



**“No one judges
you here”**

**Voices of older people
affected by a loved one’s
substance use**

February 2017

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Introduction

Adfam's Older Carers group is funded by the City Bridge Trust of the City of London to address the isolation faced by older carers of those with drug or alcohol problems. Looking around this community room in central London at the assembled group, they could be here for any reason: five women of a similar age, some chatting quietly, others waiting cautiously for the meeting to begin.

The 2011 census showed a 35% surge since 2001 in the number of older carers, to nearly 1.3 million. Whilst we do not know exactly how many of them are caring for someone who uses drugs or alcohol, there is evidence that a minimum of 1.5 million people are affected by someone else's drug use¹, and other studies suggest that this number may be up to 8 million. Whether caring for adult children with drug or alcohol dependency, or a partner who may also have dementia or another age-related health condition, there are certainly large numbers of those over 55 who are affected in this way.

Evidence suggests that those who are older often have high levels of need, but face a number of barriers when seeking support for themselves.

The stigma attached to addiction is frequently directed, by association, against those caring for the user², meaning that they are especially at risk of social isolation, compounding the lack of support experienced by most family carers³.

Older people, in particular, face a number of barriers when seeking information and advice: previous bad experiences, an unwillingness to seek information, an underestimation of their own needs, the complexity of 'the system' they are forced to negotiate, and professional attitudes can all obstruct older people from gaining useful and

timely information, advice and support⁴. It is also known that carers generally are less likely to access services such as respite.

An Adfam staff member welcomes the group and suggests a round of introductions. Some of the group already know each other, but there is a new face too. The women hold back, typically slow to acknowledge their own significance, but, with encouragement, they begin to open up. A final group member slips into the room part-way through the introductions, in which a litany of struggles with drugs and alcohol within the family become apparent: a son with a 20-year cannabis and drinking habit who can't hold down a job or live independently; a daughter who has spent a £100,000 inheritance on her heroin addiction; a niece who is spiralling out of control with multiple drug use following her mother's death.

It seemed likely to us as Adfam staff that some of the known challenges of isolation and stigma faced by families of drug users could be further compounded in a large city like London, where many areas have transient populations and communities may no longer maintain traditional social connections. This was why Adfam approached the City Bridge Trust to fund a project for older carers of those with drug and/or alcohol problems.

