

# WITH CARERS IN MIND



## With Carers in Mind

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Welcome to 'With Carers in Mind', an audio and visual project which is based on oral testimonies with carers who care for individuals experiencing mental distress and dual diagnosis. The project was initiated in 2012 at the mental health charity Mind in Bexley. Through Mind's work with carers, team members became aware of the many difficulties and challenges faced by carers who were accessing Mind's services. We became interested in individual stories of carers and we wanted to know more about their unique experience of caring, the impact of caring on family life, the obstacles they face and the role of peer support in overcoming some of these challenges.

From October 2012 to January 2013, those who attended Mind in Bexley's carer's service were invited to record an oral history interview. We recorded and transcribed fully 20 oral history interviews which reflected a range of experiences and narratives: Some gave 'life story' interviews based on their role as carers; others focused on the impact of the carer's experience on their own mental health and wellbeing. Carers also reflected on the positive impact of peer support on their wellbeing.

The recordings, together with complete transcripts, form a digital archive, which represents a rich resource for future research and development at Mind. This booklet accompanies an exhibition based on the project which will open in Hall Place, Bexley in February 2013.

## Photographs

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Audio Visual Workshops for carers were held over two days in December 2012. Photographs were taken of participants at various locations in and around Mind in Bexley. Their photographs have been added to the archive and some of the images are included in this booklet.

## 'A Day in the Life of a Carer':

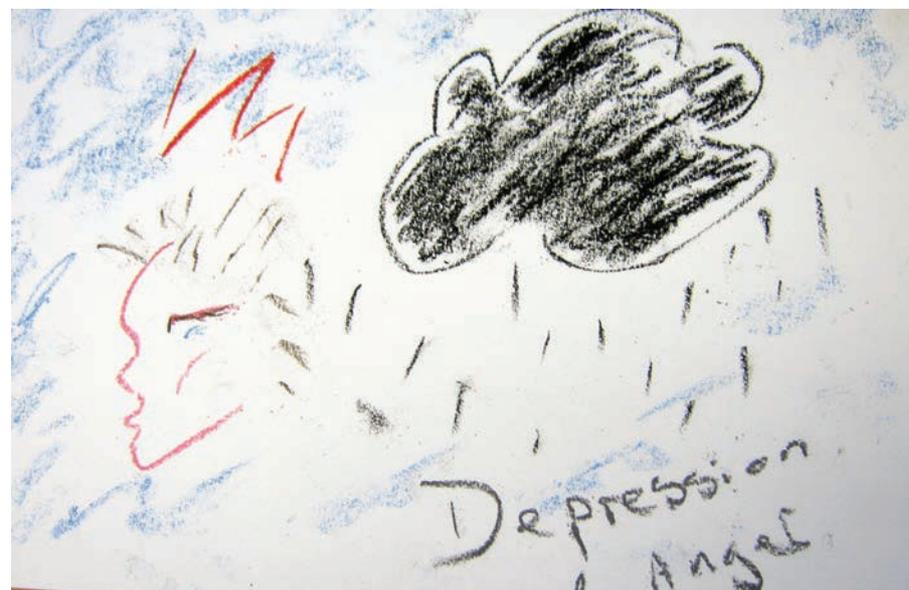
### A two day creative workshop, Mixed Media on Canvas

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A two day creative workshop was held in January 2013 which allowed participants who were interviewed to share their personal experiences as a carer, through working individually and collaboratively with different artistic media, leading to the creation of an artwork displayed titled: 'a day in the life of a carer'. This powerful work reflects the needs and often difficult thoughts and feelings of the carers who participated. Photographs of the workshops are also included in this booklet.

We are delighted to be able to share extracts from the archive with you. These are arranged around the themes that emerged during the project. Though we can only show a small number of extracts here, those displayed offer an insight into the important narrative collection we have started to build. As oral history allow individuals to tell their own story in their own words: all words from here on are the 'voices' of those who participated in the project.

### David Palmer



## You're kind of a go-between

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As many as one in four people experience some form of mental health problems. Caring for someone with mental health problems brings unique challenges. Mental health problems vary greatly in severity. Mild problems are common and can be helped with understanding and support. Severe mental illness, such as deep depression, is less common and poses more challenges. The term 'carer' can be defined as an unpaid person providing regular care (probably at least twenty hours per week) for a friend or family member. These definitions, however, are drawn from the experience of carers for frail, elderly or physically disabled people; carers of users of mental health services face distinct challenges because of the very nature of mental illnesses which may be intermittent, crisis driven and long standing. Carers come from all social and educational backgrounds and are diverse in terms of their age, gender, ethnicity and cultural background, the duration of care, their relationship to the person they care for. They support people with a range of diagnoses living together with them, apart from them or in institutional settings. Many carers made poignant and heart-felt comments about their caring role and describe in a fuller and more direct manner the support they are giving.



