

## OUT OF FOCUS

How families are affected by problem drinking, and how they look for help



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*“I think that they don’t see you as a victim, they just see it as the person. But the whole family becomes a victim and the whole extended family, you know, the parents, the uncles, the aunts, they all get into it.”*

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This scoping study has been undertaken with help from a number of people and organisations.

Principal thanks must go to the 21 family members of problem drinkers who were willing to give up their time and share their experiences in the interviews and focus groups that informed this study. Thanks are also due to the 46 people who responded to the online survey. Their input has been invaluable in gaining insight into how best to ensure support is made available for family members of alcohol misusers. Whilst this report draws on their experiences to arrive at pointers for improving access to support, in order to protect confidentiality, comments are attributed anonymously and the full stories and case histories are not included within the body of the report.

Thanks also go to Al-Anon and In Touch for sourcing people for interview, and to the family support services, Alcohol Concern and Alcohol Policy UK for circulating information about the online survey.

# Summary and Conclusions

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## Background

Adfam commissioned this scoping study to look at the help seeking behaviour of family members of alcohol misusers. Problematic alcohol use is a serious problem which affects a large number of individuals and their families in the UK: the Government recently estimated<sup>1</sup> that for every 100,000 British people, 3,000 show signs of drink dependence (with another 500 being moderately or severely dependent), 13,000 binge drink and 21,500 regularly drink over the lower-risk limit.

But what is known of the experiences of these adult family members and how they go about seeking support, if indeed they do at all? How do their experiences differ from those of the families of drug users? This report's purpose is to identify barriers to accessing support, note any particular contrasts with the experiences of the family members of drug misusers and identify recommendations for future work that might address any gaps.

An online questionnaire attracted input from 46 people and a further 21 were spoken to directly, either by phone, through one-to-one interviews or as part of small focus groups. As well as those accessing support for themselves this study also obtained input from a number of people who had not made that step.

## Key themes

### a) It often takes a number of years before families affected by alcohol use seek support

A number of factors contribute to a considerable delay in help-seeking by the families of problematic alcohol users. Recognising an alcohol problem in the first place, acknowledging the impact it has on their own life and seeking help to address it are all significant challenges for families.

### b) Families struggle to identify what constitutes an 'alcohol problem'

Given the widespread acceptance of heavy drinking in British culture, families experience considerable confusion over what amounts to a drinking problem, or how much is 'too much'. Family members could struggle to reconcile their own experiences of dealing with problematic drinking with their conception of what it means to be 'an alcoholic'.

### c) There are key differences in the trajectories of alcohol and drug problems

Evidence from the interviews indicates that alcohol problems tend to develop slowly over long periods of time. Incidents which impact on families can remain sporadic, enabling family members to tolerate otherwise unsustainable situations by providing periods of respite when a drinker does not behave in a problematic way. In contrast with some problematic drug users, many alcohol misusers are capable of retaining work and

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<sup>1</sup> HM Government (2012) *The Government's Alcohol Strategy*

functioning relatively normally for considerable periods of time. This can add to the confusion about both the existence and severity of the problem.

**d) Some family members don't recognise their own needs**

Some family members do not identify themselves as deserving of support in their own right. The focus for many family members, understandably, is on the problems of the drinker, with the assumption often made that if effective help is found for him or her then all the associated problems would also fade away.

**e) Families often don't realise that support is out there**

Even if families do realise they need support, many are not aware that dedicated groups exist for families affected by drugs and alcohol, and struggle to find information on what is available, where and when.

**f) Families are rarely signposted towards help for themselves**

There is insufficient awareness amongst professionals on the needs of families affected by drugs and alcohol. Families reported approaching their GP for advice for themselves or to alert the GP to the problematic drinking of a loved one, and most suggested the outcome of this contact was generally very poor. Experiences at specialist alcohol services were often similar, and opportunities to point families towards their own support were often missed.

**g) Binge drinking can cause significant problems for families**

Many relatives of the family members in this study could be classified as binge drinking but not necessarily alcohol dependent. However, this appeared to make little difference to the levels of stress and difficulty reported. Families reported that GPs and alcohol services did not regard non-dependent binge drinking as 'serious enough' to merit any intervention, which was a cause of frustration and division within families. However, the Governments' 2012 Alcohol Strategy<sup>2</sup> is clear that 'binge drinking isn't some fringe issue, it accounts for half of all alcohol consumed in this country'.

**h) The variety and quality of support for families is insufficient**

Families reported that the services they did access were mostly a self-help model and extremely beneficial, but service availability is limited in terms of times, locations, and the range of available options. One size does not fit all in family support, and counselling, information provision, helplines and training courses would all be useful for families who are not comfortable with the mutual aid model.

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<sup>2</sup> Home Office. *The Government's Alcohol Strategy*, 2012

## Recommendations – what needs to change

### a) Enable family members to recognise the problem at an earlier stage

In order to seek support, families must first recognise the existence of an alcohol problem. Consideration needs to be given as to how best to address the lack of knowledge around the signs, symptoms and likely trajectories of alcohol problems. Families need to be encouraged towards a position of self-empowerment where they feel motivated, confident and justified in seeking support. There is a need for education around the problems and scenarios that families affected by alcohol misuse typically face as a way of helping others to benchmark their own situations.

### b) Equip professionals to respond appropriately to families' needs

It is vital that GPs – and other health professionals that these families come into contact with – are properly briefed and equipped to respond both to alcohol problems and to the needs of family members. GPs are a key point of focus, as many family members are likely to approach them for help for the problem drinker. The findings of the report also indicate that GPs should be aware of family support organisations in their area so they are able to effectively signpost family members.

As specialist alcohol services are also a likely port of call for concerned family members, consideration could be given to providing guidelines and standards for alcohol services in supporting family members in their own right. It would also be appropriate for other professionals, for instance those working with teenagers and young adults, to be made aware of how alcohol affects families and what kind of support is available locally.

### c) A strategic approach to further develop a range of support services for families

As well as greater national leadership on how families are affected by a loved one's substance use – be it drugs or alcohol – a wider range of support services needs to be coordinated at the local level, embracing opportunities for individual counselling, self-help support, training programmes and telephone helplines. Family members would also benefit from a family-centred approach which recognises a variety of needs, rather than being purely focused on the alcohol user.

### d) Greater provision and circulation of information on alcohol use and family support at national and local level

Of the family members interviewed, very few were aware of the existence of family support organisations or online resources which may have helped them. Much could be done via public education and the internet to provide information on how alcohol affects the family and how family members can cope and seek support, as well as signposting to local services.

## Methodology

Adfam commissioned this scoping study to examine the help seeking behaviour of family members of people with alcohol problems.

The purposes of the scoping exercise were to understand the experiences and difficulties faced by family members affected by a loved one's alcohol use (in contrast to those affected by illegal drugs) and consider what steps might be taken to better support these families.

Adfam undertook a comprehensive literature review which identified a paucity of specific research on the needs of the families of problematic alcohol users, and a corresponding lack of firm conclusions regarding their help seeking behaviour. However, some general observations pertinent to this area of study were identified:

- ✓ There are very few specific services available for family members affected by alcohol misuse<sup>3</sup>
- ✓ Alcohol workers need more knowledge of how to work with families
- ✓ The legality of alcohol may encourage support seeking as families have no fear of repercussions from the criminal justice system
- ✓ However, its legal status might also make help seeking more unlikely as drinking is legal, socially acceptable and the harm of heavy drinking is not fully recognised by many people. Anecdotal evidence suggests that family members of those misusing alcohol take considerably longer to seek help compared with families of drug misusers. Research suggests that 'alcohol users take an average of thirteen years longer [than drug users] to initially recognise their alcohol use as a problem and twelve years longer to access treatment'<sup>4</sup>, which is a substantial difference, and there may be a similar delay for families.
- ✓ Much as the families of drug users experience stigma, so do the relatives of drinkers - though it may be manifest differently. The families of drug users may face stigma due to the specific drug in question – with heroin and crack particularly stigmatised – whereas alcohol is legal, pervasive and normalised.
- ✓ If domestic violence is an issue, victims may fear putting themselves at further risk and therefore avoid talking about the problem with others

A full copy of this review is attached as [Appendix A](#).