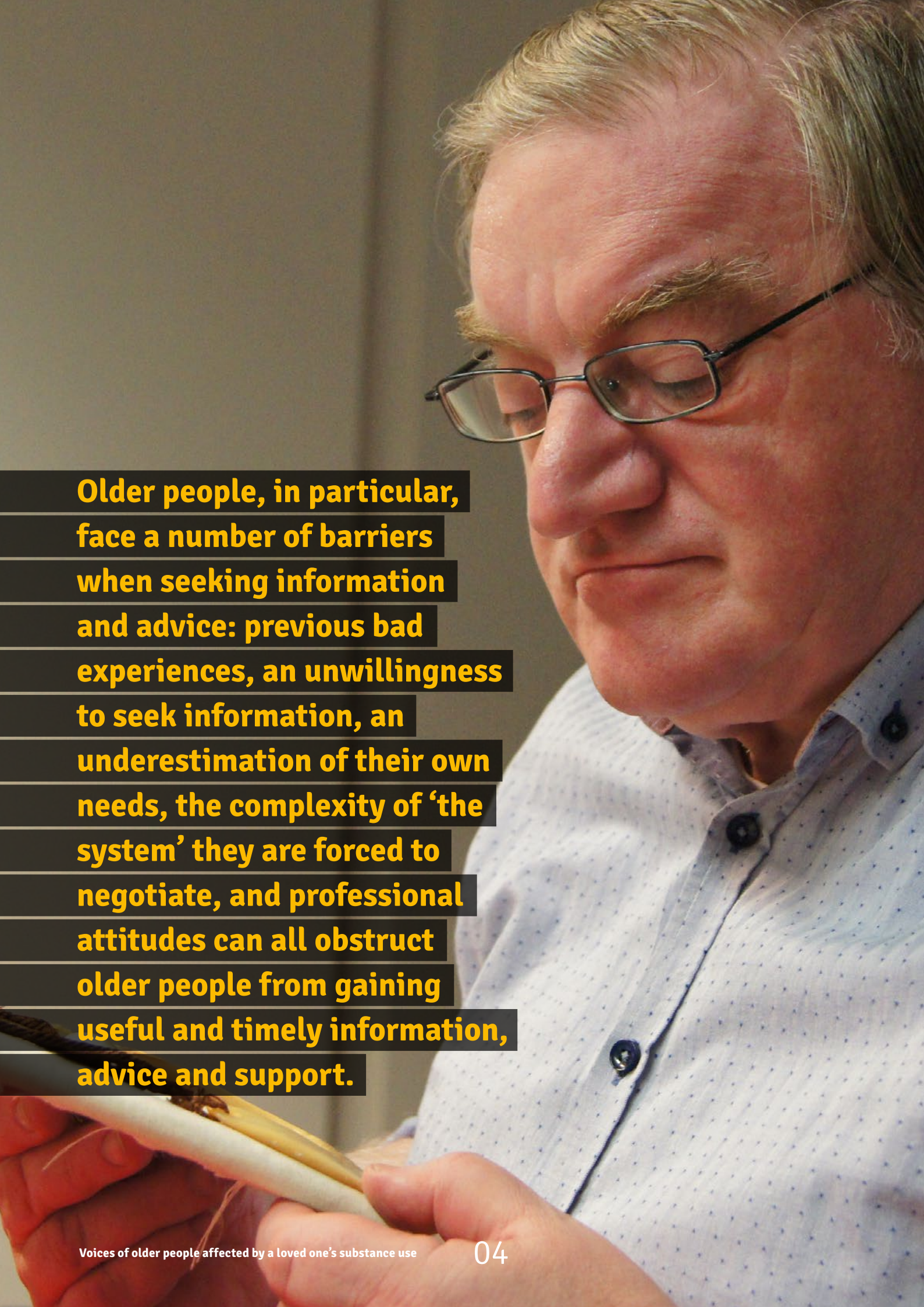
Now, two years on, Adfam has learnt a lot about the needs of carers affected in this way. This report aims to share what we have learnt so that other services can better address the needs of this vulnerable and marginalised group.

1. Copello, A, Templeton, L and Powell, J (2009). *Adult family members and carers of dependent drug users: prevalence, social cost, resource savings and treatment responses*, UK Drug Policy Commission.

2. Carers Trust (2015). *Alcohol, drugs and addiction*. [ONLINE] Available at: www.carers.org/help-directory/substance-misuse [Accessed 6 October 2016].

3. Orford, J et al (2013). *Addiction in the family is a major but neglected contributor to the global burden of adult ill-health*, *Social Science & Medicine* 78/Feb 2013, pp. 70-77.

4. A. Tinker, C. McCreadie and A. Salvage (1993). *The Information Needs of Elderly People: An exploratory study*, King's College London.



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Marjorie

A personal story

71-year-old Marjorie has a 47-year-old son, Michael, who drinks and uses drugs. He is also diagnosed with schizophrenia. He lives alone but requires continual emotional and financial support from Marjorie who struggles to know when to get involved and when to stand back.

Recently, Michael's drug dealers have begun demanding payments far in excess of the value of drugs that Michael says he has purchased from them. They come to his home and threaten him, and have even sent threatening text messages to Marjorie. Marjorie has resorted to pretending to stay elsewhere in an attempt to prevent her son coming to her home and demanding money.

'I am his unpaid carer', she says. 'I handle all his money – on the days I don't see him I don't give him any money. I pay all his bills... I was tidying up his garden... he would never do that alone.'

Marjorie lives in constant fear of what may happen to Michael when she leaves him alone, and regularly spends time trying to calm him with activities such as gardening, so that she can take a phone call or pop out for a few hours.

