healthwatch Bury

Carers in Crisis

2018

Healthwatch Bury Carers in crisis report

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Executive Summary

Healthwatch Bury completed a research project identifying issues and concerns of carers when the person, who is being cared for, is experiencing a mental health (MH) crisis. The key findings showed that caring for someone with mental health impacted on the carers own health and wellbeing with many experiencing poor mental health themselves. The demands from the person being cared for, whether deliberate or implied often have a negative impact on the carer through intensifying their feelings of guilt that as a carer they aren't doing enough.

The impact on finances having to give up work or reduce their hours put a strain on families as well. Carers described how their role left them isolated leaving little time or money for socialising. Being a carer affected family dynamics with an imbalance in the time that carers were able to give to other family members. The need for respite was highlighted but the constant anxiety caused by their situation means carers are unlikely to fully relax. Carers described their frustrations with the lack of early intervention and only when the person being cared for is in crisis do they get help.

The majority of carers who responded look after a close relative and provide personal, emotional, physical and financial support. The patients being cared for access a range of services with their local GP being the most popular. Mixed views were expressed about the quality of the services although GPs and local group support received favourable feedback. Frustration due to long waiting times and poor access to services, alongside lack of professional consistency and need for greater joined up working across services was also expressed.

Carers told us they turn to their wider family for help when their loved one is in crisis, applied practical techniques and accessed professional help when available. Carers described their frustrations with the lack of involvement of the family in discussions about the care of the service user.

Accessing local support groups and information on carer's entitlements was reported as being difficult, with carers not knowing where to go for advice and help. Carers highlighted the need for more bespoke training that would help them to deal with the different demands of the various mental health conditions.

Carers want to be given more practical advice and support, especially outside normal clinic hours with the need for an out of hours crisis centre being highlighted.

Carers in crisis

1. Context

1.1 In 2017-18 Healthwatch Bury explored service users issues in regard to mental health by exploring adult experiences of going to their GP to discuss a mental health issue. From the feedback received it was clear that families/carers have a strong role to play in supporting people with mental health problems.

1.2 Carers stated that there is lack of support, information and advice around for families and carers to help them when their family member is in crisis. To help fully understand the issues affecting carers, HW Bury completed a more detailed analysis of their concerns.

2. Aims of the project

2.1 The main aim of the work was to listen to the experiences and concerns of adults who are carers for someone suffering from poor mental health particularly focusing on when someone is experiencing a crisis.

2.2 The aim of the project was to explore:

a. The issues and concerns for the carers when the person, who is being cared for, is experiencing a MH crisis
b. If they feel they have the skills and appropriate help to deal with the situation
c. What they consider to be a crisis situation that would require additional support
d. What sort of help they need to support themselves and the cared for person in a crisis situation and how this can best be provided
e. Anything else about their experiences they would like to share

3. Methodology

3.1 Healthwatch carried out a qualitative research approach as follows;

1. An on-line survey (attached at Appendix 1) based on the aims set out above placed on-line and circulated through partners and voluntary groups receiving 32 responses
2. Met with two local mental health carer groups and ran a focus group with carers

3.2 We also completed a telephone interview with a carer who was unable to attend the focus group.

4. The Project Assumptions

4.1 A carer is someone who provides unpaid help and support to a family member or relative, partner, friend or neighbour who needs help because of their age, physical or mental illness, addiction or disability. The contribution carers make is now part of government policy. Carers save the government an enormous amount of money by doing what they do in looking after others.

4.2 The carer is often the only constant support in a patient's life, particularly those suffering from a long term health condition such as poor mental health. Their friends tend to lose touch and health and social care staff change over time. The changing nature of mental illness can cause sudden crises, often out of hours, to which the carer often has to respond. This can be very stressful as immediate and appropriate professional support is not always available. Having the right knowledge and access to support can make a difference to both the lives of the carer/family and the patient suffering from MH.

4.3 The wellbeing of the carer can be greatly improved if they feel part of a supportive team/community, with easy access to up-to-date information and support. Without this, the carer may feel unable to continue giving the practical and emotional support that is so important to the person suffering poor mental health (MH).

4.4 The importance of carers has been recognised as a key priority area in the Locality Plan 'Transforming Health and Social Care in Bury', with a specific emphasis on the health needs of carers:

'Recognise the valuable role played by those people in Bury who provide unpaid care and establish a 'New Deal for Carers' that ensures they are provided with the support that is needed'.[1]

4.5 The Greater Manchester Mental Health and Wellbeing Strategy (2016) also highlights the need to support for families and carers. One of the strategic aims is for:

'Greater integration across mental and physical health and social care services within each of the ten GM localities as well as across the wider GM conurbation. These will be patient, carer and family focused, accessed in a consistent, simple way. We will invest in community and crisis support to reduce the requirement for acute and long term care.'

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[1] Transforming Health and Social Care in Bury, Our plan 2017-2021, Enabling Local People, page 34.

5. Limitations

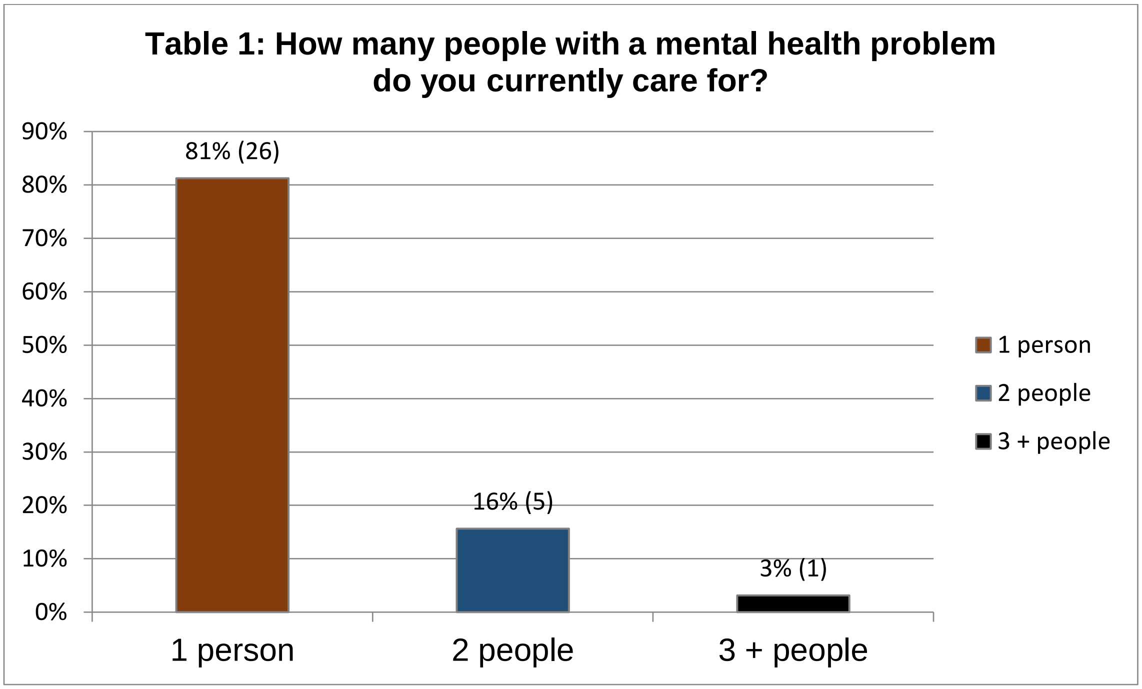
5.1 The on-line survey responses are more open to misinterpretation and less opportunity to expand and probe into experiences.

6. Survey Findings

6.1 The following sections provide an outline of the key findings from the survey and focus group responses.

7. Numbers being cared for

7.1 Carers were asked how many people with a mental health problem they currently care for. In table 1 the results reflect the national statistics which showed most carers care for just one person (83%), but 14% care for two people and 3% are caring for at least three people[2].



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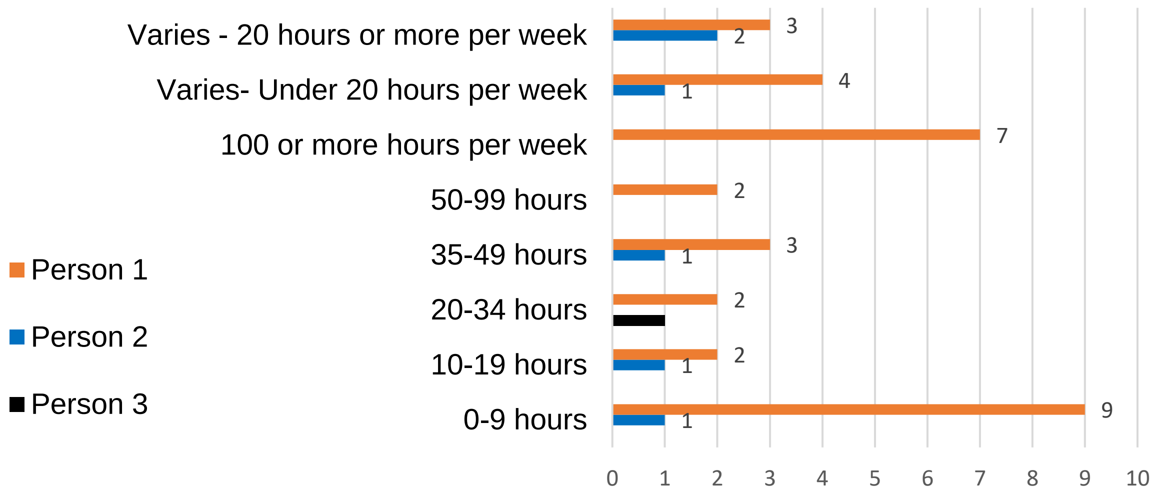
[2] NHS Information Centre for Health and Social Care (2010) Survey of Carers in Households 2009/10

8. Time spent caring

8.1 Table 2 provides an overview of approximately the number of hours a week the carers who responded, spent looking after someone with a mental health problem.

Table 2: Approximately how many hours a week do you spend looking after someone with a mental health problem?



8.2 The results show two clear time variances with 31% (11) of respondents spending up to 9 hours a week caring for someone and 22% (7) over 100 hours per week.

8.3 Carers UK states that almost 4 million of the UK's carers care for someone 1-19 hours each week. The numbers caring round the clock, for 50 or more hours each week, are rising faster than the general carer population - an increase of 25% in the last ten years compared to an 11% rise in the total number of carers[3].

8.4 Table 3 below, provides an overview of the length of time respondents have been in their carer role, with just over 32% (12) having spent over 16 years as carers.

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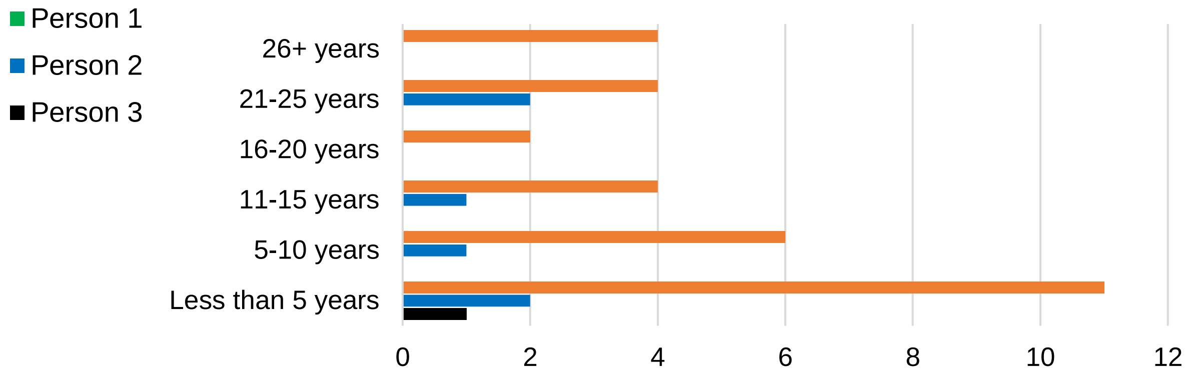
[3] Carers UK, Making Life Better for Carers, Policy Briefing, May 2014

Table 3: How long have you been a carer for the person with a mental health problem?