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*“You're kind of between, the person, that's ill, and the mental health team. And you're kind of a go-between. And you're fight, you've, you've, sort of, in some ways, fighting in the corner for yourself but you're also fighting the corner for, the person you're caring for.”*

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*“Even if the person is under care, it's still twentyfour hours a day, because you're always thinking about them. You may have, interests elsewhere, you may have relationships elsewhere but that person is always there constantly.”*

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*“I'm a mum that cares for me son, and know that my son is vulnerable and does need help. But at the minute, I feel like I'm in a tumble drier, like an old trainer really, just battering around and not knowing where [laughing] to turn or what to, which direction to sort of go to, you know?”*

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*“It's huge, it's a complete nightmare sometimes because, in a sense you feel like you've, had to put, certain aspects of you on hold or out of the way and, it is a, something that you feel the weight of all the time. It's a bit like, I feel always like I'm, dragging this extra weight around me through my life, wherever I'm going, whatever I'm doing.”*

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*“So I've al-, I always have to be strong for her. It's no good, you, you-, it's very difficult because you can't really give in to it. So in the end it's put, you, I think you tend to put their needs before your own needs. And over a long period of time as well...It's just, it just never goes away. It's always there. You're always a carer.”*

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*“Because the carer's forced to cope all the time; and, if the carer doesn't cope, you've got a lot on your shoulders, because you feel, if you have a moment where you take your foot off the pedal, what's going to happen to them? They're going, going to crumble, this'll happen, that'll happen. One of the things that you have to do as a carer is that, I had to learn to do, was to fight for things for her. It's, quite difficult...it's just like a constant battle which shouldn't be there, it sh-, you shouldn't have to do it.”*

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## If you've lived with it, for a while, you can see the signs earlier

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A further role for carers is as an 'expert' on the health and well-being of the person they care for. Participants talked about recognising early warning signs that the individual being cared for is becoming unwell or having a relapse. In this role, carers can contribute to decision-making processes and to treatment packages however some individuals highlighted that their own expertise is frequently ignored by professionals.



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*“You're kind of between, the person, that's It's just that he looks different. He, he's, his demeanour, his face, the look in his eyes, everything's different about him. Can't, it's like a different, it's like being with a different person entirely. And I said I can't explain that to anyone else, h-, what it is, but I just know, from instinct, I, I sort of, got quite hypersensitive to, to things. And, he has actually said to me, he said, 'You, you, sort of, know me more than, than even what the doctors did.' Because the doctors have never seen him like that, I'm, I'm the only one who's actually seen him like that. Unfortunately. [Laughs] But, so, I, in my mind I-, I thought if I, don't pick up on it one day or if I get it wrong, am I going to be putting my children in danger or myself in danger, you know, that kind of thing, it's a big responsibility that's, at the back of my mind.”*

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*“Because, if you've lived with it, for a while, you can see the signs earlier, and you kind of have to fight for somebody from the mental health team perhaps to, to recognise that and come when you're, and you know...when you need it. You can see, as a carer, you're able to see changes in her behaviour that other people aren't able to see because they don't have that close contact with them. So, for example I can always tell when she's, when her voices are really troubling her, because she then isn't able to concentrate on the conversation you're having with her.”*

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*“I know the early signs, but nobody will believe me, and each time I get assured that it won't happen again, but it does happen, over, he was getting ill over a period of nine months this last time. And I can see it right at the beginning, I can see that, he's, does this staring, his eyes don't look right, and then it goes on, each stage, it go-, he gets agitated, he starts swearing a lot. It's just, he gets, he-, ev-, eventually, there's no question that he is, ill. But at the beginning, he's unaware of, being ill, he doesn't know that he is ill at the beginning.”*

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## It's left me emotionally, well, put it bluntly, emotionally smashed

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For those carers interviewed, the heavy responsibilities of caring have had consequences on their wellbeing and was a reoccurring theme. A person with mental health problems may not need much assistance at certain times, but need a large amount of care at others. And, as the symptoms of mental health problems are sometimes unpredictable, it can be particularly worrying for the carer. The emotional impacts reported of being a carer include loss, grief, guilt, shock and acceptance while the wider impacts of mental illness within a family can result in isolation and stigma for carer and user. Participants reported that a lack of sleep was common and physical problems such as high blood pressure and fatigue were also common themes running through the narratives.