In order to scope the specific barriers to support for families of alcohol misusers, a short online survey was conducted and a series of guided interviews carried out.

The survey went live in January 2012 and was circulated and advertised through Alcohol Concern, Alcohol Policy UK and Adfam's networks. In all 46 people took part in the survey and a copy of the questions and results is attached as [Appendix B](#).

<sup>3</sup> Noted in Service provision for the children and families of alcohol misusers: a qualitative study, Sarah Zohhadi, Lorna Templeton and Richard Velleman

<sup>4</sup> P2, Accessing treatment for problem alcohol users: Why the delay?, Gloucester Research Unit

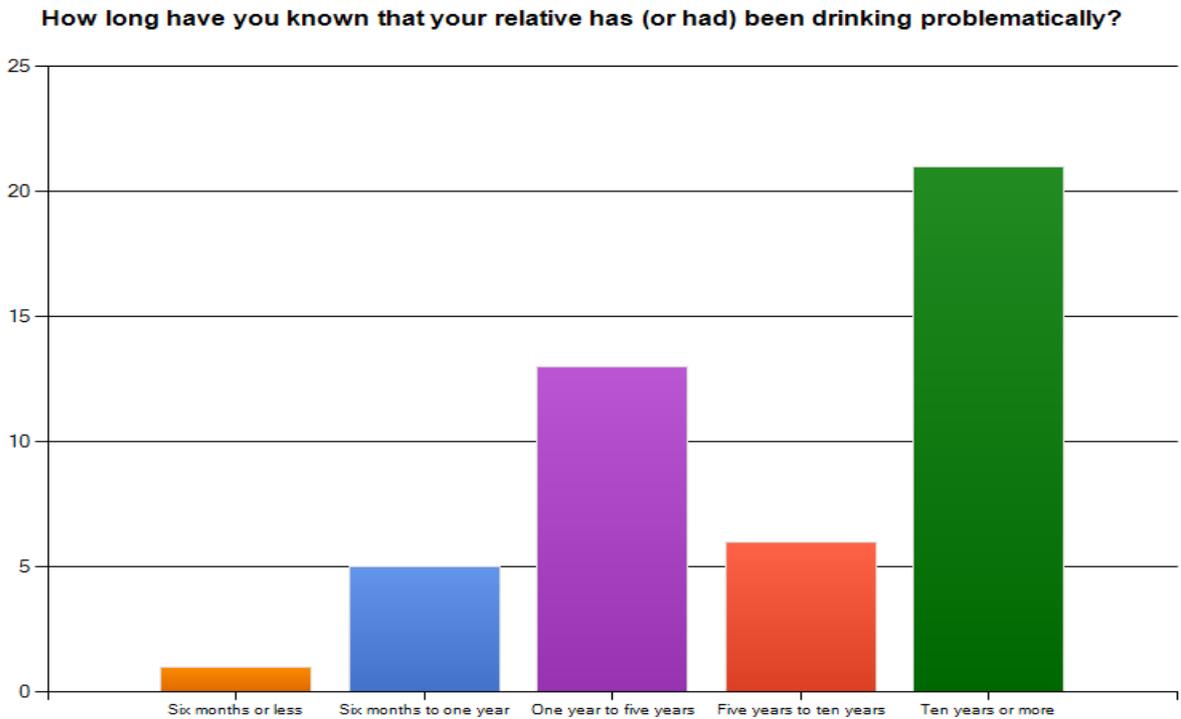
In addition, 21 one-to-one interviews were conducted with family members of alcohol misusers either on the phone or face-to-face. Interviews were in a semi-structured format and the script is attached as [Appendix C](#).

## Key findings

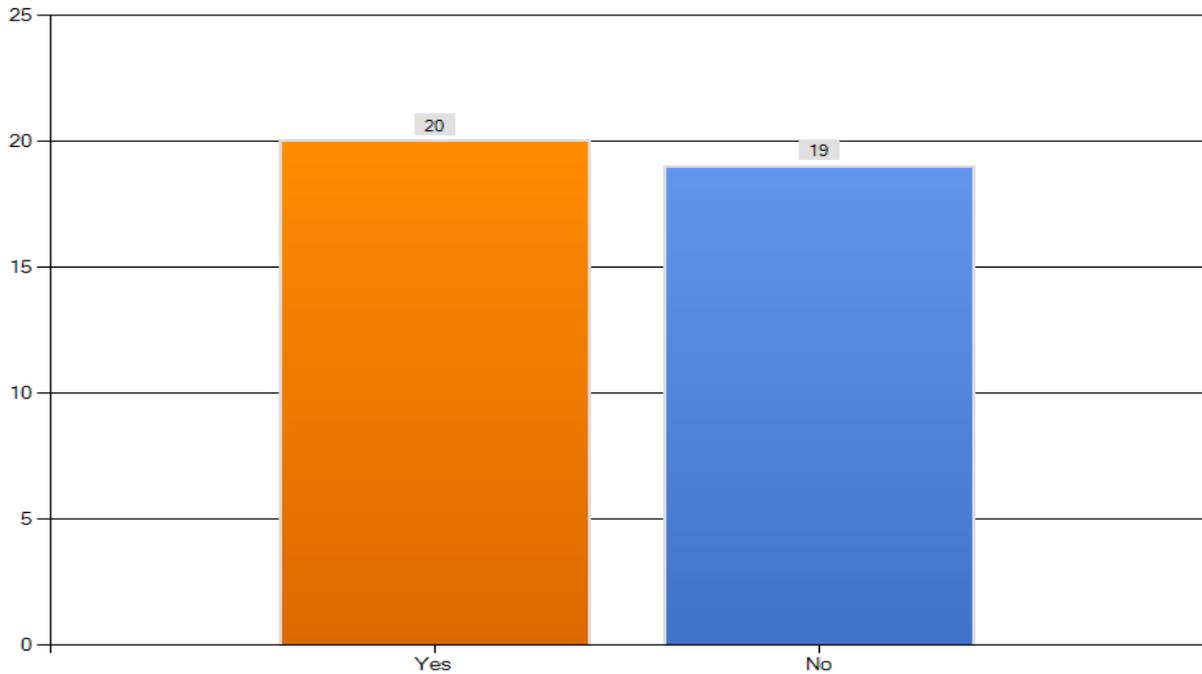
Although each of the participants had unique experiences of how problematic alcohol use affected them and their families, there were a number of common themes shown by the participants.

### Family members take a long time to seek support

The literature review undertaken for this study indicates that family members of people with alcohol problems take longer to seek help for themselves (if they do at all) than those affected by familial drug use (see [Appendix A](#)). An analysis of the responses to the online survey and the interviews appears to support this trend.

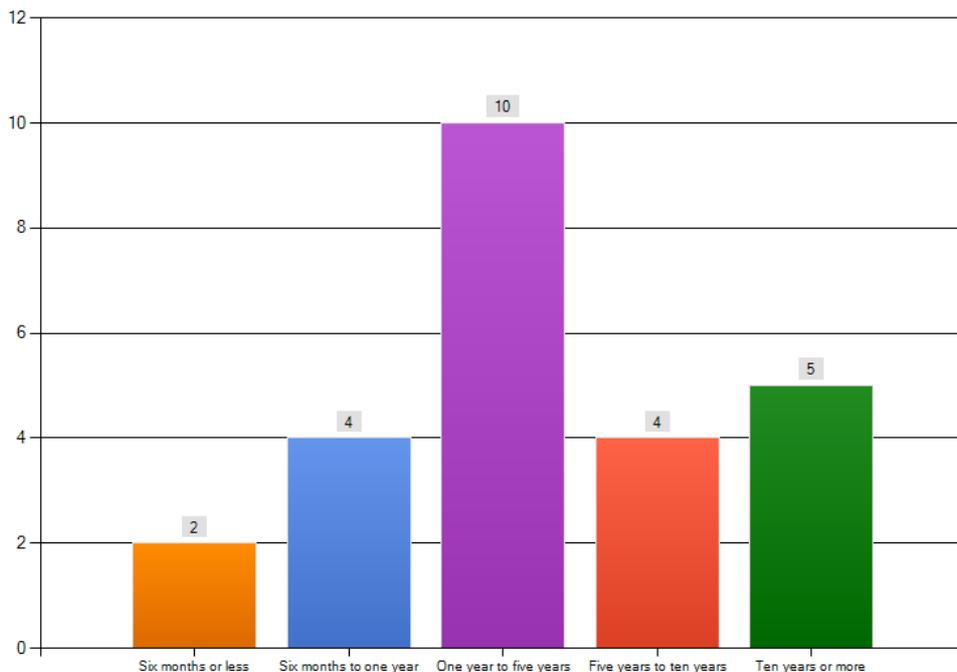


### Have you sought help or support for yourself regarding your family member's drinking?



Evidence gathered through the online survey indicates that a significant number of family members waited for years before they looked for a service. The most common length of time was one to five years, with plenty of family members waiting longer. Those interviewed in person confirmed this, with all reporting they waited over five years, and some over twenty.