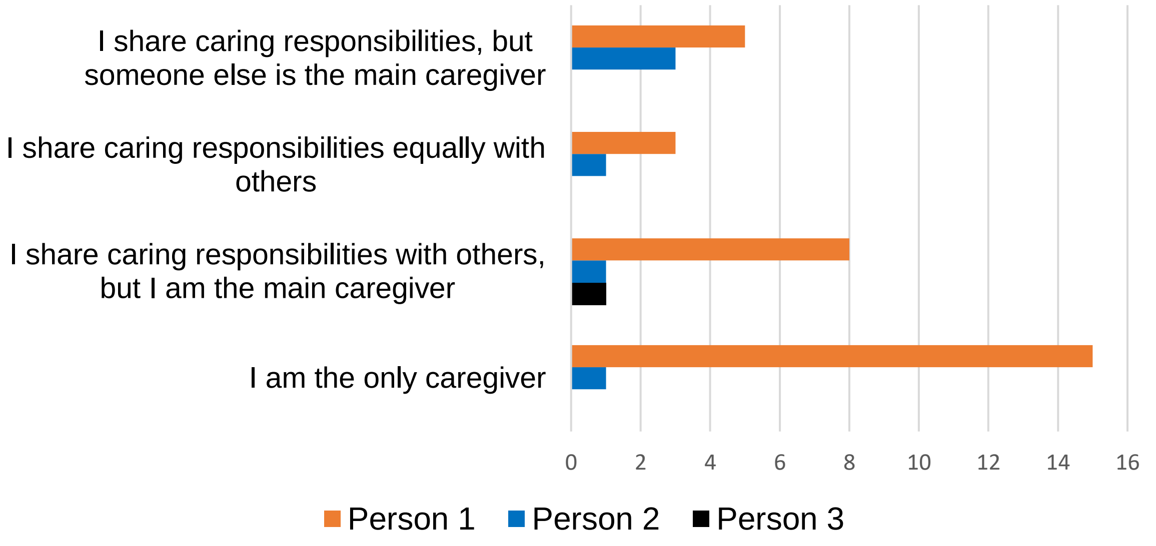


8.5 From the 28 respondents who provided their age, 46% were over 55 and 54% between the ages of 35 – 54. The 2011 census showed that the majority of carers are of working age and the peak age for caring is 50-64. Over 2 million people in this age bracket are carers.

9. Role as a carer

9.1 The survey asked respondents to describe their role as a carer. Table 4 shows that 42% (14) are the main carer with a further 26% (8) although sharing responsibilities, classing themselves as the main carer.

Table 4: Which of the following describes your role as a carer at the moment?



10. Impact on being a carer

10.1 Respondents were asked if their caring role has either a positive or negative impact on their health and wellbeing. From the responses received 78% (25) stated that it had a negative impact on them with only 13% (4) responding positively.

10.2 The comments received show clearly the huge impact this can have on a carers' health, wellbeing and financial position. The common issues have been grouped as follows:

- **Isolation**

Carers described how their role left them isolated, even within their own families. Having to concentrate on caring, often meant giving up their jobs, and left little time or money for socializing.

The 'stigma' of mental health also makes it difficult for carers as friends and family distance themselves from the carer which adds to their own sense of loss and isolation.

Carers UK research[4] found that:

- 8 in 10 (83%) carers have felt lonely or socially isolated as a result of their caring responsibilities
- 57% of carers have lost touch with friends and family as a result of caring and half (49%) of carers say they have experienced difficulties in their relationship with their partner because of their caring role
- 38% of carers in full-time employment have felt isolated from other people at work because of their caring responsibilities
- Carers who have reached breaking point as a result of caring are twice as likely to say that they are socially isolated because they are unable to leave the house and are also more likely to have experienced depression as a result of caring.

- **Impact on families**

Carers described the huge impact that their caring roles have on family dynamics. Those who were parents felt it impacted on their ability to be fair to all their children because their caring takes up so much time and energy. One carer describing it as 'all consuming'. They described not being able to give as much time and energy to their other children and even when they do spend time with someone else, it is always on their mind.

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[4] Carers UK's State of Caring Survey 2014 of over 5,000 UK carers

‘Being a carer has brought increased stress and difficulty coping with his needs alongside looking after my young family. Increased emotion in household. Difficult to give him time he requires due to other demands.’

‘…you constantly worry. Care services only offer high level support. Families are left to support siblings "in the middle".’

‘I feel that my young person suffered for a long time before getting any help. It’s exhausting being a carer and not knowing if your person will still be there when you wake up. Their symptoms can become the carers symptoms too.’

- **Financial Impact & Employment**

The financial impact on the family was also highlighted as an issue. When they had to work reduced hours or give up work it meant the family’s income was badly affected.

‘My husband has the mental health issues, which means he is unable to hold down job, so I have financial concerns. Also he can be fine for month then he has another episode, which makes making plans very difficult. I often feel isolated.’

‘I've had to give up work, survive on an income far too low and feel worthless to a wider society. The stigma of being perceived as a scrounger also hurts deeply.’

‘We all have a breaking point - we are not super human but we are expected to give up careers, livelihoods and securing to fill gaps in services to fund ourselves trapped in a downwards cycle and permanent battle with services.’

‘There isn't enough help out there for someone with epilepsy especially job wise because employers don't want to know when they hear epilepsy mentioned.’

‘Working for an understanding employer would help.’

- **Respite**

Carers spoke about the need for a break from their caring duties; having a weekend away on holiday. Although they outlined the necessity of ‘time out’, they also described how, even when they are away, the person they care for is always on their mind. They described how this makes them feel angry and how, on their way home in the car, or on the plane back they start to feel really low. They described how, even when on holiday, they dread any contact from home as they always fear that something has happened and the person they care for has hurt themselves or worse.

One carer stated, *‘it’s my first thought of the day when I wake up and last thought before I go to sleep; it’s exhausting’.*

A Carers UK report[5] stated ‘a quarter of people (25%) said they hadn’t had a day off from caring for more than five years, while 4 out of 10 carers (40%) said they hadn’t had a day off for more than a year. Having more than a day was still rarer, with over half of carers (58%) reporting not having had a weekend off in over a year and as many as 73% not having had a week off for over a year’.

‘Don't feel that I have a life, always clock watching, always available at any time of the day and night.’

‘It means I am on edge the whole time trying to avoid the next crisis.’

- **Health and wellbeing**

Carers described how it has impacted on their own health:

‘It's a constant juggling act with no time to meet my own health and wellbeing.’

‘I feel that my feelings and emotional wellbeing are put to one side and the person I am caring for must always come first. This can make me feel low and anxious.’

‘..it has resulted in high blood pressure and depression and anxiety, insomnia and both mental and physical exhaustion.’

‘My caring role has tested my stress levels and that has deteriorated over the years. I'm stressed most of the time and I easily snap more than I ever did’.

‘I have lived a different sort of life because of the person. I would have been more sociable and adventurous in other ways.’

‘Massively. I have lost my sense of self, sense of agency and wellbeing.’

‘My well-being had suffered. I find it difficult to sleep, go through periods where I can't cope (but don't want to take time off work and disclose my responsibilities to my employer). I'm grumpy, often don't want to socialise and mainly, would like to leave home and not have to speak to anyone for a long time. I don't feel I have the time or the headspace to look after myself well. I feel it's hard to know, with someone with moderate-severe MH problems who refuses to seek help, when to support them and when to tell them they are just being self-centred …. I don't have the skills to provide all the recovery support but that's what is expected of me.’

‘I find it both physically & emotionally draining whilst also working a full time job.’

‘I hate being a carer. I'm made to feel I’m like the worst person in the world by my partner who doesn't feel I support him adequately. I want to leave him because I

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[5] Carers UK, State of Caring 2017

can't cope but I worry he'll kill himself. It's a completely impossible situation. Him being unwell brings out the worst in him. He's horrible and I don't think I have the skills or mental resilience to cope with what's thrown at me every day. ………. I can't see a positive future. Sometimes I want to throw a match to the house, burn all my belongings and just start again.'

10.3 Attached at Appendix 3 are a number of case studies which help show the problems faced by carers who look after someone with a mental health condition.

10.4 On the positive side, respondents stated:

'My caring role has made me positive about life and always to try and keep active mind and body.'

'It has affected my whole life. It has been infinitely worthwhile so far. I have learned a lot about my person's condition and way of being.'

'It keeps you busy.'

'… keeping her safe at all times possible.'

10.5 Around 21% (7) of respondents stated they suffered from a physical impairment, 14% (5) with a mental health problem and around 7% (3) from a long standing illness. Of those who provided their employment status, 7% (3) were unable to work due to their caring responsibilities and 11% (4) were unable to work due to their own ill health/disability:

'I am my son's carer. Being on call was not compatible with working, and meant I had to resign from my most recent job.'

'Self-employed. Reduced hours due to caring and anxiety.'

11. Who they care for

11.1 Table 5 below shows that the majority of the respondents care for a close relative:

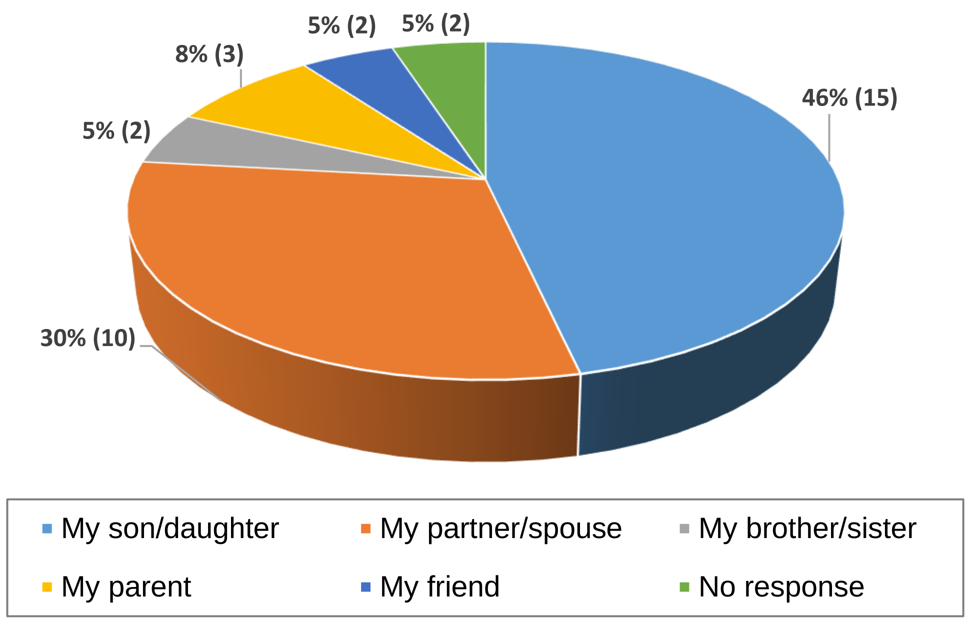
Table 5: Who do you care for?

11.2 Of the 28 who told us their gender, 79% (22) were women. The Mental Health Foundation highlights that ‘*most carers are women, whether they care for their children, partner, parents, other relatives or friends. Women carers are more likely to suffer from anxiety or depression than women in the general population. Three quarters of people who care for a person with a mental health problem are women…*[6]’.