Marjorie appreciates Adfam's project because it's the first time she's been able to access support from those who understand the addiction aspects of her son's problem. Previously she had attended groups linked to Michael's mental health problems, but she found it very difficult to talk about the drugs and alcohol because of judgements from others in the group, and ended up feeling more alone. Adfam's Older Carers groups is different:

'...it was nice when I got [the invitation to the group]. It was good to have a meeting for people who were like-minded and who have similar problems and so you don't mind going into details there.'

Marjorie recognises that there is no easy solution to her problems with her son, but nevertheless values the chance to meet others who appreciate something of her experiences and to talk about things:

'It is just to get things off your chest – it doesn't mean I expect that they have a solution and that everything will work out because I know it won't. It is down to my son and me in a way in terms of how I handle it.'

Marjorie likes that the group is just once a month:

'It is good just knowing that there is something there. I don't want to do it more - once a month is fine... It is strange really – it is good to talk to someone, but it is a constant reminder, I suppose. For that reason I would not want to come more often... you have had a meeting and you have spoken to someone and then it is nice to think, "I have done that now so I will think of something different – something for me to take my mind off it." I don't want to think of it 24 hours a day but I do, pretty much. But after [the group] I think, "I can put it behind me".'

Marjorie is fearful for the future and worries about how her son would cope if she died or became too ill to look after him.

'The older I get, the harder I find it to cope. I don't have the energy to do what I would have done twenty years ago.'



Top issues for older carers

Isolation and stigma

In common with family carers of all ages around the country, participants in Adfam's project speak of the isolation and stigma they have experienced trying to handle their loved one's addiction alone, or in seeking support. Well-meaning family members and friends often contribute to this with ill-judged advice or hurtful judgements, and in other cases people simply feel unable or unwilling to let them know at all:

'My neighbours might be scared of being robbed or something, if they knew about my son's drug use.'

'It's not their problem. Why should I make it their problem too, it's not fair.'

Friends, while well-meaning, often say the wrong thing:

'I don't have much family, I'm 65, but friends were horrified and angry that he could have carried on the way he did. At the... meetings, people were more understanding.'

One participant described how she and her husband had become so isolated that they were left without any friends or sources of support; whilst another received very little support from family and friends and often avoided contact with others.

'Yes... I need help, and as I said, friends, they don't understand do they?'

Struggling to access support

Those participants who have sought support for themselves have often found none forthcoming, been sent from service to service, or had to fight for what they need:

'They offered me CBT and I went on a waiting list, but when I eventually saw [the counsellor] she said that was not what I needed, I needed support with how to handle my son's addiction, so she refused to work with me. But no one else helped instead so I got nothing.'

'Eventually I got some counselling, but this was recently. I needed help 20 years ago when my son first had problems! Then there was nothing. There was nothing for me or him at all. When he was seven years old they said "Yes, your son has emotional and behavioural problems. He might grow out of it." That was it. Now he is 35. He didn't grow out of it.'

There were numerous examples of carers seeking support but being sent from one service to another, often only to find that none would provide them with any help. Some older people, perhaps particularly women, are sometimes patronised and ignored. Generational differences can make it harder for them to be assertive.

Don't realise they're 'carers'

In common with family members of all ages, those who provide care and support to loved ones who use drugs or alcohol often don't identify with the term 'carer'. Whether because they undervalue the support they provide or simply see it as inherent to their familial relationships, lack of recognition can prevent carers from accessing the support they are entitled to.

'They tell us we're carers and we are – we are caring for our adult children – but we don't think of ourselves as carers. We're just parents, it's just what we do. But that means we don't know that this support is there. We don't know that we're carers so we don't think to go to carers services for support.'

Don't know how to deal with their loved one's addiction

Family members often struggle to know how best to support their loved ones and, in particular, how to deal with their drug and alcohol use. This is not unique to older family members, but for those who are older there can be particular anxiety around substances they know little about. The culture of alcohol and drug use has changed significantly over recent years and the family members talk of struggling to understand what is going on, or to know when and how to intervene or make suggestions.

'I just want him to stop drinking but people tell me that actually that could be dangerous – if he stopped suddenly then he could die. It's very confusing, I just don't know what is for the best.'