### How long had you been affected by the problem drinker before you sought help?



## Explaining the delay

### Uncertainty over what amounts to an 'alcohol problem'

In identifying reasons for not accessing support, family members commonly cited their own uncertainties over what level of alcohol consumption constitutes a drinking problem.

Most of those interviewed seemed to have a reasonable degree of knowledge about safe drinking levels.

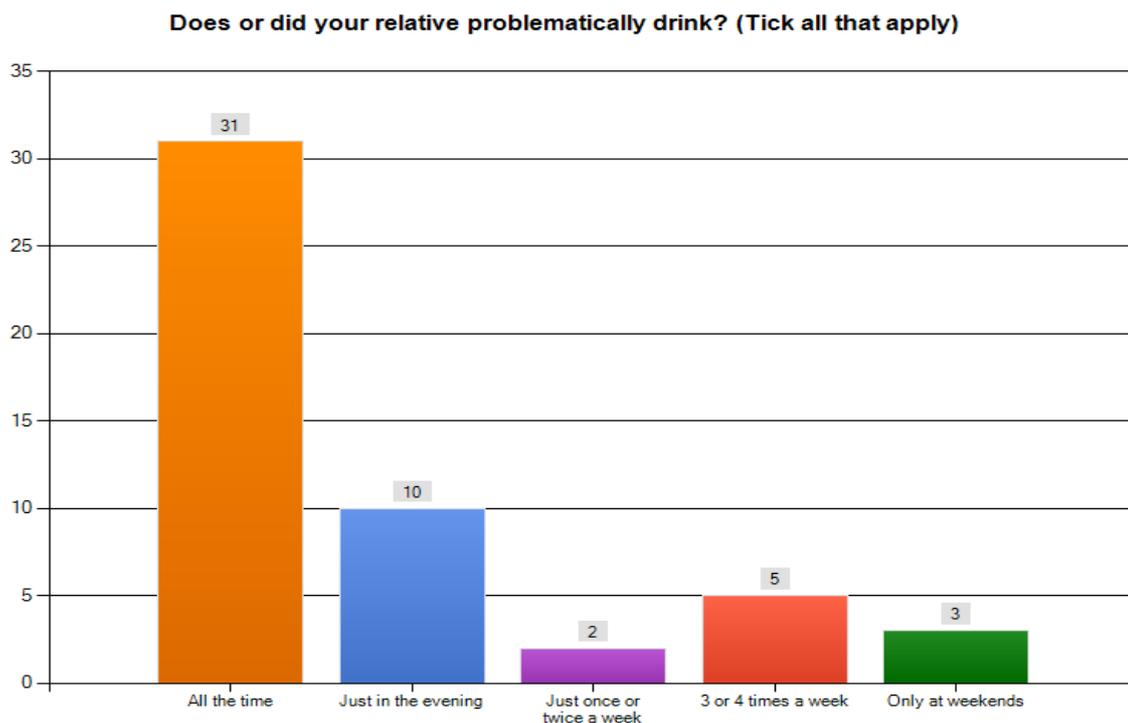
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However, because drinking above safe limits is commonplace and there is no social consensus that high alcohol consumption in itself a reliable indicator of an alcohol problem, it was very difficult for some families interviewed to identify early on that their relative's drinking had tipped over from the norm.

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For most, the consideration of what might constitute an alcohol problem was very wrapped up with preconceptions of what constitutes being an alcoholic.

- ✓ *'We didn't mind that she got tipsy on the weekend.'*
- ✓ *'We all drank a lot at the weekends.'*
- ✓ *'They all met in the pub on Friday night – getting completely wiped out happened to most of the group, most of the time when we were younger.'*
- ✓ *'I thought alcohol was affecting him but his drinking hadn't changed I don't think. He didn't seem to drink more than any of his mates.'*



Worried family members stated they had nothing to objectively test their concerns against; this was particularly important as they reported their loved ones were in denial and seeking to deflect attention from their drinking onto other issues. Families' views of drinking levels could be easily undermined, disregarded or dismissed by the drinker as mere personal opinion or judgment, and family members reported being reduced to arguing and justifying their perception against the drinker's view.

- ✓ *'I thought I was going mad'.*
- ✓ *'I thought it was just me...he wouldn't have it – that he was drinking too much. Said it was just an excuse to get at him. He would make out to the others that I was picking fault.'*
- ✓ *'I felt like I had been brainwashed that living like this was normal.'*

### **Societal attitudes to alcohol**

This uncertainty is exacerbated by the widespread acceptance of heavy drinking in modern society: drinking is often considered a normal part of most people's lives, even when consumption is above safe limits, and society is sometimes indulgent of heavy drinking and binge drinking, in stark contrast to the extreme stigma often associated with those fully dependent on alcohol.

Society's dominant attitudes form subtly complex barriers which impact on families' help seeking behaviours and coping styles throughout their own unique journeys.

## **Contrast with drug problems**

Once they realise that their loved one is using illicit drugs, the illegality of the substances involved may mean that families of drug misusers are relatively quick in believing that a problem exists. Many believe that if someone is simply using drugs then they have a problem – though it is important to note that families affected by illegal drug use still face long delays in seeking help due to stigma and, as will be discussed later, a lack of knowledge around local support services which could meet their own needs.

## **Family members are not sure of what amounts to an alcohol problem**

In the earlier stages of their relatives' drinking, the group of family members interviewed were largely unable to confidently recognise the typical behaviours, signs and symptoms of drinking problems, and struggled to ascribe difficult behaviours to alcohol.

Although family members reported feeling confused, bewildered and disempowered by the behaviour of the drinker, a lack of confidence or certainty presented barriers to fully recognising the problem or seeking help.

Few of those interviewed sought clear information about alcohol misuse initially and many in this study reported that information was not readily available. Still, surprisingly few seemed to have sought information from the internet despite it being accessible anonymously; only two out of 46 in the survey reported using the internet to seek advice or help.

## **Maintaining a 'normal life'; concealment of behaviours**

Despite descriptions of serious alcohol problems, many of the problem drinkers in the families of those interviewed were perceived as being able to maintain the semblance of a normal life-style over long periods of time. Both drinkers and their families could therefore downplay the impact that alcohol was having, and make it less likely that support was sought.

- ✓ *'For many years she only drank at weekends. She would always sober up to open the shop and it was only when the business closed that we really noticed how reliant she had become on alcohol.'*
- ✓ *'My husband has a very responsible job. I don't know how he gets away with it. It certainly helps that he now has a lift to work every day but I am amazed no one at his work has noticed that he really struggles to keep it together nowadays – they don't seem to notice when they phone him at home, that he is drunk!'*
- ✓ *'In the last few years he has lost jobs. It's because of the way he treats people but he is blind to it. The fact that he is always able to make money for them justifies everything for him. He's always been able to keep it together enough to make money.'*

Many of the situations described by families are examples of those with serious alcohol problems who can and do hold down responsible jobs. People with drug dependencies, given the illegality of drugs and difficulty of financing their use, may well find the basic structure of their lives crumbling sooner – a factor which can bring about a crisis more quickly.