12 Mental health conditions and ages cared for

12.1 Table 6 below, provides details of the conditions suffered by those the respondents care for. The most common condition from the survey responses are anxiety and depression, which mirrors the UK statistics of 1 in 6 people experiencing a common mental health problem (such as anxiety and depression) in any given week[7].

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[6] Mental Health Foundation, Women and mental health, Women as carers: https://www.mentalhealth.org.uk/a-to-z/w/women-and-mental-health

[7] McManus S, Bebbington P, Jenkins R, Brugha T. (eds.) (2016). Mental health and wellbeing in England: Adult psychiatric morbidity survey 2014. Leeds: NHS digital

Table 6: What is their illness/condition?	
They have not recognised that they have a mental health problem	3
Has not yet been diagnosed	6
Anxiety	14
Depression	15
Psychosis	8
Schizophrenia	3
Bipolar Disorder	3
Prefer not to say	2
Other	9

12.2 Table 7 shows a breakdown of the ages of those being cared for.

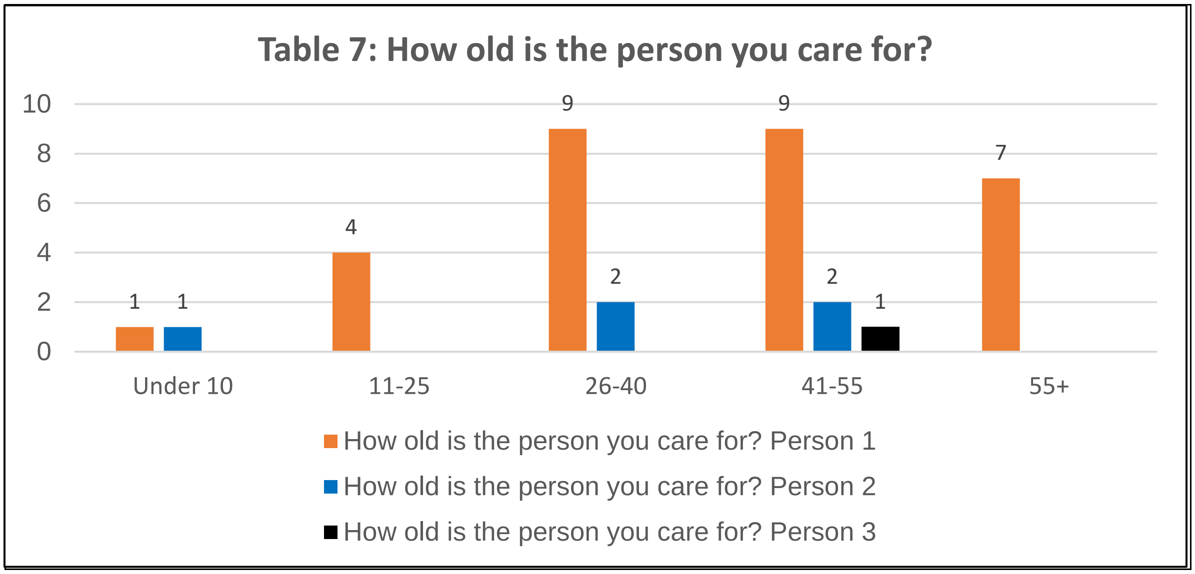


Table 7: How old is the person you care for?

13. Support provided

13.1 Respondents were asked to state the main things they do to support the person they care for. Not unsurprisingly the responses covered every aspect of someone’s life:

- Providing emotional support - reassurance, acceptance, and encouragement during times of stress
- Personal care – everything from dressing, bathing, washing, shaving, cutting nails, feeding

- Physical help - such as helping with walking, getting up and down stairs, getting into and out of bed
- Health care – ensuring the correct medication is taken
- Helping to deal with care services and benefits - making appointments and phone calls, filling in forms, developing knowledge about the policies and MH regulations
- Helping with paperwork or financial matters - filling in forms, dealing with bills and banking
- Other practical help - preparing meals, doing his/her shopping, laundry, housework, gardening, decorating, household repairs, taking to doctor’s or hospital
- Child care – cover for both short and long term
- Keeping him/her company – visiting, sitting with, reading to, talking to and entertaining
- Taking him/her out - going for a walk or drive or taking them to see friends or relatives
- Keeping an eye on him/her to see he/she is all right – including ensuring they engage with all services and encouraging contact with siblings and family.

13.2 The views expressed below show how demanding and difficult it is for carers:

‘I have to make sure she has structure to her days with clear daily objectives. I have to contact her numerous times daily and get updates as to what she is doing, were she is up to with her tasks & keep giving her the reassurance & encouragement she needs.’

‘…My husband helped her by taking her to work with him to keep an eye on her and get her out of bed each day. I helped her with a CV and to apply for jobs and I persuaded her to go for a voluntary position which has resulted in a full time job. I built up a good rapport with our local Dr. who was very supportive and assured us that he would fast track my daughter for appointments when needed.’

‘Make sure I am always available for the person to talk to whatever time of the day or night. Encourage them to see the doctor and take medication when prescribed. Be with them when they are feeling bad. Accompany them to doctor's appointments. Offer help and reassurance when needed.’

‘I make sure they take their medication and the right dose, I watch them going upstairs, cook and clean, encourage them to drink plenty when it's warm and try to encourage them to do some form of exercise. And I do all the shopping and appointments.’

‘Medication management. Managing risk re suicide intentions and attempts. Arranging appointments. Taking him to appointments. Advocating on his behalf with mental health team. Increased parenting and house work for myself to

relieve demands on him. Financial strain due to not working. Managing his finances.'

'Trying to obtain medical intervention. All aspects of day to day living'

'Emotional support, super-parenting (this cannot be described as usual parenting), ensuring physical and mental safety, taxi service, advocate (with all agencies, including having to battle every agency to try to secure support, which requires me to develop an understanding of their conditions, as well as legal frameworks, policy and guidance.'
'Physical caring, keep them safe, talk through anxieties, offer solutions, support at medical appointments, and give medication.'

'Encourage contact with GP and counsellors. Do much of the admin for home … Remind him to keep in touch with kids and rest of his family. Get him to wake up and eat. Encourage him to …, get out into garden, basically to stay awake and not sleep all day.'

We often feel that we are battling things on our own and there is no support for our person or us.'

13.3 When asked about any concerns they may have with the support they provide of the 27 who responded, around a third (9) said they had no concerns.

13.4 A number appear to struggle with how to provide the right level of care and challenge:

'It is sometimes hard to decide what is too much and what is too little. She has got back on her feet now but we still have times of feeling anxious and watch her like a hawk which she doesn't like and says she is ok. We probably overact sometimes now but we feel like we need to be on alert.'

'Coming from just me, the above is seen by my spouse as nagging and interfering so this ends up with arguments. Could do with someone else reinforcing the need to self-care. GP will advise gently but cannot force him and the more times I comment the worse his mood becomes.'

'Sometimes I struggle to ignore behaviour as advised as I have grave concerns around his health and the consequences'

'…….... I also think my support is not challenging enough and this is partly because of my partner's previous suicide attempt and a fear that if his depression gets really bad he'll try to commit suicide again.'

'I have concerns that person 1 isn't doing enough for themselves and could do a bit more.'

Others were worried about the future due to their own advancing ages:

'…don't know what is going to happen when I and my husband are not here as we are in our seventies.'

'I'm in my late 70s and have my own family to concern myself with too!'

13.7 With 58% (19) of respondents stating they currently live with the person they care for and 8% (3) some of the time, carers struggle to get any respite or break from their role as carer.

14. Additional support

14.1 Alongside the support provided by the carer, we asked what additional support the patient receives:

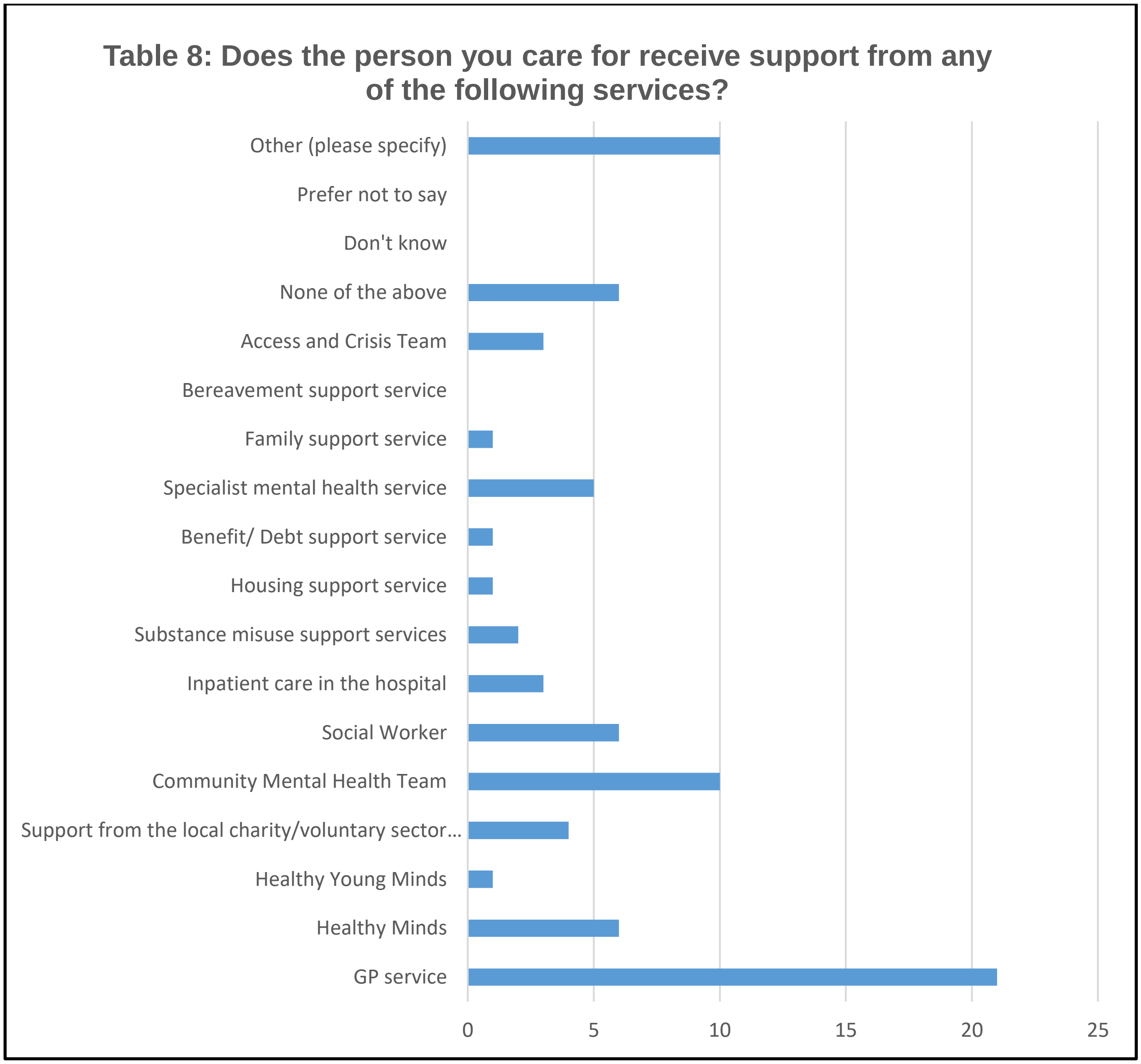


Table 8: Does the person you care for receive support from any of the following services?

