently available?



- Yes
- No
- Unsure

'they knew I was, they were rubbish'

Do other health professionals ask if you live with and/or support someone?



- All of the time
- Most of the time
- Some of the time
- Rarely
- Never

'somebody who could get my partner to go to the doctors'

'Free aqua mobility sessions in small pool, early evenings not just day time/term time'

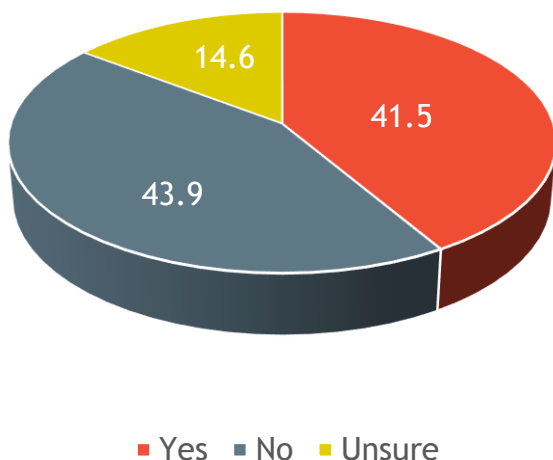
'Having somebody who I could trust to go in and check on him'

'respite on a par with foster carers'

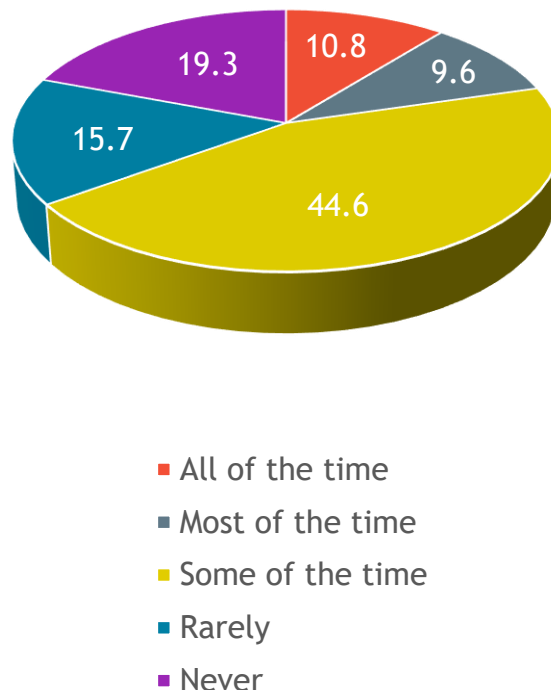
'It would be nice if there was somebody at the end of the phone who would listen'

'social workers, direct payments, care agencies to better communicate with each other'

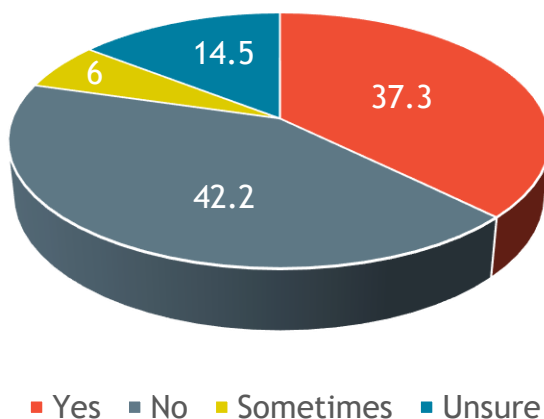
Do you need any support or help in your caring role?



Do you ever feel lonely and/or isolated?



Does the person you live with and/or support need any other help or support?