*“I've certainly, the periods he's been home, haven't had enough sleep. That's certainly had an impact on my health. I've had a heart attack now, a couple of years ago, probably as a result of stress...if he hadn't been hospital I think, I'd have to move out frankly. I say it's ruined me marriage, ruined me career, ruined me health.”*

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*“These fifteen years, nearly sixteen years of his, drug addiction and binge drinking have really, as a mum, has been quite devastating.”*

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*“It's always at the back of your mind. It never goes away, you're, you're kind of never at rest. It is, you're always kind of, waiting for a 'phone call, what, what state he's gonna come home in, what will happen next, you know, wh-, how is he going to be, sort of in the morning, you know.”*

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*“It's very hard so some days are really bad...because it's, I am very, very low. But, I say to myself you can't, be allowed to be low today...But in the evenings, in the evenings when I'm all on my own and I love my home, I could cry my eyes out, but no-one will see, no-one will see.”*

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*“It's left me emotionally, well, put it bluntly, emotionally smashed. Completely. Now I'm just picking up the pieces ... Because of the stress, it is massive stress, massive stress.”*

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*“With my health, at the minute I'm off sick, I kind of just had enough, of coping, of being seen to be able to cope, when I clearly, I wasn't say, I've had a breakdown, I wouldn't say I'm depressed, I'm overwhelmed. You know I don't, I don't feel, depressed, I feel exhausted.”*

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*“Well, [laughs] put it this way, according to my oncologist I'm not supposed to have any stress, I think, my life couldn't be any more stressful if I tried. But, I'll always remember when I first got the cancer, [laughing] because it was an aggressive cancer, and the consultant said, 'No more stress.' [Laughs] But, not much you could do is there? You just got to battle on.”*

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*“I had gone out that evening to a, quiz night and I came back, she was lying in bed, seemed to be okay and then I s-, noticed her doss [sic] boxes and they were empty. And of course, I realised what happened, I got her, mit-, for about five ten minutes I was in a complete state of panic. I was banging on the floor, almost hysterical then because I was, just totally, shaken by the whole thing.”*

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## It's wrecked the whole, the whole family really

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Caring affects relationships within families and while, this may not always be for the worse, illness-related changes in life situation were reported to endanger relationships, social life, financial security and occupational functioning. We identified the main burdens as limits on family members' activities, family friction and disruption to household routine. Carers also stated that siblings had been adversely affected by their mentally ill brother or sister.

*“Well, we haven't got a life anymore, really. It's wrecked the whole, the whole family really, when he's ill, he just wrecks the whole family because we're all frightened of him, because when he really gets ill, he gets, doesn't actually hit anybody, but he gets really aggressive and it's frightening. I don't, don't think that we've got a life really, we never go out, I gave up me business, and he's constantly on me mind, all the time.”*

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*“So the marriage has gone-, -the job's gone, I mean I've retired now anyway but, it didn't help me job prospects. Holidays go out the window. [Laughs] I've generally been next to useless most of the time.”*

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*“And, what people don't understand that, when someone becomes mentally ill, the parents, or, the wife or even the girlfriend and the sisters and brothers, it's a death. You're grieving. Because that person that you knew isn't, you're never going to get them back. They might get reasonably well, but you never get that person back. So all, all the things you look forward to for that person, are gone. You know. There's not much in their life.”*

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*“It's like a, dropping a stone in water and the waves just spread out. It affects a large number of people who you wouldn't even think were affected by it...it's like a, any, with all caring roles and with these illnesses and addictions and so on. It's, it spreads out like a, circle on a water. It affects a lot of people who you wouldn't even realise. Indir-, who are indirectly affected.”*

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## Guilt and responsibility is, is like two bags of luggage that I carry

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Being a carer can raise difficult personal issues about duty, responsibility, adequacy and guilt. The experience of mental illness in a person's life, either as a person experiencing mental illness or as a carer, can have a profound impact on people's emotions. Mental illness, often being episodic and unpredictable, evokes the full range of emotional responses, including anger, grief, embarrassment, shame and despair. A powerful strong emotion that was often presented in the narratives was guilt.