14.2 From table 8, it can be seen that there is a wide range of services being accessed with the GP being the most frequent service. To help assess how these services impact on the carer we asked for their comments, both positive and negative, on the services.

14.3 GP and professional support services received a number of favourable comments:

‘We have a good relationship with our doctor and my husband seems to form positive relationships with the staff that have worked and are now working with him from Healthy Minds.’

‘Our local GP was excellent and provided his mobile telephone number to our daughter should she continue to have suicidal thoughts. He gave her an appointment to see him straight away.’

‘Generally helpful support from GP’

‘My son doesn’t communicate well he’s quite non communicative and struggles in social situations. He appears to be engaging with services and doesn’t see appointments as inconvenient so I think he sees services as helpful in terms of keeping him motivated and focused.’

‘CMHT come every two weeks. Great service.’

‘Healthy Young Minds are invaluable support for me and offer excellent CBT’

‘We feel we can phone the early intervention team for help or advice.’

14.4 Carers experiences of local support groups also received favourable comments:

‘Since going to One Recovery in Bury, my Husband has started to come to terms with his alcohol issues and they have identified he needs help with his mental health problems, for which he awaiting a referral.’

‘Salford Autism provide a 24/7 service manned by 2 volunteers to meet/talk on telephone when in crisis. They also provide an advocate to help in work management meetings.’

‘A local church counsellor has volunteered to offer sessions to help the person and has built up a good relationship with them.’

‘At present the only person supporting me is in Gaddum Centre in Bury.’

14.5 There were however, some negative comments highlighting a number of areas that carers find frustrating:

- **Waiting times and access to services**

'……. Waiting times for talk therapies too long.'

'The only downside was that because he requested a one-to-one appointment then he had to wait four months between bereavement counselling and anxiety management.'

'They never turned up on time - Cannot get hold of them when you phone up.'

'Appointments with Psychiatrist at Outpatients keeps getting cancelled. This is a trigger to my Son.'

- **Changes in health care professional and differing diagnosis**

'Every time my daughter went for therapy with the NHS - she was seen by different people all the time so there was no consistency. The person she was seeing would then spend ages reading through her notes and asking her the same questions. She has had therapy in scruffy unwelcoming places - untidy offices - very clinical and not somewhere where a person with depression and suicidal thoughts wants to open up. Time wasted reading notes and back tracking. Side effects of medication were terrible and made her feel tired and listless. Not enough emphasis on diet and routine and sleep etc. She kept on getting a different diagnosis from seeing counsellors and at hospital. She was in private therapy for over a year and it was absolutely the key. One person seeing her, in a beautiful, homely setting where she could build up trust. Not looking a computer screens or back tracking. Her therapist prepared for her visit and offered ways of contact e.g. email, texting. of course there were rules that my daughter would not get an instant response but should would get a reply within a couple of days - from the same person that knew her well and just give helpful advice and encouragement.'

'2017 - Suicidal - GP sent him to Fairfield via casualty. Only saw nurse practitioner and nurse visited home several times. No psychiatrist - referred to Healthy Minds - not any use.
2018 - Referred to Rapid Access Unit at Fairfield. Saw nurse practitioner twice. No medication so referred for further assessment - still waiting. No therapy at the moment although GP and team at Fairfield know he is out of house sleeping in car and still highly stressed/depressed. No further plan of action.'

'When CMHT off side (like ours) - no back-up.'

‘When they are suffering from a physical problem it is very difficult i.e. the consultant psychiatrist told my husband to go to the gym. That is very difficult to do.’

- **Ability of service user to engage with MH services**

‘…. I consistently raised need for support but this has to come from my brother. He doesn't recognise his problems. My family and I do.’

‘The person with MH issues has to engage, but a person with MH issues is mentally unable to engage’

‘I felt like my partner missed the point of counselling and didn't want to do any of the hard work himself; he wanted to be fixed. The services appear to have been decimated - Healthy Minds isn't what it was so the support I can access is limited now.’

‘If he runs and isolates himself no one can see how he is coping.’

‘He often returns when he chooses but I cannot predict when or how long so hard to plan to get help or even plan my own life.’

‘He stops medication and stops engaging with CMHT. He gets so unwell he has to be sectioned for his own safety. I can't always cope.’

- **Lack of joined up working and poor processes**

‘Horrendous disorganisation between services.’

‘Terrible services. No information sharing. No joined up working. No support. No concern. Long waiting times. Gaps in services therefore no support available that is appropriate. No consistency of worker. No interest in service user e.g. don't read notes before. No link between services therefore big gaps and chances to go into crisis. False promises. Neither service knows what the other does. Both lie about referrals made. Diabolical risky services that do not achieve anything for either service user or family.’

‘No professional support to go alongside due to poor mental health services in Bury. Falls between services due to gaps. Sometimes seen as too much risk for Healthy Minds but not unwell enough for hospital admission or to be overseen by psychiatrist in community therefore no services to offer any support.’

‘Issues are getting worse, lots of assessments but no support, and we can't keep going like this’

‘We had a social services assessment done which was no help and has actually made person 2 worse. We now have nowhere to turn and his health is deteriorating.’

‘Poor service from Rapid, Assessment, Interface and Discharge (RAID) team. Very muddled communication re assessment appointment. Damaging effects of mental health assessment, set them back several weeks.’

15. Crisis situation

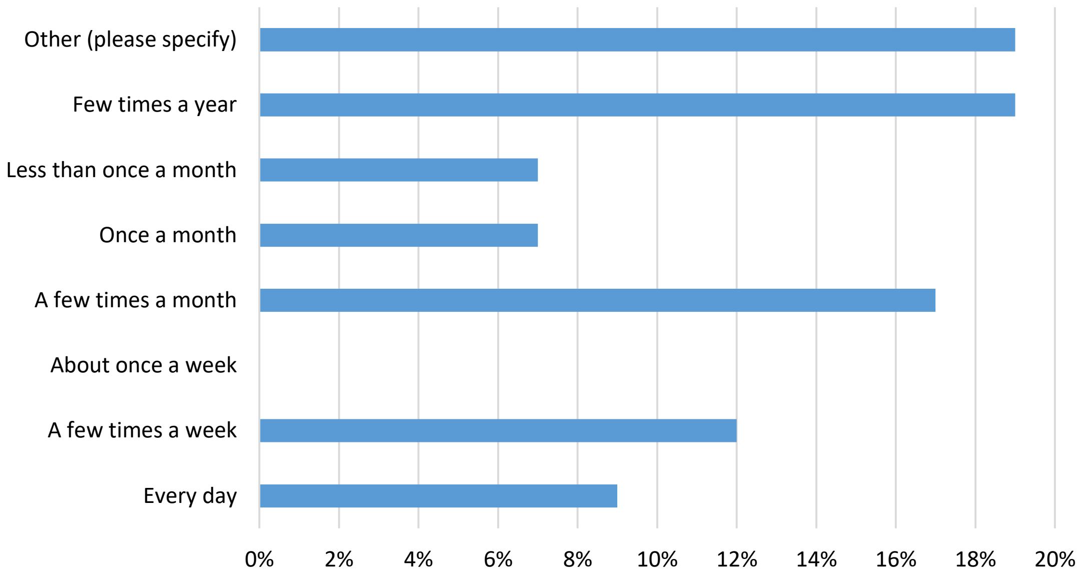
15.1 We asked carers to describe what a crisis situation issfor the person they look after. The most common have been grouped in table 10 below:

Table 10 – Crisis Situation

Crisis description	**Number of times referenced**
Suicidal tendencies	12
Depressed/anxious	6
Aggressive behavior	5
Self-harming	5
Psychotic behaviour	5
Sleeping too long or not enough	3
Unable to leave the house	3
Distressed state & incoherent	3
Self-neglect (not eating etc.)	3
Self-medicating/overdosing	2
Unable to work/attend college	2

15.2 To try and understand the impact of a crisis on the carer, we asked them how often the crisis situation occurs.

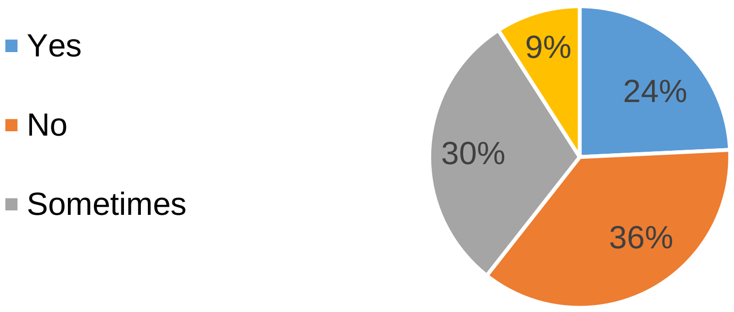
Table 11 Frequency Crisis Situation Occurs



From the responses received, it can be seen that around 45% of incidents happen once a month or more, which places a huge demand on carers.

15.3 This strain on carers is further highlighted in the next table. Table 12, shows if carers feel able to manage the person they look after when they are in crisis. Only 24% (8) feel able to manage with 66% (21) stating either no or sometimes.

Table 12: Do you feel able to manage when the person you look after is in crisis?



15.4 When trying to manage the crisis carers told us they accessed the following services:

Table 13 – Services used during a crisis	
Service	**No. of responses**
GP/Counselor	6
None	5
CMHT/Crisis Team/Early Intervention Team	5
Hospital	3
Social Worker	2
Police	2
Ambulance	2
Voluntary sector/support group	2
A&E	2
HYM/Healthy Minds	2
Relatives/friends	2
Carer support worker	1

15.5 When asked how they are able to manage the crisis situation, people described a number of techniques and approaches:

- **Use of wider family support**

  'Spread the load with other family members'

  'Because we got help as a family - the therapist that helped our daughter met us as a family too including talking to our son so we all knew the situation and could help our daughter. We were given literature and our family life and relationship with our daughter was discussed so that she felt she could always talk to us and we wouldn't judge and she felt we supported her. She struggles with relationships and making friends and decisions so we learnt as a family that she could rely on us. She has certain buzz words to use so that when she feels down and wants alone time she can just tell us so that we don't fret and go into her bedroom and overreact.'

  'I have no choice... at times as a family we have had to pay a lot of money for support services such as rehab.'

- **Applying practical techniques**

  ‘Distraction techniques, finding a quiet space, patience, time.’

  ‘Breathing techniques usually work and telling the truth and making him see things through other people's eyes and point of view.’

  ‘Using CBT techniques, emotional support’

- **Other**

  ‘Care from hospital/GP/Psychiatrist.’

  ‘We do the best we can for him and try to access support when it is available’

  ‘This required visit to A&E. Our neighbour was helpful. A&E was not helpful, but the act of going made us feel we were doing something.’

  ‘Skills, or practical support from a p.a., emotional support from someone who absolutely understands and does not judge - for all of us. Genuine, suitable breaks that suit us.’

15.6 Those that stated that they were unable to manage a crisis situation described the issues as:

- **Dealing with aggressive behaviour and threats**

This appeared to be a common situation that carers find themselves in on a regular basis.

> *‘My daughter doesn't sleep, is aggressive and gets lost.’*
>
> *‘My son becomes dangerous sometimes.’*
>
> *‘She threatened to kill me and herself.’*
>
> *‘The issues are that they get frustrated and angry, extremely angry banging doors, shouting and don't want to listen to reasoning.’*
>
> *‘….. is too abusive.’*
>
> *‘Feel panicky when he has an episode.’*

- **Needing professional medical help and intervention**

Carers described needing professional intervention:

‘It can be hard assessing the severity of situation when there are a lot of stresses externally so I cannot always be sure if it is necessary to call medical professionals or not.’