'I became isolated because I was stopping in all the time'

'haven't really got a companion anymore, hard when he's been a husband for 50 odd years'

'rarely, I have a good network of friends'

'some of the time, I feel there is no way out'

'all of the time, gone from full time job to full time carer'

'all of the time, I felt like I was on eggshells all the time'

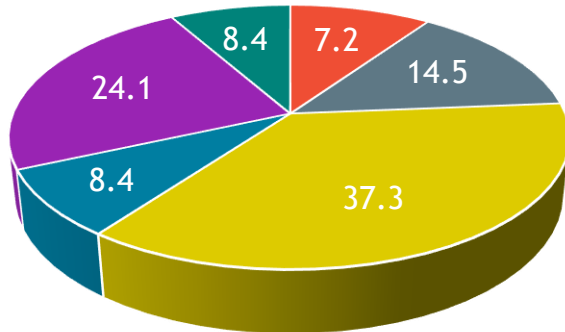
'He feels frustrated and at a loss. I feel he is ungrateful sometimes for the things I do'

'I think he needs it, I don't know if he would accept it'

'it would be good if someone followed up on their social aspects, I have found it difficult to get my father in law to take interest in outside activities'

'I need the care, to help me cope'

Does the person you live with and/or support ever feel lonely and/or isolated?

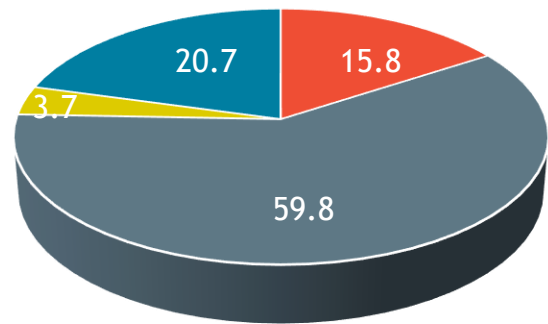


- All of the time
- Most of the time
- Some of the time
- Rarely
- Never
- Don't know

‘not being able to get out and socialise is a problem for mum as she always had a wide circle of friends’

‘not as bad now he has a guide dog’

Do you feel living with and/or supporting someone with a physical or mental health need has an impact on your own health?



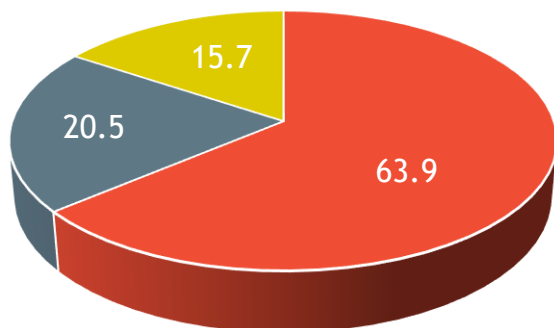
- Positive
- Negative
- Both Positive & Negative
- No impact

‘not as active as I used to be, snacking on food because I am in more. You don't tend to look after your health’

‘Stress has brought on allergies & blood pressure’

‘I retired five years ago because of stress, nerves, burnout. Caring has caused me one breakdown and am trying to avoid another one.’

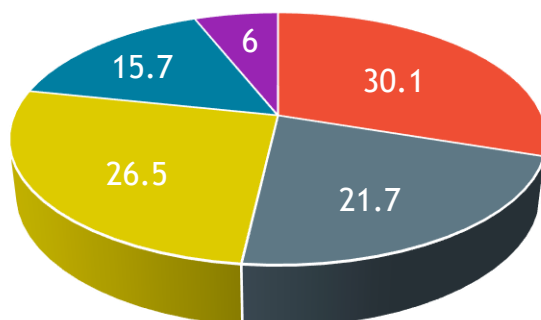
Do you feel you have the right support to look after your own health & wellbeing?



■ Yes ■ No ■ Unsure ■

'I attend a Adult Carers mental health support group, they have been really helpful. I only found out about the group when my daughter was hospitalised in March even though she has been under the mental health team for four years!'

Do you have someone you can talk to?



■ All of the time
 ■ Most of the time
 ■ Some of the time
 ■ Rarely
 ■ Never

'They get fed up of listening to the same thing, you bottle it up'

How much time do you spend caring for the person you live with and/or support?