For David, it was the uncertainty that was hard to deal with:

'We get a little bit of warning that something is wrong but it is so difficult to deal with as it is so intermittent: like the British weather there are as many sunny days and as many rainy days. He can try to put on a face after work 'Hi dad, hi mum' and you think he is fine and then the next thing – bang.'

Guilt and self-blame

Most of the Adfam project beneficiaries are mothers supporting adult children. They struggle with feelings of self-blame and guilt, wondering what they 'did wrong' in their child's upbringing to result in the addiction they have today. Whilst they find the education they are receiving around addiction and emotional health useful, in some cases it can also shed light on ways in which they have intervened in less helpful ways up to now. Whilst participants speak very positively of the value of this information and support, it means that accessing support is not always easy. Disentangling what is their own responsibility from what responsibility must be handed back to their children is complex. However, the non-judgemental environment is key to ensuring that family members are able to share and process what they are going through, learn not to blame themselves and discover constructive solutions for the future.

‘I try to understand what caused it. Why does my child have an addiction? Could I have done something differently? But the information we receive at the group is very helpful, and coming and talking about everything helps so much. No one judges you here; there is no stigma or shame.’

Consistency of support

‘We are as vulnerable as the people who use drink or drugs.’

Older carers place a high value on the consistency of the support provided. It is important to them that the group is at a regular time, in a regular place and with the same Adfam staff members each time.

‘We have enough chaos in our lives already. It is reassuring and feels safer and less stressful if we know what we are coming to. It means it’s not just another thing to manage.’

Caring for grandchildren

A significant minority of older carers are also permanently caring for grandchildren as a result of their own children’s drug or alcohol use. This can create huge additional challenges for grandparents who may suddenly find themselves navigating legal proceedings and having to house, clothe and provide for small children at short notice with little support. Some carers talk of the physical and mental exhaustion of managing both their children’s dependency issues and caring for their grandchildren becoming increasingly difficult to manage as they get older. Often they must balance their own health issues with caring responsibilities. Even keeping hospital and GP appointments can be difficult around caring for the children. Grandparents Plus and Adfam have produced several other reports highlighting the very high needs of this group^{5,6,7}.

5. Wellard, S and Wheatley, B (2010). Family and Friends Care: *“What if we said no?”*, Grandparents Plus.

6. The West Midlands Regional Forum (2015). *The West Midlands Kinship Care report: Supporting kinship families affected by drug or alcohol use*, The West Midlands Regional Forum.

7. Robson, S and Conqueror, K (2011). *Breaking the vicious circle: addressing the barriers and difficulties faced by grandparent kinship carers in Sunderland where the birth parents are involved in substance misuse*, Sunderland Carers Centre.



Carers' views: good and bad support experiences

Prior to joining Adfam's group, the carers had had mixed experiences of seeking support for themselves in relation to their loved one's drug or alcohol use.

'Years ago I went to Al-Anon for many years,' says Dawn. 'It was helpful at the time, but then I began to feel frustrated with their approach. They saw addiction as a disease, and said we were all helpless unless our loved one wanted to change. I didn't like that approach.'

Dawn was not alone:

'I went to Al-Anon in the 80s for 10 years and the emphasis there was on the family as sick and you are all seen as dysfunctional and I think I am railing against that.'

However, someone else described Al-Anon as helpful in teaching her how to enforce boundaries and make her realise that she was not alone.

Some participants had supportive GPs, and others had been referred to counselling which had been a positive experience. One participant in the project had prior experience with another group for carers affected by drugs and alcohol, and had found that extremely useful, feeling able to speak freely without fear of judgement.

For many carers, this has been their first experience of support specific to their loved one's drug and alcohol problems or, for some, the only support they have ever received:

'It's just good to know that there is something there and someone there.'

Some carers had had access to wellbeing, meditation and mindfulness courses which they had found helpful, providing some well-needed time for themselves to relax. Some had also had practical support, for example to fill out benefit forms, and this had also been much appreciated.



What support do older carers want?