‘He needs professional help and I'm not skilled in this alongside trying to keep my head above water.’

‘I can only offer love and support. I am not medically trained.’

‘She would benefit from a professional checking in with her at regular intervals, maybe every 3 months, just so she knows that the help is there if she needs it and so that any issues could be picked up before crisis point is reached. Also maybe an occasional home visit so the health professional can see how she is living & it can help put her current condition in to context.’

‘Regular follow ups scheduled by GP (at least) would be helpful or by someone connected to a mental health team somewhere.’

‘Someone for me to liaise with as his carer would help me to evaluate severity and decided a plan of action if concerned.’

Contact for husband to speak to if he recognises symptoms worsening but is reluctant to make a GP appointment at that time.’

‘Person 2 should have been sectioned well over a year ago (my professional opinion as a qualified nurse). No intervention was taken. Its cost the tax payer significant amounts to manage the number of emergency calls that have been made in desperation by that individual. They recently started with severe health condition and are in a high dependency unit. A shocking failure by services to intervene earlier.....’

A number of carers made reference to the need for earlier intervention by health services. They felt that it was only when the person they cared for had hit crisis point that support was offered. Yet, while attending a service or receiving treatment, the person did so much better and things start to improve for not only the person but their family as well. If they had been given help earlier, many carers felt that their situation would have been far more manageable.

- **Time in the services**

One volunteer who attends a carers group and has been a community support worker described how she often sees community based support discharge their patients after 6 months (when they have just formed the relationship with their patients). She described how patients end up back in the service because there is not enough staff, beds or funding. This she feels proves to be a false economy as the patient ends up back in crisis and the whole process starts again.

Other comments received, support those views:

'…. did see a counsellor for 6 weeks but I don't feel it's enough. I feel they need more as their moods can be bad and verbally abusive.'

'Counsellors and therapists don't seem to help, they don't spend enough time with the person and don't sort the problems the person has. If someone has epilepsy, their mind is affected in lots of different ways to others so they need more help.'

15.7 When asked what support and or information carers felt would help them manage a crisis situation the main suggestions were for:

- **Greater family involvement in care planning and overcoming confidentiality blockages**

A key issue emerging from the survey and group discussions was the frustration felt by carers about not being involved by health and social care professionals in discussions about the care of their loved one.

Confidentiality and data protection was described as a major blockage by those in one of the carers group. The carers described that their loved ones are often in such a bad state due to the use of alcohol or drugs, that they are unable to make any sound decisions. The carers explained that they don't want to make decisions on behalf of their loved one but wish that someone would just listen to them and understand how things actually are for their loved one and people around them. For example, carers described a patient with an alcohol problem when sober, don't often tell the full story, lie or just don't remember what they have actually done. They explained how often their loved ones are in denial about their addiction and do not understand the full impact that their addiction has on their families.

Others described wanting:

'People to listen to the main carer as they know better than anyone.'

'Permission to discuss situation with health professional.'

'Carer permission to discuss with NHS professionals. This should be done at "discharge" stage.'

'If the NHS had involved us in the therapy part with our daughter. It is the family that are with their children day in and day out and have to cope but if your child is over 18 they are expected to cope alone. Families need to be encouraged to get involved and get help to understand what is going on and given encouragement that people can recover from a mental health problem. One of the first thing my daughter was told by the NHS was she had mental health problems that she would have for the rest of her life which she understood to mean she would feel suicidal for the rest of her life which has not been the case but because she was told that - she didn't see any point in getting help. It was only because we got in touch with a private therapist who then contacted our daughter by telephone and managed to persuade her that she could help.'

'For someone to listen to me when he is becoming unwell. I hate having to watch him get to the point he is so ill he has to be sectioned. I wish MH Services would help sooner.'

'For MH services to accept that a cared for is sometimes too poorly to engage.'

'I do not have anybody connected to my husband's care who I can talk to get their perspective on his mental state before he runs and it worsens.'

This is a common and complicated problem involving ethical and legal obligations and patient consent. The Royal College of Psychiatrists have produced a free leaflet 'Carers and confidentiality in mental health' (July 2018), which describes the common issues and provides examples of good practice including a good practice checklist.

Carers were clearly frustrated with the failure of mental health professionals to listen to, and include, family members in their relative's treatment and care plan. Attached at Appendix 3 is a set of principles developed by 'The World Fellowship for Schizophrenia and Allied Disorders'[8] which mirrors the values outlined by our carers which could be easily adapted and adopted by health professionals in Bury and across GM.

- **Training and Information**

Carers highlighted the need for bespoke training designed around the needs of carers that helps them to address the different mental health conditions they have to deal with. The need for practical advice and training was also raised as

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[8] World Fellowship for Schizophrenia and Allied Disorders. Principles for working with families. 2001 http://tandemcarers.org.au/images/APPENDIX%201%20-%20Principles%20for%20Working%20With%20Families.pdf

one carer stated, ‘I need the tools to support the person with mental health issues, I am constantly walking on egg shells not sure what to do or how to help’.

Those who had received some training such as ‘Community Reinforcement and Family Training’ (provided by One Recovery) found it had helped them to think differently and to have a life outside their caring role.

Carers also suggested producing a fact sheet that GP’s or mental health professionals could hand out to carers. The fact sheets could provide information about the various conditions and what to expect at the different stages of the patients’ lives, for example, through school into adult life. What to expect and where to get help, key contact numbers and support groups available.

The Pennine Care NHS Foundation Trust has produced a series of self-help guides covering a range of mental health issues. These provide practical advice and support. The booklets can be found on the Trust web site.   The web-site also promotes the on-line referral form for people who would like to talk to someone about their mental health generally.

There is also a website for prescribed psychiatric medication for Pennine Care service users, carers and healthcare professionals to proactively support them with medicines management.

The published clinical guidance on the NICE website can also be accessed through the Trusts website.

It would be helpful if additional information designed around the needs of carers, such as the fact sheet outlined above, could be added to the web-site.

Further suggestions included:

- Mental Health awareness course
- Mindfulness training
- Acupuncture
- Crisis management training (covering specific MH needs for example bi-polar, various addictions and also include emergency planning)
- Applied Suicide Intervention Skills Training
- How can I help someone else seek help?
- Helping someone who self-harms
- CPR Training and awareness of all kinds of mental health
- Anger management
- Medication management

Other suggestions/comments included:

‘I would like to know more about the chemical inbalances in the brain that cause problems and which kinds of medication can help. I would like to know the right things to say and do.’

‘Training in how to keep calm and when to seek appropriate advice or when to just back off and let situation run and just wait to see.’

‘Pda training and coaching. Staff across agencies to have enhanced knowledge of autism, pda, add and sensory processing disorder.’

‘More training and access to support groups.’

‘Training for care home care workers ….. that shouting will not get a result with dementia.’

‘If I had some mental health training I'd feel better equipped to manage his behaviour.’

‘I have attended a 6 week craft course with One Recovery, which is helping me cope with all the different aspects of my husbands issues.’

‘How to cope with being blamed without it affecting my own mental wellbeing.’

‘Help with their anger issues and some coping measures in place.’

- **Accessing local support groups and information about what carers are entitled to**

  The carers we spoke to emphasized the importance of local carer support groups and how much of a life line to carers these groups can be but many had found it difficult to find them or get information about what is available. They felt strongly that more information about what is available should be promoted through GP practices and other key public reception areas.

  A group of carers described how, through meeting at a carers group they had formed their own WhatsApp group to help support each other. As one carer said, ‘it really helps us with our highs and lows.’

  Carers need to be informed about what they are entitled to. Even at the carers groups it was apparent that not every carer knew, for example about registering at their GPs as a carer and the annual health check offer.

‘There should be a quick reference guide of all things to be considered from all relative services.’

- **Crisis Centre**

Carers described needing:

‘Reliable contact with a person not an answerphone when crisis starting - not needing to retell story each time.’

‘Someone to give advice and take them where they cannot hurt themselves or anybody else.’

‘It is where does the support come from and what should you do at the time. You feel helpless.’

‘Someone to come out in an emergency.’

‘A contact to discuss concerns without needing to involve GP yet.’

‘Crisis team.’

‘Flexibility and accessibility of services, staffed by experienced well trained people.’

‘Access to professional support.’

‘I wish there was someone I could directly go to in times of crisis. It makes me ill trying to get him help.’

One of the carers groups proposed the development of a crisis centre (one stop shop) to provide a more holistic service offering a wide range of services to help support carers and the person in crisis. They felt this would be most effective during out of hours as there is currently limited access to support outside normal office hours and A &E was considered by the group to always be the most appropriate option.

This need has already been identified and a proposal is currently being developed, Bury CCG are currently working with key partners on the ‘Safe Haven’ initiative which will be a safe, specialised and supportive place for those in mental distress to visit, as an alternative to the A&E department.

- **Customers not just patients**

A number of carers commented on health professionals not turning up for appointments and the detrimental impact that then has on the person they are caring for. One carer felt that if they treated their patients more like customers and provided explanations when they couldn't make appointments, then it would help carers manage the situation and impact.

15.8 When asked what support would help the person in crisis help themselves, carers responded with similar themes:

- **Access to activities/social events/home support**

'He doesn't like going out. It would help if he was encouraged to go out with someone from EIT to meet and talk to other people and socialise.'

'Some activity outside the home or anger management.'

'Someone to visit him to check on him.'

- **Access to therapy/trained staff**

'Effective access to counselling.'

'Having access to talk to trained staff.'

'Group therapy with other young people. An expert in the types of medication needed to stop the lows without destroying the good feelings and not making the person a zombie who can't stay awake.'

'Someone other than GP/hospital for him to speak with at the onset of symptoms and before getting the urge to run and isolate himself. At this stage he is very reluctant to consult GP but might open up to someone else.'

'1-1Intervention.'

- **Assessments and early intervention**

'*To be taken for an assessment in a caring environment.'*

'Annual health assessment for those who have been sectioned under the mental health act.'

‘Early access to interventions and assessments to prevent things escalating to this mess (despite me asking and begging for help for over 8 years and being blamed as well as denied services).’

‘I do not consider there is an infrastructure to support adults who have suffered breakdowns. There needs to be lifelong periodic assessments.’

16. Recommendations

i. Promote details of local carers groups through GP practices and local services to encourage carers to access support and help.
ii. As outlined in paragraph 15.7:
  a. Develop a series of mental health fact sheets to meet the information needs of carers
  b. Adopt the best practice check list and principles for working with families. In particular to be introduced as part of the development for the new ‘Safe Haven – acute crisis care pathway’ and encourage the wider adoption across all mental health services.
  c. Develop with carers a series of bespoke training and practical tools.

17. Conclusions

17.1 The review showed how difficult life as a carer for someone with mental health problems is and how the impact of a 24/7 caring role has a negative impact on their health and wellbeing. Carers gave the impression of feeling trapped in their caring role and struggling with the pressure and responsibility of ensuring someone doesn’t harm themselves or worse.

17.2 Carers wanted greater access to support and more involvement in decisions around the patients care. They wanted practical advice to be better equipped and prepared to help the patient when in crisis. They wanted more advice and access to support out of normal office hours and a life outside caring.

17.3 Healthwatch Bury would like to thank all those who responded to our survey and took part in our group discussions. We are grateful for your honesty and openness about your experiences as carers. Your stories were emotional and hard hitting.

Appendix 1

Carers Dealing with Crisis Survey

Healthwatch Bury are interested in understanding the experiences and concerns of adults who are carers for someone suffering from poor mental health when the person who is being cared for is experiencing a mental health crisis.