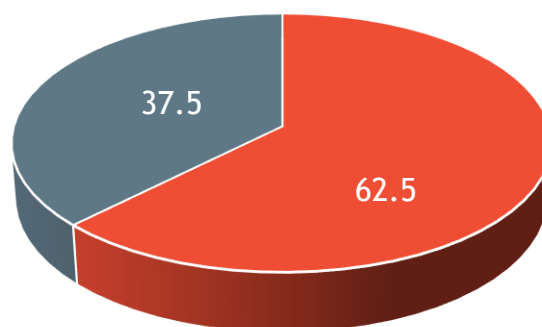
65.8% of participants said their caring role was a 'full time job' (24/7)

11.8% spent between 3-6 hours per day in their caring role

6.6% struggled to identify how much time they spent caring & said it often varied

'24/7 x 365 + counting'

What impact does this have on your family and/or social life?



■ Big Impact ■ Not much impact

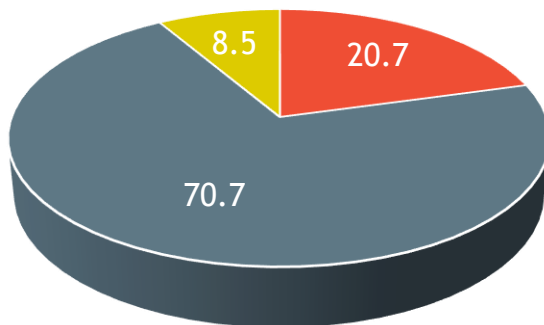
'Friends don't come as often, only time I get is when he goes to hospice for a few hours and when dementia buddy comes'

'I've chosen to care so this is my choice'

'I don't have a social life, my family is falling to bits, it has an impact on marriage and family'

'wrecked it'

Do you feel you have faced any discrimination and/or stigma in your caring role?

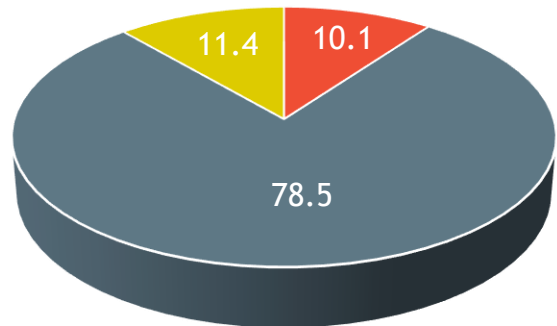


■ Yes ■ No ■ Unsure ■

'My GP has been a pain and has no idea when I have gone to him for pains in my head through stress, he does not care and has never discussed my role as a full time carer'

'not taken seriously by social services & care agencies'

Do you have a plan in place if you can no longer live with and/or support the person?



■ Yes ■ No ■ Unsure

'never really thought about it. As long as I live I'll support him'

'I will get a life'

Conclusion

Participants carried out a range of tasks to support the person they cared for with 24.1% carrying out all the needs for the individual.

76.8% of participants hadn't been offered or attended training to help them carry out their caring role, although those who had attended found it helpful with 76.2% finding it good or very good.

55.9% of participants were aware of local services that could support their health & wellbeing, yet almost 30% of participants were not aware.

Those who had accessed services had a mixed response, third sector organisations on the whole received positive feedback whilst participants were less favourable towards Social Services having had poor experiences, particularly with the length of time & the feeling of 'going round in circles'. Carers Service was mentioned on numerous occasions as being helpful, as was YSYC.

31.7% of participants didn't know where to get information about services that support unpaid carers, whilst 32.1% didn't know where to get information that could support the person they cared for.

63.9% of residents knew about respite care although only 17.3% of participants had used it. One participant mentioned how it only seemed to be offered to those with Physical rather than mental health needs.

Only 22.1% of participants felt valued as a carer all of the time with 19.5% of participants saying they never feel valued. Social Services & GP's received negative feedback.