*“While I was, in, in, you know she went into another room and self-harmed, yeah I felt guilty about that because, I didn't recognise that she was at that stage of self-harming. And had I have recognised it, I would have been able to do something about it, I would have, but, obviously I can't watch her all the time and I gave her that sort of, time alone. I th-, I thought she went in the bedroom because I could hear noise and, she was tidying up the bed-, I thought she was tidying up in there but what it was was, I didn't know but, K was a bit of a hoarder, of medication from, from the past, and she happened to have, some tablets, down the back of the, in the back of, bottom of the wardrobe which she, which she'd taken. So yes I felt guilty.”*

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*“The guilt that I'm, knowing that he's not, he hasn't got up, he's not eating, the guilt is with me all day. I, oh I've got to go and see if he's alright, I've got to make sure he's eating. And when I ring him at the end of the evening, I always get, 'I haven't done anything, I haven't eaten.' And I feel, I'm not saying it's right, but I feel it's because I haven't been there. And that guilt is always there, constantly, eating away at me.”*

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*“You do feel guilty. And I did feel guilty when, about why S was like it. I felt even more guilt when she did, what, when she tried to commit suicide. Oh yes, you do feel guilty.”*

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*“You feel really, you feel guilt, you feel angry. When, when it happened with S, because of the nature of my job, which I do love, and I know I'm good at and I know I can do, but when it happened with S, I felt like resigning from my job, selling my house and running away. Because I felt so ashamed, so guilty, I felt just worthless.”*

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*“Guilt and responsibility is, is like two bags of luggage that I carry with me every day. And when, and you can't put them bags of, luggage down.”*

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## I think well, who's going to look after him, when I'm not here?

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Some worried about what would happen in an emergency and how they'd find replacement care. Concerns were also raised by carers as to who would look after the person they cared for if they became seriously unwell or passed on.

*"You know, the dual diagnosis, the mental health, and it's kind of like at some point, these parents are going to die. And, that person will be left, again, in the community, without support around them, without wanting to get support, because they don't know how to get it and they don't like getting it because of their mental health, it's a constant, it is, it's just a game of table tennis."*

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*"I'm getting older now and I think well, who's going to look after him, when I'm not here? Because I mean in, he's the younger, I've got two daughters, one's thirty-nine, the other one's thirty-seven, and then there was a big gap and I had D. And, so obviously, I'm, I'm not going to be here, around, for, when he's still young, and I think, well who's going to look after him, you know, who's, that's, I do worry about that... Well I wonder what's going to happen when I'm not around."*

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*"And then's the problem of when we're, when we're no longer here, what happens to her then. So it's people needing to know that they need to make direct provision for, a, a child with mental health problems. Erm, well not a child now really. And, how they go about doing that."*

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## It's like a game of never-ending tennis

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Communication between carers and professionals is a problematic area identified in the narratives and miscommunication and unsatisfactory communication was viewed as frustrating for all parties.

*“It’s like a game of never-ending tennis, you know, it just, you to me, to me to you and it’s just like, he’s in the middle like pass the parcel being passed around, because he’s not Asperger enough, he’s not alcoholic enough, he’s not mental enough, and it’s like you, he just, he says to me, ‘I feel like an alien, I feel like I shouldn’t be here.’ And, [crying] some of the times I’ve, you know, I’ve actually thought it would be better if he wasn’t here because it’s like, he, he and others, where are they meant to fit? Do you know what I mean? He’s, he’s got a lot of problems and he’s got a lot of mental health issues now which he never had. He wasn’t this bad. But, as you get older and you have deal with more things, social wise, and life wise, it become, becomes more unbearable for them. And then they turn to the things that they think, take the pain away, numb them, make them feel more confident, and it’s just masking the things that they can’t deal with, you know?”*

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*“I suppose, I mean I suppose you can get a bit angry, if things get, get muck-, mucked about with. [Laughs] Erm, there’s been a lot of changes with C ... and I suppose there’s a feeling of, you can get a bit, start, you can get a bit frustrated by things. I think it’s more frustration than anger.”*

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*“Oh, I, I, get very angry [laughs] and very frustrated, with the whole system. The whole system needs looking at.”*

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*“They don’t get my side of the problem. They only get hers. And what she tells them is quite true. I do shout at her, I lose my temper. It’s got worse now, because, it’s all the time, day in day out. You don’t get a break and that, tells on you.”*

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## I'm thinking of you love, keep going love. And your spirits are lifted

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All carers are different and their circumstances vary so help to combat stress needs to suit the individual. There are different things that cause pressure for different people in a caring situation. Peer support was highlighted as one of the most crucial ways of helping carers cope. Importantly, peer support groups were valued as a space for carers to share information and experiences; these groups were also the first chance new carers had had to meet people in a similar situation.