We are interested in finding out:

a) What are the issues and concerns for the carers when the person who is being cared for is experiencing a mental health crisis
b) Did the carer feel they had the skills and appropriate help to deal with the situation
c) What do they consider to be crisis situation(s) that would require additional support
d) What sort of help the carers would need to support themselves and the cared for person in a crisis situation and how this could best be provided
e) Anything else about their experiences as a carer for someone with poor mental health that they would like to share

Results are anonymous and will go towards a wider Healthwatch Bury study and report around carers dealing with crisis and mental health. If you wish to stop the survey at any point you can do and your results will not be included.

The survey is aimed towards either those who live in Bury or who are registered with a Bury GP.

If you would like support in completing this survey please contact: 0161 253 6300

About you as a carer:

1. **How many people with a MH problem do you currently care for?**

	1 person
	2 people
	3 + people

2. **Approximately how many hours a week do you spend looking after someone with an MH problem?**

	Person 1	Person 2	Person 3
0-9 hours			
10-19 hours			
20-34 hours			
35-49 hours			
50-99 hours			
100 or more hours per week			

Varies – Under 20 hours per week			
Varies – 20 hours or more per week			
Other (please specify)			

3. **How long have you been a carer for the person with MH?**

	Person 1	Person 2	Person 3
Less than 5 years			
6-10 years			
11-15 years			
16-20 years			
21-25 years			
26+ years			

4. **Which of the following describes your role as a carer at the moment?**

	Person 1	**Person 2**	**Person 3**
I am the only caregiver			
I share caring responsibilities with others, but I am the main caregiver			
I share caring responsibilities, but someone else is the main caregiver			
Other (please specify)			

5. **Has your caring role had a positive impact on your health and wellbeing? (Please describe below)**

6. **Has your caring role had a negative impact on your health and wellbeing? (Please describe below)**

About the person you care for

7. **Who do you care for?**

	Person 1	Person 2	Person 3
My son/daughter			
My partner/spouse			
My brother/sister			
My parent			
My friend			
Other (please specify)			

8. **What is their illness/condition?**

	Person 1	Person 2	Person 3
They have not recognised they have a mental health problem			
Not yet diagnosed			
Psychosis			
Schizophrenia			
Bipolar disorder			
Depression			
Anxiety			
Prefer not to say			
Other (please specify):			

9. How old is the person you care for?

	Person 1	Person 2	Person 3
Under 10			
11-25			
26-40			
41-55			
55+			

10. What are the main things you do to support the person you care for?

11. Have you got any concerns about the support you provide?

12. Do you live with each other at the moment?

	Person 1	Person 2	Person 3
Yes			
Some of the time			
No			

13. If you answered ‘No’ to the previous question, where are they currently living?

	Person 1	Person 2	Person 3
Own/rented accommodation			
Supported accommodation			
With other family member/friend			
Care home			
Hospital			
Other (please specify below)			

14. Does the person you care for receive support from any of the following services?

	Person 1	**Person 2**	**Person 3**
GP service			
Healthy Minds			
Young healthy Minds			
Support from the local charity/voluntary sector organisation			
Community Mental Health Team			
Social worker			
Inpatient care in the hospital			
Substance misuse support services			
Housing support service			
Benefit/Debt support service			
Specialist mental health service			
Family support service			
Bereavement support service			
Access and Crisis Team			
None of the above			
Don’t know			
Prefer not to say			
Other (please specify)			

15. **Please share any positive comments about any of the services they receive below?**

16. **Please share any negative comments about any of the services they receive below?**

Crisis Care

17. What would you describe as a crisis situation for the person you look after (If it's more than one person please refer to 'Person 1', 'Person 2' or 'Person 3')?

18. What can be done to help prevent the mental health crisis occurring in the first place or reduce the severity of an episode when it does occur (If it's more than one person please refer to 'Person 1', 'Person 2' or 'Person 3')?

19. How often does the crisis situation occur?

	Every day
	A few times a week
	About once a week
	A few times a month
	Once a month
	Less than once a month
	Few times a year
	Other (please specify)

20. Do you feel able to manage when the person you look after is in crisis?

	Yes
	No
	Sometimes
	Other (please specify)

21. If you answered yes to Q20 please describe how you are able to manage the situation (skills, coping tools, techniques, other support accessed)

22. If you answered no to Q20 what are the issues?

23. What support and or information would help enable you to manage the person in crisis (please be as specific as possible for example if it's a training need please state the type training?

24. When the person you care for is in crisis what services do you access?

25. How helpful are the services offered?

26. What support would help the person in crisis help themselves?

27. Is there anything else you would like to share with Healthwatch Bury regarding your role as a carer?

Demographics – About you

28. What is your age?

	18-24
	25-34
	35-44
	45-54
	55-64
	65+

29. What is your gender?

	Male
	Female
	Prefer not to say
	Other

30. What is your employment status?

	Employed full-time
	Employed part-time
	Self-employed
	Unemployed
	Retired

	Student
	Unable to work due to caring responsibilities
	Unable to work due to ill-health /disability
	Prefer not to say
	Other (please specify)

31. Please indicate in which area of Bury you live

	Ramsbottom
	Prestwich
	Radcliffe
	Whitefield/Unsworth
	Tottington
	Bury
	Other (please specify)

32. Do you have any of the following?

	A physical impairment or disability
	Sight or hearing loss
	A mental health problem or illness
	A learning disability or difficulty
	A long-standing illness
	None of the above
	Other (please specify)

The questions below are additional questions about your demographics. Please note these are optional.

33. What is your ethnicity?

	White British
	White Irish
	Gypsy or Irish Traveller
	Other White
	Indian
	Pakistani
	Bangladeshi
	Chinese
	Asian
	Black African

	Black Caribbean
	Other Black
	Arab
	White and Black Caribbean
	White Asian
	White and Black African
	Other Mixed
	Prefer not to say
	Any other background (please specify)

34. What is your sexuality?

	Heterosexual
	Gay
	Lesbian
	Bisexual
	Prefer not to say
	Other (please specify)

Appendix 2

Case Studies

Carer 1

‘I have been a carer for my wife for the last 9 years since 2009.

We are very happy with the services, we feel we have been lucky in that way.

The biggest issue for us is isolation. We live near XXX, we get lonely and public transport is the biggest issue for us. We are reluctant to ring the ambulance because we cannot afford to get a taxi back home. It costs £16 in a taxi one way from Fairfield Hospital. Last time when my wife had crisis I had to deal with it myself. We have contacts who we can ring during the day but there is nowhere to ring between 9pm and 5am. I wish we had someone to ring later in the evening after office times.

Mental health crisis for us means suicide. My wife has attempted suicide on several occasions.

We have children who are registered as young carers. They can also take time off from school to go to the appointments with my wife. The nature of the disorder is that when my wife is high she can apply for three jobs and feels ‘very happy’ but the high is often followed by the very low. She does irrational things when on a high.’

Carer 2

Revealed how she is a carer for her adult son:

‘He doesn’t live with me and I don’t feel like I’m in control. I don’t want to control his life, I just want to keep him safe and make sure he is well. I am in my late 80s myself.

My son’s condition has not been diagnosed. He has physical health issues as well as mental health issues. My son’s going worse and I am not sure how I should speak to him. He often falls over and has anger outbursts. He sometimes breaks computers in an anger. He doesn’t go out much, he doesn’t look after himself, his diet, hygiene etc.

I am not sure how to respond when my son is in crisis. I just want to help him and I am scared of telling him the wrong things and scared that anything I say might tip him over the edge. I feel like saying to ‘snap out of it’ but not sure that’s the right thing to say. I just don’t know and need someone to help me and tell me how to support someone with mental health issues. My son is really disappointed with the doctors and hospitals and refuses to go and see the GP.

I would like someone who could help me and tell me what to do.

We had a crisis in the family, my son’s girlfriend dropped him. My husband died. It seems to be the nature of the mental health illness – people are often up and down. My son has given up on doctors and hospitals.

I was told by my son not to interfere and if I want to commit suicide I will. My son rings me most days but when he doesn't I get really worried and down.

Books and words bring me comfort.'

Carer 3

'My husband was diagnosed with a mental health condition and he has been in employment for a long time. Since the diagnosis things have gone awful and he is being discriminated against at work.

He has been off sick from work for months and has been sleeping in the car.

I am the main carer for my husband over the last year. We have many arguments and when he gets angry he gets in the rage.

In the first two weeks I had a telephone number in case of the crisis but after that two week period I have no one to contact in the event of crisis and no support.

My husband got some support from an out of Borough Organisation but the local CCG doesn't fund that any more unless we can prove that there is nothing else locally available.

My husband is not eligible to access the Healthy Minds, they say he needs a higher level/different level support. He can't access the Access and Crisis team either. There is a gap in the services.'

Carer 4

'I am the carer for my daughter who has a number of mental health conditions. I have been the carer for her for the last 10 years.

We are involved with the Early Intervention Team. The worker visits once or twice a week. They provide brilliant support and help with cooking meals, confidence building.

My daughter also sees the Community Psychiatric Nurse and sees the psychiatrist in every three to four weeks.

We also have a Family Support Service and CBT.

She also attends the local peer support groups.

We have a telephone number for the crisis situation and the trained staff member can help in these situations.

For me the health professionals should treat their patients more like customers with the respect they deserve and if they cannot show up to appointments to let the patients know rather than just not show up.'

Appendix 3

World Fellowship for Schizophrenia and Allied Disorders

Principles for Working with Families

In Comprehensive Mental Health Care

This information was developed by members of the World Fellowship for Schizophrenia and Allied Disorders in conjunction with Professor R.H. Falloon, Professor Julian Leff and Professor William McFarlane, international psychiatric researcher clinicians working with families in many parts of the world. The principles were drawn up as part of the 'Families as Partners in Care' initiative and are based on positive research findings found when family members were included in comprehensive treatment and care.

The text below lists the principles and explains the rationale for work with families. It is particularly relevant for countries where a mental health workforce is available to be trained in 'family interventions'.

- *Coordinate all elements of treatment and rehabilitation to ensure that everyone is working towards the same goals in a collaborative, supportive relationship.* Working together ensures that the goals for treatment and care are understood and agreed by the treatment team which includes the family. This will overcome the isolation that is experienced by both professionals and families.
- *Pay attention to the social, as well as the clinical needs of the patient.* It is insufficient to focus exclusively on medication management. Needs for appropriate accommodation, employment or alternative occupation, economic support, recreation and a supportive social network must be taken into account.
- *Provide optimum medication management.* Clinicians should be alert to signs of overmedication and to the unpleasant and disabling side effects of antipsychotics. There should be regular reviews of the medication with the patient and family. Education about medications plus regular assessment, particularly in relation to side effects, will encourage compliance.
- *Listen to families and treat them as equal partners.* Relatives have gained a great deal of experience and have much to teach professional caregivers. Their expertise should be acknowledged and valued. Clinicians should consult with family throughout the treatment and care program, to improve effectiveness, understanding and empathy. Speaking to families in their homes may help in initiating family contact.
- *Explore family members expectations,* concerning: a) the treatment program (each family member may have different expectations; because these may be unrealistic it is important to explain what the team hopes to achieve); b) the patient (after an episode of illness, particularly at the beginning, family members may expect the person to return rapidly to his/her previous level of functioning: the family will need to

adjust their expectations and form new goals; throughout the treatment process, family and patient expectations have to be regularly evaluated).