One respondent reflected on her husband's problematic relationship with alcohol over the past fifteen years, saying it was hidden for about a decade and only came to light around five years ago. After the birth of their first child he started working night shifts and began to drink in the morning to help get to sleep during the day. 10 years later, when the family moved house, his wife discovered a huge quantity of empty bottles and cans stashed in the attic. This occurred long before his behaviour became obviously problematic but the sheer quantity suggests the existence of problematic drinking levels prior to it being recognised by the family.

Another interviewee stated that she realised her husband was drinking problematically when he was *'simply unable to stand up on his skis'*. In the interview she commented that with the benefit of hindsight she was able to see that *'the problem had probably always been there'*, masked by the social norms of their peer group and his ability to maintain key responsibilities. In this case it took a specific event to bring home the reality of what was happening.

## **The slow development of drinking problems**

Many of those interviewed reported that the increase in levels of drinking amongst their family members was quite a slow journey. This can dull awareness and perception of the severity of the problem and make it hard for families to recognise a tipping point. Some families in this study stated that they simply became *'used to it'* and learnt to adapt and work around difficult situations.

Those with binge drinkers in the family, who drank very heavily when they did drink but were also able to have days of abstinence, were also affected by this slow build-up. They argued that having periods of no drinking served to mask the fact that the times when the person *was* drinking were becoming more severe.

This contributes to a time lag in families recognising a problem, and is therefore another reason behind the delay in seeking support.

## **Insignificant or manageable impact on family members**

The impact of someone's drinking on their family will depend on a number of factors, including the severity and frequency of drinking, the behaviours associated with it, and the closeness of the relationships within the family. In some cases, even close blood relations can be sufficiently insulated from problems – in particular, day-to-day impact is considerably lessened if the family members do not cohabit, as it can take longer to recognise the extent of the problem and feel its effects.

Those not living with the drinker were either adult children or the adult siblings of a problem drinker where, with the exception of one person, the drinking problem was not part of their childhood.

One man said of his experiences as a teenager with an alcoholic mother - *'my mum was drunk quite often but it didn't get in the way of my life, I simply didn't care – I wasn't at all bothered about what she was doing or the rows my parents had over her drinking. I was only interested in my life and being with my friends. It wouldn't have entered my head to worry about it. Later on I am absolutely sure I would not have gone forward for help myself. I didn't want anyone to know outside our family that my mum had a drinking problem. Even if I had known about support, looking back, I can't think of anything that would have made me think differently at that time.'*

## **When a problem is acknowledged**

Even for those families who recognised that their loved one had a drinking problem, this in no way guaranteed that they would go on to access support for themselves. A number of barriers remain for these families.

### **Poor knowledge and understanding of substance use disorders**

From the interviews conducted, even when there was mutual agreement that a problem exists, the lack of understanding about its likely trajectory acted as a barrier to seeking outside support. For example, family members showed little, if any, understanding or awareness that a reduction in consumption or abstinence might be impossible for the person psychologically or physically without expert help.

- ✓ *'He said he would cut down and I believed him, but it would always creep up again.'*
- ✓ *'She just got more sneaky about it - hiding it all over the house and denying that she was drinking – even when we put the evidence right in front of her'.*
- ✓ *'For many years I believed him when he said he would stop; that he wanted to. But he clearly didn't want to enough.'*

Few interviewees discussed any awareness of the likelihood of relapse after a period of abstinence. One expressed relief that her sister, after a drinking problem spanning two decades, had been dry for nine months following an extended stay in hospital. The family members described the alcohol use as *'finally being over now that she is detoxed and well clear of being dependent'*. Though of course many people who have had alcohol problems do make successful and lasting recoveries, some do not, and it is important that lapse or relapse is recognised and planned for.

### **Not recognising the family's unique needs**

Many families did not recognise that they could be legitimate recipients of support in their own right. A number of respondents initially reacted to the question with a version of '*I didn't need help – it was x who needed help!*'. Some of the families were not clear why they might need support for the worry and concern caused to them by the person drinking.

One-to-one interviews were held with eight people who had never sought or used support for themselves. Of the eight, five were female and three male. Six were the adult child of a drinking parent, one was a sibling and one was the spouse of a problem drinker. Amongst this group, the view that 'the drinker is the one with the problem' persisted, and they were generally reluctant to acknowledge the impact of stress on their own wellbeing.

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### **Others, viewing the issue with hindsight, recognised the impact the problem had had on their own life.**

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For example, looking back, one son was able to see the stress caused by his mother's drinking (he lived next door) and how the years of dealing with her when drunk had affected his own life, risking his marriage and relationship with his daughter. One woman we spoke to reflected on the impact of her husband's drinking on her nearly grown up children: at the time she felt she protected them well, but later wondered about the impact it has had.

The family members interviewed struggled to step back and view the situation with any degree of objectivity because the focus was always on coping with the practicalities of day-to-day life, such as dealing with difficult and unpredictable situations and protecting others from harm.

### **Negative attitudes towards help**

As well as families believing they did not need, or were not entitled to, support, there were also those who simply doubted that it would make a difference, and were sceptical about how it could be helpful to them. This negativity was sometimes exacerbated by poor experiences of support services – as is addressed later (see page 19).

### **Lack of knowledge of support services**

For families who had recognised that their loved one had an alcohol problem, and also acknowledged the impact this was having on their own life, not knowing that support services existed to support them was another common reason given for why it took so long to make use of them. And even after this, families who *did* seek help reported difficulty finding suitable services in their area. Travelling distance and inconvenient opening times were also reported as barriers for those seeking help further afield.

## **Stigma**

Some family members felt that stigma had been a key factor preventing them from talking to others about their problems earlier. One mother reported being concerned that her children's friends would not be allowed to come to play if they knew of her husband's drinking. A son who was interviewed simply did not want people outside his immediate family to be aware of the problem, and did not wish people to think badly of his mother: families feared that full articulation of the problem could demonise the problem drinker in the eyes of others. Family members reported being aware of the part stigma played in maintaining secrecy, but the specific ways in which stigma created barriers to seeking help was difficult to draw out.

As well as not wishing to stigmatise the drinker, families also feared being judged themselves. The families we spoke to feared criticism of why they were 'putting up with it', that outsiders would consider them weak and therefore somehow to blame, or to be colluding due to financial reasons - *'it's hard enough without judgment from others.'*

Again, this was worsened by common acceptance of, or confusion over, acceptable drinking levels. Families stated that in order to really convey the problems they were facing, they were forced to focus on the drinker's problem behaviour, which risked horror and incomprehension from friends and family.

## **Confronting broken relationships**

Family members reported that the fact that the drinker's behaviour did not change in response to their distress, or only improved temporarily, raised the painful and threatening reality that the problem drinker would not stop drinking, even if it was severely damaging their relationships. For some this led to the thought of a family breakup, which was further complicated in many situations by financial relationships between the drinker and other family members. In some cases participants reported that the drinker was the sole breadwinner for the family and in others they were wholly reliant on the family to provide. Either situation complicated the decision and made it even harder for family members to contemplate splitting up the family. This was understandably very difficult to consider, both emotionally and practically, and something family members preferred to avoid altogether – particularly if children were involved.

## **Barriers: concluding remarks**

The participants indicated that there is rarely only one simple reason as to why family members do not seek help. What is clear is that families must break through several layers before they are able to access effective support for the impact of a loved one's alcohol misuse.

They must be able to identify that their loved one's alcohol use is problematic; they need to recognise that they have their own consequent support needs for the negative impact it is having on their lives; they have to feel willing and motivated to seek out support for themselves; and the services that they contact must either provide them with this support, or point them to someone

else who can. This is a challenging journey for families, and can prove seemingly impossible at many different stages. It can be years or even decades before an approach is made to services or an effective intervention is made by a professional.