A chance to meet and share with others in a similar situation

Peer support helps to address the social isolation and stigma felt by many who care for those with drug and/or alcohol problems. It is a huge relief to realise that they are not alone, and this helps to reduce the sense of shame and guilt, especially when the drug/alcohol user is their own child.

'With these kinds of groups, there's just something about people with a common need together in a room. It sounds silly but it's very powerful.'

Benefits of peer support are identified as:

- Acting as a 'talking therapy'
- Being able to share information and discuss experiences in a non-judgemental environment
- Reducing isolation and loneliness
- Regaining some perspective of the issue and being able to focus on themselves, rather than the user
- Providing a safe space to take part in 'normal' activities like a trip to a museum, or a Christmas lunch, free from worry of stigma

Listening support and a chance to talk

The carers appreciate having somewhere to come and offload, to talk freely and share their emotions and concerns. Being listened to with empathy and without judgement brings a level of relief and reduces their stress, leaving them feeling better able to face the challenges they face in their daily lives with their loved ones.

Structured information

A number of project participants have spoken of the value of information and structured sessions to help them deal with their situation. Topics such as enabling, setting and maintaining boundaries, drug and alcohol education, addiction and positive communication have given the carers tools to deal with their loved one's drug and alcohol use more constructively. They were keen that the group was 'solution-focused', with the provision of practical information about their rights as carers, and coping strategies.

Social activities

Some of the carers have few social networks and have valued the opportunity to simply connect and relax with others; to get away from their daily lives and forget about their troubles for a few hours. As older carers who no longer work and often live at a distance from other family, social contact can be minimal. The project has included a number of trips and social afternoons to meet this need. We have had fantastic trips to the British Museum (where the group was met by a member of the engagement team who ran an education and exhibit handling session), the Victoria and Albert Museum and the Barbican Centre.

Signposting

Older carers in the project usually did not identify as carers and many had not considered approaching carers services for support. Some had approached statutory or voluntary services but lacked the confidence to know what to ask for, or what they may be entitled to. As part of the project, participants have been able to learn what services may be available, and what support they may expect from them. This has given them greater confidence to approach other providers and ask for what they need.

Regardless of the format and type of support, participants are clear that the group should be somewhere where the focus is on them, the carers – rather than on their loved one who uses drugs or alcohol and dominates much of their lives.

‘Dos’ and ‘Don’ts’ of older carers support

Do

Make sure the expectations in the group are clear

Run sessions in the middle of the day so we can get to and from them in daylight

Provide structured sessions and information as well as listening support

Keep the venue, time and staff constant. We live with enough chaos already!

Let us know that we fit the description of ‘carer’ and therefore have access to available support

Let us go at our own pace

Don’t

Don’t make assumptions based on our age – some of us are very active and socially connected!

Don’t promote one solution or approach to the exclusion of others

Don’t assume all families of drug and alcohol users are the same

Don’t patronise us

The benefits of being older

Along with the challenges of supporting their loved ones as an older person, some participants noted a number of benefits arising from their age:

'I do have more time now than I did when I was working and caring for children.'

'I suppose we have a certain wisdom and experience to draw on.'

'I think we're more willing to be open and share experiences than we may have been when we were younger.'

One participant commented that statutory services took her situation more seriously because of her age.

Jane

A personal story

Jane is 61. Her sister, Sarah died earlier this year of FTD, a rare and aggressive form of early-onset dementia which went undiagnosed for many years. Due to the FTD symptoms, Sarah's daughter, Laura, had a chaotic and inconsistent home life. Jane believes that this is one reason that Laura turned to drugs and alcohol.

Now 21, Laura is struggling to cope with her mother's death. Jane is executor of her sister's estate and, as such, responsible for managing the process for Laura to inherit Sarah's house and money. Jane knows that Sarah has already blown over £40,000 and is anxious about what will happen when Laura has access to more money, or is able to sell her mother's house. Jane struggles with how to support her niece, whilst maintaining her own wellbeing and not making herself ill.