21.6% of residents felt listened to by Health & Social Care Services all of the time whilst 21.6% of them never felt listened to. Carers spoke of 'giving up' & not being appreciated.

Those being cared for had a similar experience with only 15.9% of Carers feeling they were listened to all of the time. 24.6% felt those they cared for were never listened to.

52% of participants said their GP had never asked if they lived with or supported someone with a Physical or Mental Health need. The experience of the 25.3% who had been asked wasn't always a positive one.

Participants spoke of various things that would benefit them, in particular having somebody to talk to, better communication & trust in professionals.

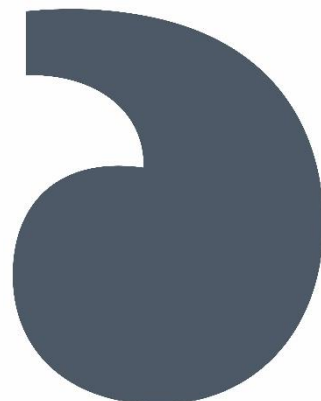
41.5% of participants felt they needed support in their caring role with 37.3% saying the person they cared for needed extra help or support. Participants spoke about needing help to cope, whilst a number mentioned about how they were unsure those they cared for would accept the extra support.

10.8% of participants felt lonely or isolated all of the time, this was down to them having to stay in much more, people spoke of feeling trapped or having no way out. 44.6% of participants felt Lonely or Isolated some of the time, only 19.3% never felt this way.

59.8% of participants felt their caring role had a negative impact on their own health, with people speaking of stress, being less active & poor mental health. One person said 'you don't tend to look after your health, you concentrate on them', many spoke in a similar way. While this was the case 63.9% of participants felt they had the right support to look after their own health & wellbeing.

20.7% of those who took part felt they had faced stigma or discrimination in their caring role, with participants mentioning not being taken seriously or being respected in their caring role.

Only 10.1% of participants had a plan in place if they could no longer live with or support the person they cared for. For many it was just something they did & they hadn't ever thought about what would happen if the situation changed.



Recommendations

- The language used to identify adult carers should be thought about carefully as often people don't identify with this label. Asking if an individual lives with and/or supports someone with a Physical and/or Mental Health Condition or Substance misuse Issue could prove more affective.
- Health professionals should respect & listen to the carer as they are the ones most likely to have an in depth understanding of the individual (cared for).
- GP's should ask all adults if they live with and/or support someone with a Physical and/or Mental Health Condition or Substance misuse Issue.
- Health professionals should involve & inform the carer in any key decisions if the cared for consents & finds appropriate, this is in accordance to NICE clinical guideline C9138 1.3.10 & C9138 1.3.11.
- Health professionals should affectively signpost carers to services that can offer support, including third sector partners & training.
- More information should be made available in regards to respite care & the options available if the carer can no longer fulfil their role.
- Caring for those with a Mental Health Condition or Substance Misuse Issue should be treated with the parity of those caring for individuals with a Physical Health Condition.
- The role of those who care should be promoted widely, raising awareness & reducing stigma.

Patient experience in adult NHS services: improving the experience of care for people using adult NHS services: NICE Guidelines C9138

- 1.3.10 Clarify with the patient at the first point of contact whether and how they would like their partner, family members and/or carers to be involved in key decisions about the management of their condition. Review this regularly. If the patient agrees, share information with their partner, family members and/or carers.
- 1.3.11 If the patient cannot indicate their agreement to share information, ensure that family members and/or carers are kept informed, but be mindful of any potentially sensitive issues and the duty of confidentiality.

Contact Us

Address:

Suite 20 Blackburn Enterprise Centre
Blackburn
BB1 3HQ

Phone Number:

01254 504985

Email:

info@healthwatchbwd.co.uk

Website:

www.healthwatchblackburnwithdarwen.co.uk



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