## **Tipping points: factors that prompt families to seek help**

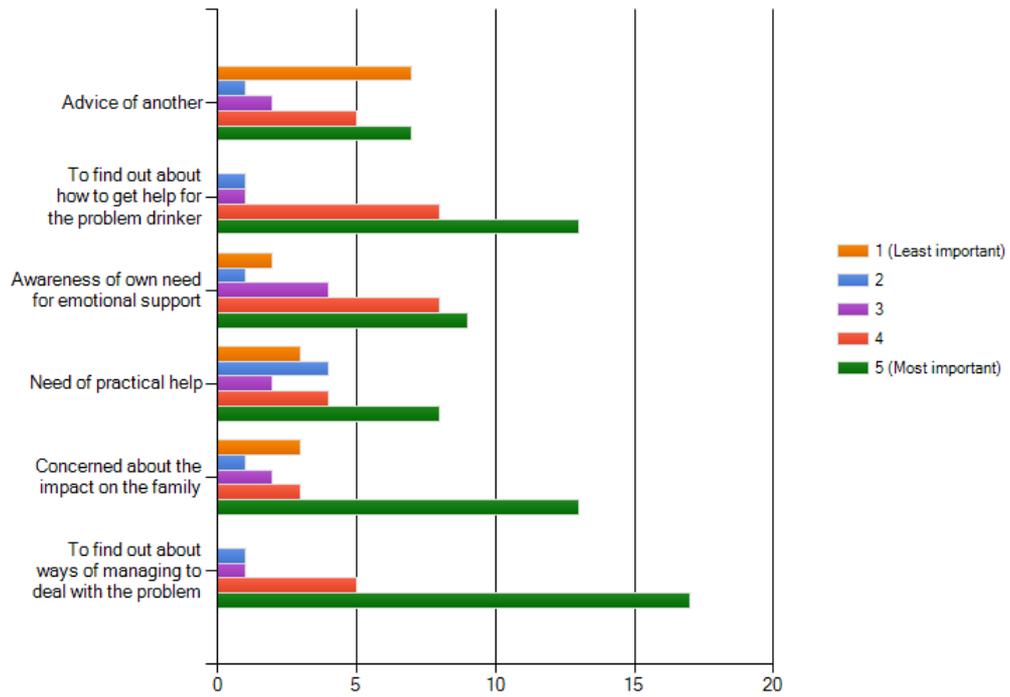
For those families who did seek help, a number of different triggers and variables were identified, which often varied depending on family norms, circumstances and expectations. It's important to note that even when help was sought, it was likely to be on behalf of the drinker.

Key factors included:

- ✓ The drinker's **refusal or failure to cut down** or stop drinking. Families said that only when such a situation had persisted for some time that help was sought.
- ✓ The **extreme behaviour** of the drinker. The more overtly difficult the behaviour, the harder it was for family members to deal with, and the quicker their tolerance level was reached. Examples of difficult behaviour included financial problems caused by household income being spent on drink; embarrassment on social occasions; extreme drunken incidents such as crashing the car; being incontinent; or persistently getting involved in fights. Some families reported a higher tolerance to such behaviours than others.
- ✓ **Aggression and violence** in the home were very likely to prompt help seeking behaviour. However, as noted in the literature review, some partners affected by domestic violence may be reluctant to admit to a problem and contact services due to fear.
- ✓ **Frequency of problem drinking**. For example, despite very heavy drinking over nearly two decades, the fact that one husband tended to have *'one day on and one day off'* made it bearable for his wife. She said *'I didn't have to worry about what he was doing every single day...that's why I think I put up with it so long'*.
- ✓ **Ability to contain the problem** within the immediate family unit (or at least the semblance of being able to). For one person a turning point came when he realised *'half the street knew about my mother's problems. Up to then I thought we had at least got her under some sort of control – damage limitation really'*.

Respondents to the online survey were less conclusive on this point. Triggers were more likely to involve recognition of their own needs or those of other members of the family, but seeking help for the problem drinker still featured highly.

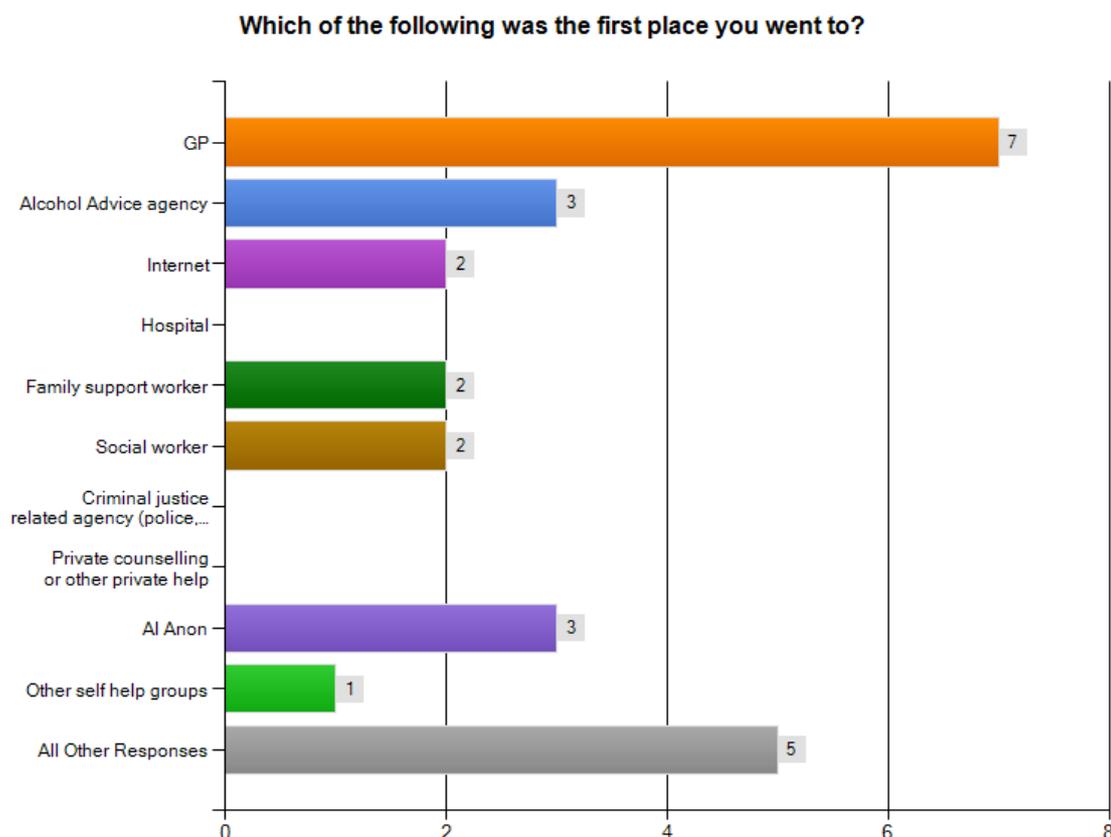
**What were the main triggers in deciding to try to get help? (Rank in order of importance)**



## Experiences of services

### Getting support through seeking help for the drinker

As explained above, some family members were unlikely to consider themselves as potential recipients of help and support for some considerable time – if ever. The impetus towards seeking help for many, therefore, had to come from another source. The GP was the most common first port-of-call for family members, followed by dedicated alcohol services.



However, the majority of participants reported that neither GPs nor specialist alcohol services mentioned the option of support for family members and the potential benefits of this. Indeed the most frequent statements from those interviewed who were not using a support service were - *'it did not occur to me and no one mentioned it'*.

Most of those interviewed who were in touch with a support service described finding it by chance – for instance through mentioning the problem to a friend who knew someone else in a similar situation, or coming across a leaflet or notice at a specialist service when they had accompanied their family member. In the study, there was only a single instance of family members being offered support in their own right, being encouraged to seek it or being signposted to a service by the professionals from whom they sought help on behalf of their family member.

From the experiences of families spoken to, agencies, whether generic or specialist, are not sufficiently aware of the needs of family members, the nature and location of support available and the potential benefits of them getting support in their own right.