'My niece is a very vulnerable girl, but she is manipulative and dishonest. She tells us what she thinks we want to hear. Ultimately, she is now an adult and needs to make her own choices, but I fear for her future. She has had a string of boyfriends who have not treated her well. She is now engaged but we believe he is just after her money. She won't engage with education and just doesn't seem to live in reality, but she won't engage with us either. I worry for her but I also worry for myself. I know how easy it is to get sucked in and for it to start affecting your health and taking over your life.'

'I'm lucky to have lots of friends and a strong support network, but I also find the group really useful. I like the fact that we are all older. I didn't want to sit down with young people.'

We are all very different and come from different perspectives, but it just works. Knowing others are going through it too, you don't feel so bad. I really value the information and advice that we get; that is the most useful for me.'



Older carers participating in an artifact-handling session at The British Museum

Messages for professionals

‘We’re all different. Don’t make assumptions about older carers and what their experiences are or how they experience things. There’s prejudice if you are an older person and even more so if you are an older carer. There is a stereotype but people who fall into this category can have very different needs and experiences.’

‘Getting older means we increasingly don’t have the resources to deal with these situations. We are worn out. It can feel like a treadmill and it is really detrimental to our health.’

‘Services need to be better linked and look at the whole picture. I was proactive but nothing was offered.’

‘Continuity of care is really important. There’s enough chaos in our lives already so having stability, security, a regular place to meet, a regular time and the same members of staff, is really important.’

‘Don’t judge. So often we are stereotyped or blamed, “What did you do wrong?” It’s very isolating to face this kind of stigma.’

Conclusion

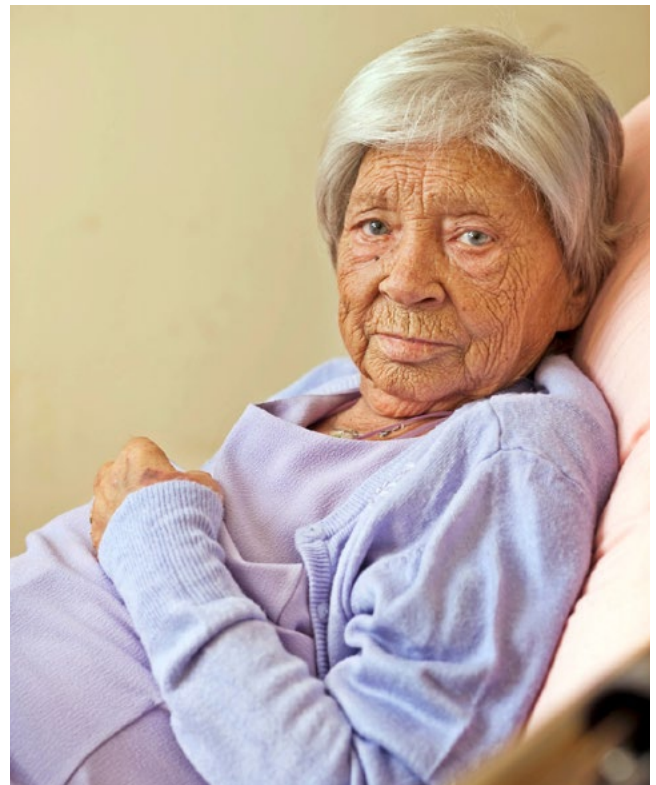
This project has highlighted the sheer range and severity of impacts on older people of caring for someone with drug and alcohol dependency. The impact on carers' physical and mental health, finances and social relationships are significant and support is often scarce.

Whilst many of the impacts described by older carers are not unique there are ways in which getting older exacerbates challenges that put a strain on anyone, at any age.

Diminishing energy levels and sometimes poorer health make life more of a struggle, even without the additional challenges brought about by a loved one's drug or alcohol use. Changing social structures and the evolving nature of drug and alcohol use make it difficult for many older carers to know how to deal with their loved one's dependency. Several of the group have lived with these challenges for many, many years, frequently with little or no support.

Adfam's project has provided a safe haven, information and friendship; somewhere carers know they won't be judged, can offload their emotions and discuss what they are facing, and receive vital empathy and support, often for the first time.

All names have been changed.





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