*“And, and, and so, and I think that’s the wonderful, it’s the mystery if you like, because you can go o-, go in there sometimes, on your knees and then you get someone like dear old D, that’s her age, and, and, and the little miracle happens within you where you say, you think to yourself, you know, come on D, I’m thinking of you love, keep going love. And your spirits are lifted. And that’s just what keeps you going.”*

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*“Nobody knows what it’s like, only someone-, your best friend doesn’t even know what it’s like. Only someone that’s going through something similar to you. And, w-, you form a bond with these people and, when new people come into the Carers’ Group, you always notice there’s a new person come, everybody gives that person a chance to speak, to pour out their emotions, to give them the ba-, box of tissues. You know, because we’ve all been there. But I don’t think anybody knows what it’s like to be a carer only the carer”*

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*“I think it’s important for other carers who are going, to see that there can be light at the end of the tunnel and that things aren’t always going to be as terrible, hopefully things aren’t always going to be as, terrible as they seem at the moment. I think the groups are brilliant, I think it gives people a, place where they can go, and they realise that they’re not the only person who’s got this problem, there are other people who have the problem...so it’s, it’s, carer, led rather than led from the top.”*

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*“What I liked about it was, you’re not alone. You f-, you feel you’re alone, until you go into a group like that, and you see that there’s other people. When I hear other people’s stories, which I have done, I think, my goodness, what am I complaining about? And I feel lucky, when I hear other people’s stories. And we all work as one. We all look after each other, and we give each other good advice, good advice that we may not know.”*

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*“Don’t lose heart, don’t lose hope. And, and, as you’ve got the Carers’ Group, I would say, go, go, go, to that group. Don’t hold it, it’s not you, it’s not you, you don’t need to feel guilty, you love the person you’re caring for. And you’ve got people around you that love who they’re caring for and they’re on their knees and we come together and we just sit there, prop one another up for an hour. And, you, I always, I always thank God.”*

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*“I just, I just really like it, I think, just by listening to each other, you know, it’s a support and, and knowing that, you know, you’re not on your own, that there are other people out there who are suffering.”*

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*“Because I feel for them. I’m not concentrating on me. And I can feel for them. I feel that although, not everybody comes to the carers’ meetings, at the carers’ meetings when we’re talking, we’re representing those people who haven’t come along and haven’t had a voice.”*

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## There's a lot of things to do with private and confidentiality

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Patient confidentiality and the problems respecting a patient's right to privacy is a common theme in our research. The right to control information about oneself is a basic right yet sharing information to make good treatment decisions to keep all concerned safe is essential. Access to information and involvement in decision-making seems to be one of the major challenges and sources of dispute in partnership working with carers; the limits of patient confidentiality are often at the heart of these conflicts. Narratives evidence the frustration of carers' who argue that patient confidentiality is often used as a way to withhold information from carers. Carers commonly reported feeling excluded from treatment decision-making and it was argued that barriers to carers upholding rights to participation in care can be overcome by better communication.

*“So at the minute I'm still in the loop. But there could come a stage, where S does sort of say, 'I don't want anyone knowing.' And then I am kind of stuffed, you know.”*

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*“I'm not allowed in, I'm, I'm just nobody. But when they want something done, oh, we're .....Well, change of the tablets. It might sound simple, but it's not, when the time comes. That is a nightmare, changing tablets”*

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*“But they won't listen. And I've actually had it said to me that, unless we see it ourselves, we will not take any action at all. So, the triangle of care isn't working, common sense confidentiality isn't working, they put my family at risk this time”.*

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*“I'm fortunate that A has actually signed, a document to say that I have full disclosure. Had he not done that, I'd be completely and utterly in the dark, they don't, they're not forward in explaining things or, or anything like that.”*

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*“So the triangle of care, there's obviously the medical profession, the individual i.e. the patient-, -and then the carer, but she's trying to exclude you, so this is a difficult one isn't it? So- And if she says no, it's no. Well that's, that's wrong. Because she's still living in the family home isn't she? Yeah, yeah. It's not that so much, they don't see it my side of it.”*