## GPs

Many of those interviewed described considerable efforts to bring the issue to the attention of their family GP. They reported making phone calls and visits, both with the drinker and in advance, to ensure they were fully aware of the problem. Some described writing letters as they felt that professionals did not take them seriously and believed the symptoms and behaviour they reported were exaggerated. Two family members had videoed their loved one and showed their GP the evidence of the problem drinker naked, incontinent, collapsed on the floor or being abusive in order to prove the extent of the problem.

Many of family members perceived the GP as someone who could influence the problem drinker and were frustrated so little came of their efforts to make them aware of the situation:

- ✓ *'I went to the doctor countless times...I would say 'my mother's doing this' and they would say 'until she wants to do something about it there is nothing really much we can do'. I took a video of her drunk and I showed the doctor and he said 'well I can see why you are going on' but I don't think he took me seriously – you get a bit disheartened with that so I changed GPs'.*

Evidence is clear that primary healthcare can have a significant impact on problem drinkers<sup>5</sup>. However it is clear from this study, with one notable exception, that GPs did not offer support to the families; and since they were the most likely recipients of enquiries from families, this is an important gap in provision.

## Specialist alcohol agencies

The degree to which specialist agencies either offered to work with family members or signpost them to other support services was very variable. Research participants stated that often alcohol services did not offer support for families, nor think to mention it as a possible service provided elsewhere. There are services which do offer bespoke support for family members – HAGA in North London, for example, was mentioned as one which had proactively followed up on the needs of a mother who had referred her daughter.

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<sup>5</sup> The research on brief interventions by primary care workers is extensive and fairly conclusive as an effective intervention for many. It is noted in 'Brief Intervention in Primary Care Settings, A Primary Treatment Method for At-Risk, Problem, and Dependent Drinkers', Michael Fleming, M.D., M.P.H., and Linda Baier Manwell amongst others.

Family members also reported a lack of clarity amongst alcohol practitioners and other professionals on what actually constitutes an alcohol problem, which compounded the difficulty they were already experiencing in making sense of their situation.

### **Binge drinking**

A number of people cited a particular issue relevant to their relative's drinking which, whilst being outside the scope of this study, featured significantly in their stories.

Many of the family members interviewed did not perceive the drinker as dependent on alcohol as they were able to be abstinent for periods of time or did not drink problematically every day. This led the professionals they talked to to question the nature of the presenting problem.

One problem drinker who did agree to see the GP was informed he didn't have a problem, despite heavy drinking, as he was showing no ill effects.

Two other family members reported having been able, with help from the GP, to get their relative to attend an alcohol service. However following assessment, the agencies declined to offer treatment because they were deemed not to be alcohol dependent. This was despite excessive drinking over many years being the cause of a range of damaging problems for the family. The partners felt they had ended up in a worse situation as their spouses now had 'expert opinion' on their side when claiming that the drinking was not a significant problem.

From the survey it is also clear that family members are likely to be just as concerned about problem drinking in the absence of an evident serious dependency - just under half of the respondents reported that their family member drank problematically only in the evenings or less frequently.

There is a need to explore further the reactions of alcohol services and health professionals to non-dependent problem drinking as this appears to be an issue for the families we spoke to.

### **Family support services**

For families who did find and use them, support services were reported to be very helpful – 'a lifeline'. They explained the realisation that their experiences were shared by others as one of huge relief, amazement and comfort.

The range of support mentioned by people in this study included groups run by Al Anon, local family support groups, independent self-help groups (and the training courses run by them) and counselling services available in some specialist alcohol services. Families also mentioned access to telephone support as and when they needed being particularly beneficial.

The main benefits of support services reported by family members included:

- ✓ realising that they were not the only person experiencing the effects of a problem drinker in the family
- ✓ learning about the common behaviours caused by alcohol problems and being able to understand their explanations, which relieved much of the guilt often experienced by families
- ✓ learning new ways of dealing with situations that arose day-to-day
- ✓ understanding the nature of the problem and the issues of treatment, detox, recovery and relapse
- ✓ taking back control and over time becoming more confident in their decisions
- ✓ learning how they might inadvertently enable the problem drinker to transfer responsibility and discovering strategies for avoiding this, ensuring the drinker has to confront the consequences of their behaviour
- ✓ ongoing support over time – this is necessary as problems are not generally resolved quickly
- ✓ training courses on particular issues and skills, equipping participants to deal with the problems they face and take care of themselves.

Points taken from the focus group as to what helped and why:

**Counselling** - talking about problems; making you realise it's not your fault; not worrying about what other people think; realising you are normal; having the grieving process explained.

**Support Groups** – talking to other carers and concerned others; not being the only one dealing with problems; finding out information about what's available; knowing others are going through same situation; having moral support and somewhere to go; socialising; finding out what to expect after detox; being encouraged to look after yourself.

**Campaigning for better services** – keeping busy; keeping mind off own problems; can help others even though can't help own family member; gaining advice; giving advice; gaining knowledge.

**Signposting** – keeping busy and keeping self and others in touch with services; keeping up-to-date with new or closed services.

*(Notes from focus group – February 2012, Manchester)*

## Limitations

The main source of support reported was self-help groups. These were very popular with those who attended but there did seem to be some barriers to people accessing them. Not unlike Alcoholics Anonymous and other peer support services, each group has its own character and some may be more accessible than others. One woman described how she found it difficult to use

the support of the group she attended as most people there were experiencing a wide range of long standing social problems alongside a problem drinking family member: hearing vivid descriptions of poverty and violence, she felt uncomfortable talking about her problems and issues with her husband as their circumstances were very different. Other comments were made to a similar effect reflecting on the often more extreme stories that arose from family members of drug misusers - *'sometimes the drug stories from the families are so bad and extreme it's hard to relate to them'*. It is worth noting, however, that these quotes do not illustrate a problem with self-help groups – they simply show that these people had perhaps not found the right groups.

Many of the partners interviewed said they attended these groups still loving their family member and wanting to find positive ways of saving their relationship. They reflected that some discussions about ending the relationship within the groups made them feel further isolated. A more understanding approach would enable them to reach their own conclusions on their own terms.

Families said that a greater variety of support options would be beneficial – including helplines, counselling, training courses and the better provision of factual information. Capacity building or training for the leaders of self-help groups would also be welcome. Given the widespread lack of services in certain areas, mutual aid support groups will be working with a large and diverse group of family members and those responsible for this should be as skilled as possible.

## Conclusion

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Families affected by alcohol use often live lives of emotional turmoil marred by confusion, denial and secrecy. They may go for years suffering the effects of a loved one's alcohol use and face numerous barriers to reaching out for support.

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Even when families do decide to take action, preliminary experiences of seeking help can be just as fraught as the struggles which precede it – for example negative reactions from alcohol services, or not being taken seriously by GPs.

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Services need to be properly attuned to the destructive impact that alcohol can have on relationships, as well as treating the health harms experienced by the users themselves.

It is important that families are able to recognise drinking problems at an earlier stage. Without drinkers and their families being able to identify the problems they face and seek help to address them, the pernicious effects of alcohol misuse will continue to grow.

Of course, families cannot be 'forced' to access support, and insisting against their own feelings that they are 'suffering' risks stigmatising and alienating them even more. They should, however, be confident and motivated to ask for support when they feel that they need it – and this support should be openly available.

Another noteworthy issue is that drinkers do not have to be technically dependent on alcohol in order to have significant negative impacts on family life. In terms of what constitutes a 'drinking problem', then, it would be helpful to emphasise behavioural considerations rather than relying on definitions based purely on the number of units or drinks.

It is telling that when families do finally access support for their own needs, their experiences tend to be positive, and it's important to build on this. As well as helping to address their own needs, evidence also shows that when families access support, substance users can also be encouraged to enter treatment themselves<sup>6</sup>. Improving the availability and quality of family support therefore, should be a central aim of national alcohol policy.

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<sup>6</sup> Emma Rattenbury and Oliver Kempton March 2012, The Social Return on Investment of Drug and Alcohol Family Support Services: Assessing Adfam's contribution

# Appendix A: Literature Review

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## Alcohol Literature Review – Alcohol and Family Support Project

September 2011

### Aims:

- ✓ To investigate the comparative attitudes, approaches and experiences of families with a member experiencing, respectively, problematic alcohol and drug use in seeking external support.
- ✓ To draw out lessons for commissioners and providers in order to facilitate easier access to support for families of problem drinkers.