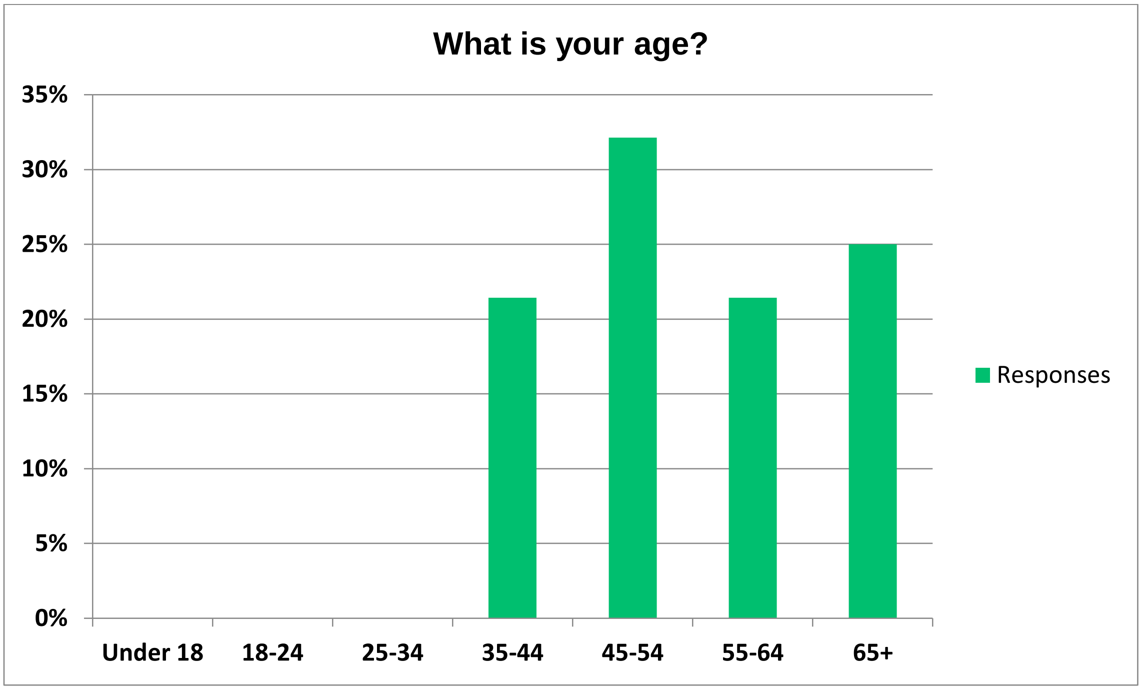
- *Assess the family's strengths and difficulties*. It is too easy to focus on the family's problems and ignore their strengths. Simply staying together constitutes a strength. A major strength is their intimate knowledge of the patient and what they have learned through a process of trial and error. Caring for someone with a mental illness exacts an emotional toll. Anxiety and depression should not be neglected. These symptoms reduce their capacity to support the patient.
- *Help resolve family conflict by providing sensitive response to emotional stress*. Anger, anxiety and guilt expressed by family members should be dealt with in a sensitive way. Anger can usually be reframed as showing concern. Expressions of warmth are encouraged. Recreational activities should be promoted that are likely to lead to family members enjoying things together. When conflicts stemming from antagonistic relationships arise, clinicians need to listen to the differing viewpoints impartially and seek resolution through compromise.
- *Address feelings of loss*. Family members experience loss of hopes and expectations for their sick relative. They also feel that the person they know has been changed by the illness. Their grief needs to be acknowledged. They need help in coming to terms with both these kinds of loss.
- *Provide relevant information for patient and family at appropriate times*. An introductory education program is an effective way of engaging families, but needs to be followed by continuing education throughout the period of treatment and care. Clinicians and families need to appreciate each patient's individual signs of relapse in order to bring about an early treatment intervention. Each family has its own concerns which need to be addressed. In addition, clinicians should recommend that the family attend a support group.
- *Provide an explicit response plan for crises*. The family should have access to the treatment team when they know that their relative is in danger of relapse. A provisional plan, which includes relevant telephone numbers of key contacts and services, should be in place.
- *Encourage clear communication among family members*. In some families, members find it difficult to communicate with each other. They have stopped listening. It is common for the person with mental illness to be left out of discussions. Clinicians need to suggest simple ground rules for clear communication, and support the family in their efforts to observe them.
- *Provide training for the family in structured problem-solving techniques.* This cognitive-behavioural approach is of great value in helping families to tackle the main problems they face in caring for a person with mental illness. It is sensible to guide the family towards applying the techniques to a simple problem first, so that they are likely to achieve success.
- *Encourage the family to expand their social support networks.* Families tend to withdraw from their natural support networks through burden, shame and embarrassment. Initially they benefit from social interaction through relatives' support groups, or multi-family problem solving groups. It is important that the caring role does not absorb all their life and that a balance be maintained. Patients may be

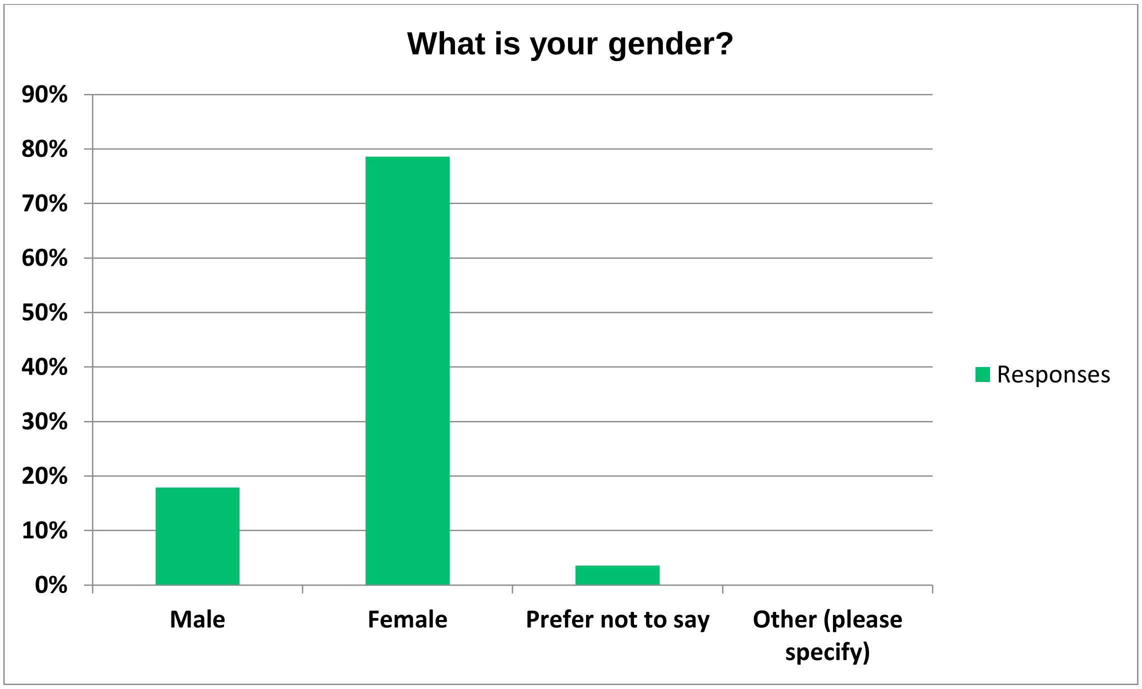
helped to increase their social activity by social skills training, often with the assistance of siblings and friends.

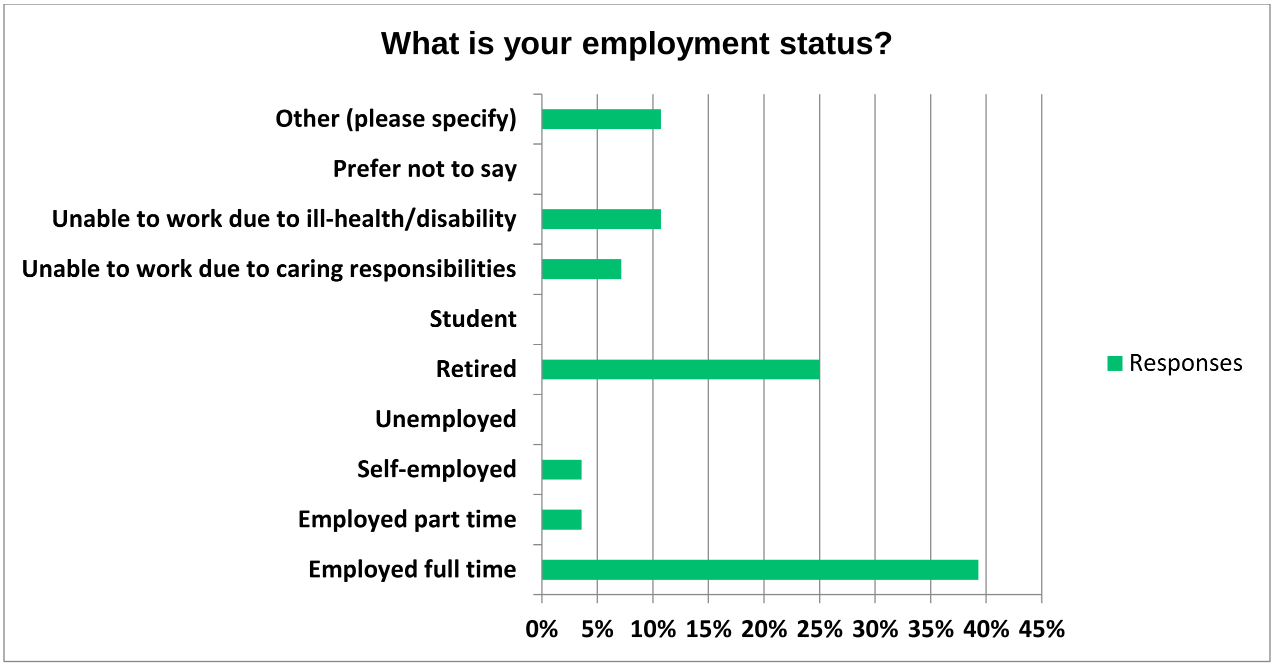
- *Be flexible in meeting the needs of the family.* Clinicians may decide to work with a single family or groups of families. Family members and/or the patient may need to be seen separately. The patient may need to discuss some concerns privately when they do not concern the family.
- *Provide the family with easy access to a professional in case of need if work with the family ceases.* It is essential to leave the family with a phone number and a named person who will deal with any future enquiries. Sometimes a telephone discussion will suffice; at other times additional sessions may be required to help family to cope with a crisis or a change in their circumstances. Some family carers who gain confidence in their caregiving role should be used as:
- *Educators and trainers of mental health professionals.* Work with families can take place through a 'reflective' learning process between family care and professionals at undergraduate and postgraduate levels of training as well as in-service workplace training.
- *Advisors at all levels of policy development in mental health services.* Family and consumer perspectives must inform mental health policies through advocacy groups alerting governments to mental health issues.
- *Advocates for community acceptance of mental illness.* Carer organizations have an important role in mental health advocacy, particularly through community awareness campaigns aimed at reducing the stigma associated with mental illness.