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*“Without us carers, you've probably heard this a lot, but we save the government a lot of money. And yet, we get pushed aside. And there's a lot of things to do with private and confidentiality this is a big thing for us carers. Now if we're good enough, to do this role for the government, and save them money, we need to know what's going on, and we need to know if there's any, skeletons in the cupboards, who we're caring for, so we can, we can act on it and we can help them. But this private and con-, confident-, -dentiality, is a headache to us carers, it really is.”*

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## The demands obviously of having someone that's got a serious drug addiction

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Caring for someone who has problems with issues of drugs or alcohol alongside mental health problems can be very challenging and hard to manage for carers. The relationship between the two disorders is complex, controversial and varies from individual to individual. Carers reported feeling stigmatised and isolated as a result of their loved ones substance use. Additionally the stigma associated with mental health can cause a dual stigma for carers. Carers consistently reported difficulties in accessing the support they need, when they need it.

*“So, it, it's like you become schizophrenic. You, on the one hand you're being a really, nice mum, ‘Try and sort it out son, you can deal with this, we can get through it,’ and that may work for a day, a week. Then you take so much of it, like the, the drinking, the behaviours, and then you go like down the hard line and you're like, ‘This is you that's doing this to yourself, if you're going to die, it's out of my hands.’ So you kind of use the shock tactic. And then, that might work. And then you go down, and it's like you become all the people you see. I do know stuff about things, but at the end of the day, I'm just a mum. I'm just a mum. I can't fix you, I can't sort you out, I can't make you better, it's got to come from you. But when he's, like, crying, ‘I can't do this, I can't deal with this anymore, what do I do mum?’ .....it's an emotional roller coaster and it's just like sometimes it just never stops and it's, [crying] I don't like roller coasters anyway [laughs] you know, I do, I really don't like fast rides.”*

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*“He was diagnosed well over thirty years ago, and I think initially they said it was schizophrenia but then, they now, now said it's bipolar. And sort of about ten fifteen years that's been combined with alcohol, so it's been like a double, barrel thing.”*

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*“And you're kind of in this constant battle [laughs], it is, it's, it's just a battle ground really you know, you, [crying] why can't he get it, why can't he just stop? He can't just stop because of the alcohol and because of the Asperger's, and it's, it's very very difficult, very difficult, [laughs] and it breaks your heart.”*

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*“I run a home, so I'm, I'm a carer for, running my home, erm, but the demands obviously of having someone that's got a serious drug addiction, and the consequences of that and anyone, that knows, that, what an addict's life is like with the police raiding your home, fights, stealing, all the things that usually follow, erm, er, er, I, I've tried, you know, I've really really tried.”*

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## Who cares for the carer?

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From the interviews it is clear that carers want to be involved, want to be valued and want to secure the best care as early as possible for the person they care for. Too often individuals reported feeling left out of the loop by professionals; they feel under-valued and are left to fall back on family, peer support and friends for support. Although things are getting better for many and some examples of good practice were highlighted, Carers reported that they continue to find themselves excluded from the process of recovery. Clearly there is more work to be done.

*“So, it all comes back and affects us and, there’s an old saying, ‘Who cares for the carer?’ If we don’t care, who’s going to be there to care for them? And the majority of us don’t get no, nothing from the government, once you become a pensioner you can’t claim carers allowance, so, all in all, the boroughs and the government and everyone, do quite well out of us because we’re the unpaid carers. And I really do think they should take notice of us.”*

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*“You know, if they’re going to cut all these things for people that are carers, there’s not much there as it is, then, you know, I don’t know what’s going to happen to some of the carers that come into the borough. Like, come into the system, the new ones. I just feel so sorry for them. ...But, there, there does need to be more of a carer’s voice in the community, they need to know, there does need to be more there...”*

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*“But I think maybe, it’s becoming a little bit more higher profile than it was. Because I think it, sometimes with carers they have a tendency to slip through the net. And I still think there is probably some, that are out there. That have slipped through the net and, so it is important that there are, people recognise the role of carers. All, all spectrum of carers. You know, like mental health and the physical, and the ones that have got, maybe children, or young adults with learning disabilities, all, sorts or types of carers out there. Because there’s a lot of them. [Laughing] There’s a lot of us ...”*

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## Thank You

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contributed their stories to this project.**

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