### 1. Introduction

In researching the background literature on the help seeking behaviour of family members affected by another's alcohol use (and barriers that prevent them accessing it) the one thing that quickly becomes clear is the paucity of material specifically dedicated to the topic. There is, however, a relative wealth of material covering barriers to *individuals* with alcohol problems seeking support and some covering the process of support seeking for those affected by familial drug use. There also exists, of course, a great deal of literature of general background interest covering the negative effects of living with a drug or alcohol user, the effects on children of parental substance use, the general importance of involving families and carers in the treatment of individuals and more. All these provide vital, if at times tangential, insights into the matter and in this review have been used together to build up a picture of how families affected by problematic drinking might go about seeking help.

To complement the formal literature available, material from more informal Adfam online consultations and focus groups has also been used. This provides useful real-life experiences from families affected by substance use.

### 2. Family experiences of living with a problem drinker/drug user

Although undoubtedly 'alcohol plays an important part in the cultural life of this country'<sup>7</sup>, 'alcohol is an unremarkable part of many families' lives'<sup>8</sup> and most UK citizens drink or come into regular social contact with alcohol without evident harm, there are clearly some families for which this is not the case. It is estimated that 2.6m children live with parents who drink hazardously, and 705,000 live with dependent drinkers.<sup>9</sup>

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<sup>7</sup> Drug Strategy 2008

<sup>8</sup> P1, Alcohol consumption and family life, Joseph Rowntree Foundation

<sup>9</sup> Manning *et al* (2009) *New estimates on the number of children living with substance-misusing parents: Results from UK national household surveys*

Living with a drug or alcohol user has a profound effect on family members. All of the literature reviewed agrees on this point, whether through general statements on the negative effects on happiness and wellbeing or more detailed commentary on worsened physical and mental health, financial instability, social isolation and stress. Turning Point write in *Bottling It Up*, for example: 'Parental alcohol misuse damages and disrupts the lives of children and families in all areas of society, spanning all social classes. It blights the lives of whole families and harms the development of children trapped by the effects of their parents' problematic drinking.'<sup>10</sup>

The Government's 2010 Drug Strategy states that drugs and alcohol dependence are 'key causes of societal harm, including crime, family breakdown and poverty. Together, they cause misery and pain to individuals, destroy families and undermine communities.'<sup>11</sup> Research tells us: 'Substance users cause problems for their families – it has been estimated that every problem drug or alcohol user influences two family members to the point of them requiring primary health care services'.<sup>12</sup>

Adfam's own literature is full of real-life experiences from family members who have suffered a great deal as a result of the actions of their siblings, children, partners or parents. At focus groups, parents have reported that at the worst times they sometimes wished their children were gone entirely from their lives. One parent put it succinctly, describing her life with a son using drugs and alcohol as 'a living nightmare'<sup>13</sup>.

Policymakers, academics and family members, then, all agree: having someone in your family with a serious drug or drink problem demonstrably worsens outcomes and has serious negative impacts on day-to-day quality of life. Families affected by alcohol therefore need and deserve support in their own right.

Apart from being adversely affected themselves, family members can also offer an enormous reservoir of support to loved ones with drug or alcohol problems. Family members with good support themselves will be in a better position to offer support to the person with the substance problem. Adfam note in *Adfam's manifesto for families*: 'there is an increasing recognition that involving family members in treatment can make a significant contribution to effective outcomes and facilitate recovery for both drug users and family members'<sup>14</sup>; this is mirrored by the Government's official Drug Strategy, which states that 'treatment is more likely to be effective, and recovery to be sustained, where families, partners and carers are closely involved'<sup>15</sup>. The support that families currently do provide is enormous – annual savings to the NHS and local authorities are calculated at £750m by the UK Drug Policy Commission, who write that families 'are frequently an unrecognised, unappreciated and

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<sup>10</sup> P5, *Bottling it up – The effects of alcohol misuse on children, parents and families*, Turning Point, 2006

<sup>11</sup> *Drug Strategy 2010 - Reducing Demand, Restricting Supply, Building Recovery: Supporting People to Live a Drug Free Life*, 2010

<sup>12</sup> *Supporting families and carers of drug users: A review*, Velleman, 2002

<sup>13</sup> Child – Parent Family Abuse focus group, 2011

<sup>14</sup> *Adfam's manifesto for families*, 2010

<sup>15</sup> HM Government (2010) *Drug Strategy 2010: Reducing demand, restricting supply, building recovery*

unpaid resource providing economic and other forms of support to their drug using relatives'<sup>16</sup>. Before seeking external support for either their substance using relative or themselves, families are likely to put in years of care, energy, and emotional, social and financial support in attempting to get the best for their loved one.

### 3. Seeking support

#### a. Type and extent of support available

All the available literature points towards the fact that the amount of support available to families of alcohol users is not very significant – there is ‘a lack of services *specifically* for children and families affected by alcohol misuse’<sup>17</sup>, research indicates. There is of course a higher treatment focus on the individual themselves, but services ‘historically tended to be very individualistic in their approach to treatment, viewing clients in a vacuum isolated from their families, friends, networks and communities’<sup>18</sup>.

Other literature confirms that more could be done to engage families, with the National Treatment Agency acknowledging this importance by pledging in 2008/09 that ‘all services will be focused on considering family issues by 2011’<sup>19</sup> and research with family members finding that ‘family members seemed to have very little by way of current support, either from within or external to the family’<sup>20</sup>. A respondent to a 2010 Adfam consultation said ‘some areas have very good support services for families and friends of drug and alcohol users while other areas have little or none’<sup>21</sup>.

Attendees to focus groups held by Adfam typically cite a range of places they go to for help (friends, GPs, social services and even the police if confronted with extreme behaviour) but opinion generally varies on the effectiveness of the support offered, with a strong theme of being failed by ‘the system’ apparent. As a representative example of opinion, attendees at a recent group said that mental health services refuse to deal with anyone with drug or alcohol problems and ‘pass the parcel’; the ‘police were absolutely magnificent’; ‘social services judged me’ and there is ‘so much rubbish on the internet’<sup>22</sup>.

Anecdotal evidence through focus groups indicates that the internet is an early port of call for family members. However this searching is generally weighted towards drugs rather than alcohol, with many parents saying they had very little knowledge of drugs and used the internet to look for basic information rather than more advanced support.

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<sup>16</sup> P1, Supporting the supporters: Families of Drug misusers, UK Drug Policy Commission, 2009

<sup>17</sup> Service provision for the children and families of alcohol misusers: a qualitative study, Sarah Zohhadi, Lorna Templeton and Richard Velleman

<sup>18</sup> ‘Planning the service’ section, Working with the children and families of problem alcohol users: A toolkit – University of Bath

<sup>19</sup> Business plan 2008/09, National Treatment Agency

<sup>20</sup> P4, Working with Family Members in Specialist Drug and Alcohol Services: Findings from a Feasibility Study, Lorna Templeton, Sarah Zohhadi and Richard Velleman

<sup>21</sup> Families and Childhood Taskforce Consultation, 2010, Adfam

<sup>22</sup> Child – Parent Family Abuse focus group, 2011

When asked at focus groups (for parents of children using drugs and/or alcohol) what support would be best to meet their needs, family members strongly and almost unanimously suggest local family support organisations. Numerous attendees described family support organisations set up by others who have themselves been through the struggle as invaluable – ‘a Godsend’ and ‘a lifeline’<sup>23</sup>. One attendee said, ‘if it wasn’t for this place I wouldn’t be here’. Other positive statements on the benefits of attending a family support group with other family members included: ‘nobody is shocked by anything’; ‘I’m seeing here [in other people] exactly what’s going on in my life’; and ‘everyone is so lovely and welcoming’<sup>24</sup>.