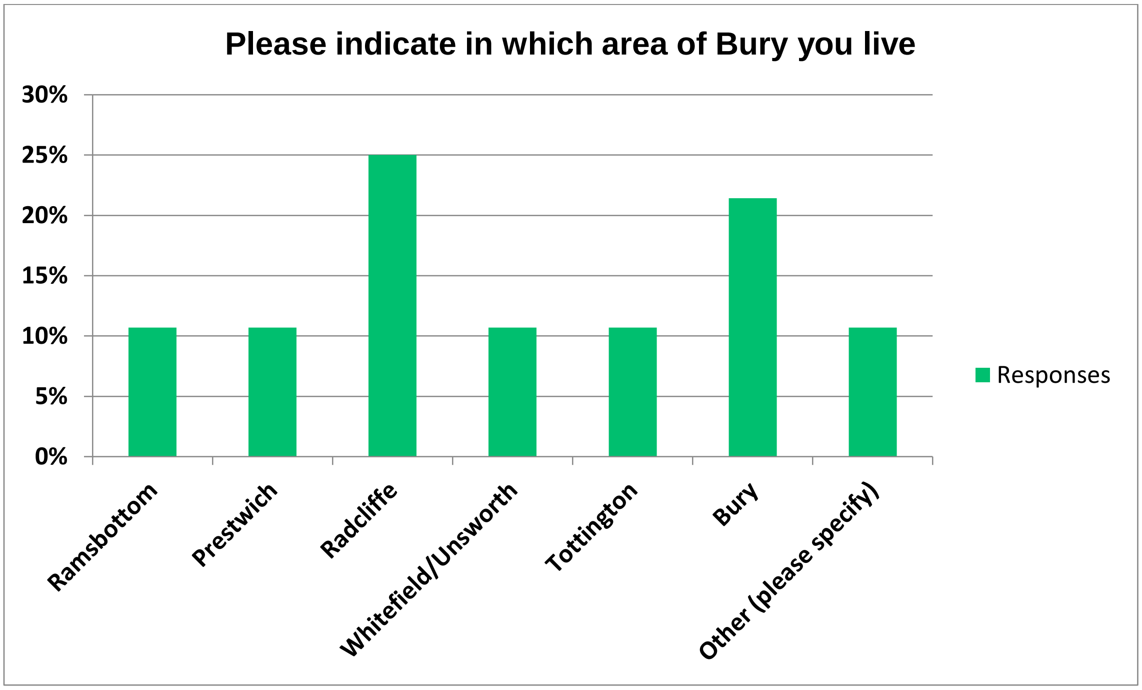
Appendix 4

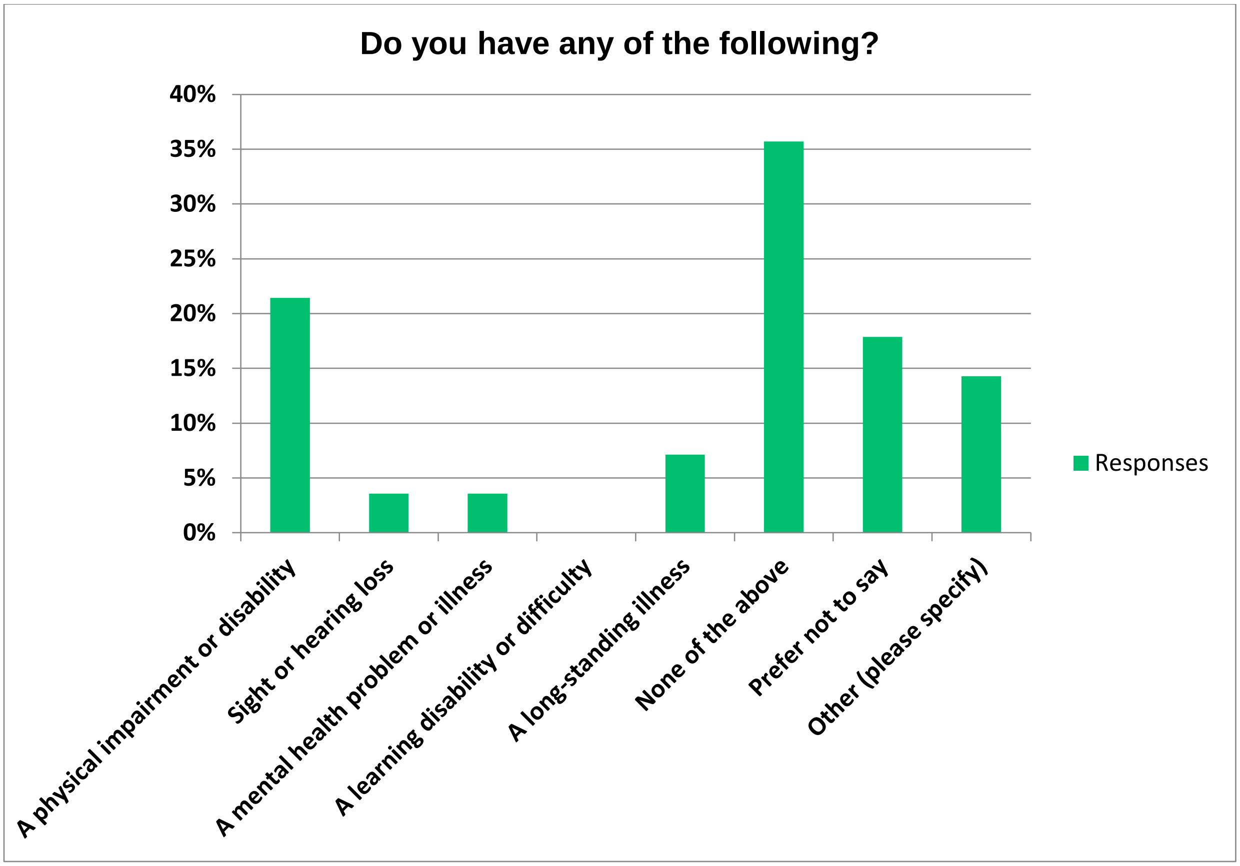
Demographics

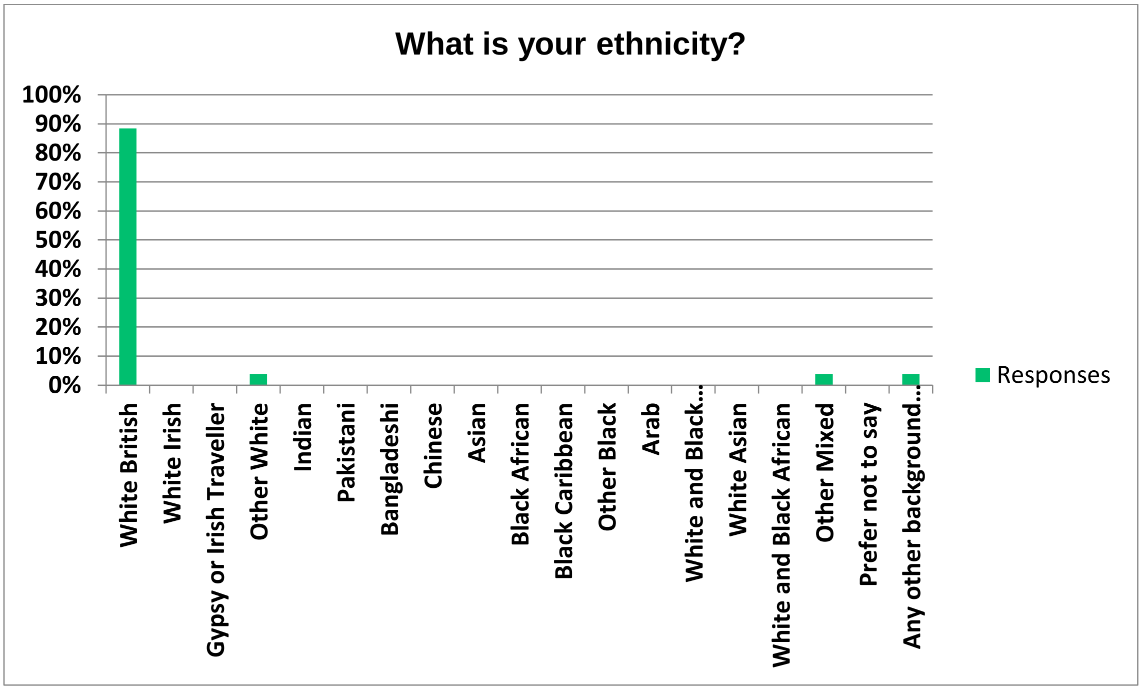


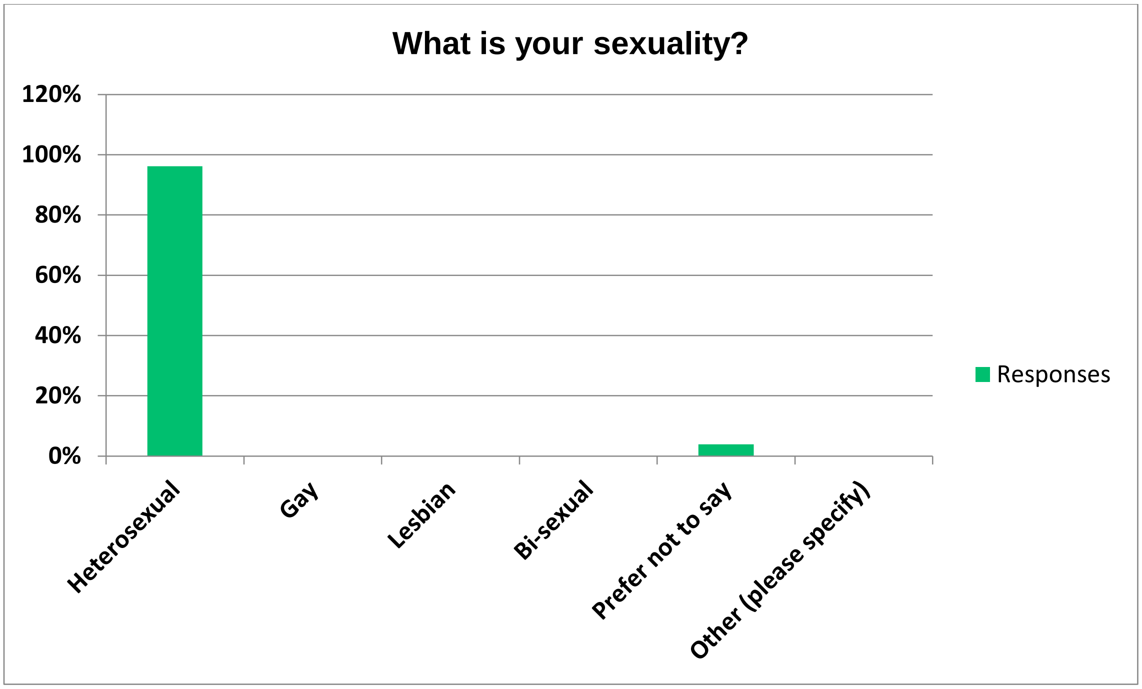



What is your employment status?
Other (please specify)
Prefer not to say
Unable to work due to ill-health/disability
Unable to work due to caring responsibilities
Student
Retired
Unemployed
Self-employed
Employed part time
Employed full time
0%
5%
10%
15%
20%
25%
30%
35%
40%
45%
Responses


Please indicate in which area of Bury you live
30%
25%
20%
15%
10%
5%
0%
Ramsbottom
Prestwich
Radcliffe
Whitefield/Unsworth
Tottington
Bury
Other (please specify)
Responses


Do you have any of the following?
40%
35%
30%
25%
20%
15%
10%
5%
0%
A physical impairment or disability
Sight or hearing loss
A mental health problem or illness
A learning disability or difficulty
A long-standing illness
None of the above
Prefer not to say
Other (please specify)
Responses


What is your ethnicity?
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
White British
White Irish
Gypsy or Irish Traveller
Other White
Indian
Pakistani
Bangladeshi
Chinese
Asian
Black African
Black Caribbean
Other Black
Arab
White and Black...
White Asian
White and Black African
Other Mixed
Prefer not to say
Any other background...
Responses


What is your sexuality?
120%
100%
80%
60%
40%
20%
0%
Heterosexual
Gay
Lesbian
Bi-sexual
Prefer not to say
Other (please specify)
🟩 Responses