Given this lack of support available for families, the option of ‘doing it yourself’ understandably appears in the literature. Historically where family members have found the existing provision for their needs insufficient or even non-existent, they may have found the best way to deal with the problem was to create a support network themselves. *Adfam’s Setting up a family support group* offers practical advice on how best to create and sustain a local support group with the express purpose of providing ‘confidential support for family members who are concerned about someone else’s actual or possible drug or alcohol use, so that they can deal with the situation confidently and constructively in their family life’.<sup>25</sup> The need for this type of guide by its very nature indicates a lack of existing effective support. Many family support services have been started by family members themselves (who are a key audience of this resource), which is an effective tool in harnessing families’ invaluable expertise from years of real experience. As one family member and project coordinator says in the guide, ‘we were all carers and we knew the service we needed’<sup>26</sup>.

On a related note, a practical guide also exists for practitioners looking to create a service for the families of problematic alcohol users. *Working with the children and families of problem alcohol users: A toolkit* states that ‘generally alcohol services struggle to grasp to what extent working with children and families should be part of their remit’<sup>27</sup> and goes on to outline the practical necessities of setting up a service, covering many of the same areas as Adfam’s guide, albeit just from the perspective of the practitioner rather than also the parent – although as mentioned above, these boundaries may blur when family members set up their own services to support others. The existence of these guides an encouraging response to a lack of support that aims to empower people to use their own experiences to provide help.

## **b. Positive and negative factors in accessing support**

Factors that aid or impede families seeking support must be drawn and inferred from a variety of sources.

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<sup>23</sup> Ibid

<sup>24</sup> Ibid

<sup>25</sup> P4, *Setting up a family support group*, Adfam

<sup>26</sup> Ibid, P10

<sup>27</sup> ‘Planning the service’ section, *Working with the children and families of problem alcohol users: A toolkit* – University of Bath

Many of the barriers that exist for individuals accessing treatment for their own alcohol use may be of interest when considering similar barriers for their family members. Not all are directly relevant, and the needs of the substance using individual remain quite different, but underlying issues may help to bring together a picture.

Literature that discusses barriers to accessing support for individuals or families affected by drug use will naturally also be informative and useful, although there are some key differences in the problems faced in the two situations - indeed The Alcohol Education and Research Council unambiguously state that – ‘problem alcohol users experience a set of treatment barriers that are specific to alcohol use’<sup>28</sup>.

## Services

✓ **Alcohol services not being obliged to provide family support** is a problem that families may come across: ‘it is possible that the way alcohol treatment services currently operate, for example within the UK, and the expectation of how services must report to commissioners, with the focus on the number of clients engaged with, retention rates and success with regards to alcohol consumption and criminal behaviour, are preventing the required move towards consideration of a broader range of outcomes for clients and their families’.<sup>29</sup>

Though not so much a barrier to accessing support as an actual shortcoming in the support that does exist, it is worth bearing in mind. This is especially likely in a financial climate of hardship, with services under budgetary pressures, and it would be understandable for services to stick to delivering only what they are contractually obliged to provide.

It seems that the best way to rectify this would be to include family support within the range of services that agencies are commissioned to provide – ‘work is needed to understand the best ways of assessing outcomes and integrating the consistent use of outcome tools...so that routine assessment of outcomes for all family members receiving a service becomes embedded into routine practice.’<sup>30</sup>

The current move towards payment by results (PbR) could act as a double-edged sword – on the one hand it would be easy for an alcohol service to justify not providing support for families by pointing to the specific treatment targets on their reward sheet for their PbR scheme, but on the other hand PbR schemes could be used sensitively and effectively to incorporate targets on meeting the needs of families and therefore provide a financial incentive for services to provide family support. PbR could also mean that services reach out to families to help them improve their outcomes by supporting the user through their treatment journey.

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<sup>28</sup> P1, Why do individuals delay accessing treatment for alcohol concern?, AERC

<sup>29</sup> P19, Psychological interventions with families of alcohol misusers: a systematic review – C Russell, Lorna Templeton and Richard Velleman

<sup>30</sup> Ibid

- ✓ **A lack of family expertise in services** is also likely to be a barrier to families seeking support. The literature suggests that for some practitioners, contact with children and families is perceived as excessively difficult or beyond their standard skill set. ‘Staff in children’s services have lacked the knowledge, skills and confidence to address parents’ alcohol- or drug-related problems, even when these are clearly impacting upon the child with whom they are working’<sup>31</sup>, state the Scottish Government.
- ✓ **A lack of joined up working between services** is another potential barrier for families seeking support. Good links between services and improved referral pathways would mean that the family of an individual seeking treatment for their alcohol problem would routinely be given information on family support services. ‘Effective collaboration, good joint working and a sharp focus on the family as a whole, are essential if children of substance misusers are to receive appropriate help’, write the Scottish Government<sup>32</sup>.

### Families

- ✓ **The legality of alcohol** is a factor that could encourage support seeking. Unlike families containing an illegal drug user, people affected by alcohol do not necessarily have to worry about the police being involved, their loved one entering the criminal justice system or being jailed. ‘There are significant differences between alcohol and drugs in the stress and strain experienced by families coping with drug use because of illegality and associated criminality’, write the Centre for Research in Families and Relationships<sup>33</sup>. The legal status of the drug in question (alcohol rather than, say, crack or heroin) is therefore one positive factor for family members when seeking support.

The legality of alcohol may act in another way, however. Given its high levels of consumption and social ubiquity the legality of alcohol here may have an adverse effect, with the perception amongst family members that the use of a legal drug is somehow inherently more acceptable and less damaging than an illegal one. The Joseph Rowntree Foundation state that ‘children are not taught to recognise the health consequences of drinking...health risks do not resonate with parents’ experiences of drinking’, meaning that family members may not be aware of the actual damage being done by problematic drinking, whether in physical, emotional or other terms.

- ✓ **A lack of knowledge and understanding around alcohol** on the families’ part may play a part in preventing them from seeking support.

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<sup>31</sup> P54, Getting our Priorities Right: Good Practice Guidance for working with Children and Families affected by Substance Misuse (2003) –The Scottish Government

<sup>32</sup> Ibid

<sup>33</sup> P14, Supporting families and carers of drug users: A review, Centre for Research in Families and Relationships

The previous Governmental alcohol strategy ,published in 2007, stated that ‘[many] harmful drinkers, don’t realise that their drinking patterns damage their physical and mental health and may be causing substantial harm to others’<sup>34</sup> which adds further weight to this point. Research indicates that ‘alcohol users take an average of thirteen years longer [than drug users] to initially recognise their alcohol use as a problem and twelve years longer to access treatment’<sup>35</sup> which is a huge disparity. It is entirely likely that this disparity is mirrored in the time taken for family members to seek support, since help seeking is partly predicated on how long it takes to identify a problem in the first place.

- ✓ **The stigma around seeking help** is a related factor. Although alcohol is not a prohibited substance, the idea of seeking help from professional services to address a family drinking problem may still be too much for some families. Families may also not want to access a service in case they see someone they know.

Another form of stigma that may be relevant is an unwillingness to access services that are felt to be the exclusive territory of drug users. This may be through a genuine belief that services specialise in treating just drug users, or a prejudice against illegal drug users in general. ‘[I had] heard about the service for smack-heads and drug users, [but] didn’t realise that there was help for drinkers’, one focus group attendee stated<sup>36</sup>, with another saying ‘I don’t like the fact that most of the people who go to [the treatment agency] are drug addicts’<sup>37</sup>.

There may be additional stigma surrounding alcohol in certain communities which prohibit drinking on religious or cultural grounds. The Government states that ‘within families or communities where alcohol is taboo, making a disclosure, early identification and treatment [is] much harder’<sup>38</sup>.

- ✓ **Domestic violence** may also be a barrier to families seeking support. Although we know ‘there is no simple causal relationship between substance use and domestic violence’<sup>39</sup>, domestic violence is manifest as a ‘pattern of abusive and controlling behaviour through which the abuser...seeks power over their victim’<sup>40</sup> in which alcohol may be a contributing or complicating factor. If family members are victims of domestic violence perpetrated by someone who also drinks problematically, they may be unwilling to seek support and talk to services in case the abuse is uncovered and the perpetrator punishes them through increased violence.

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<sup>34</sup> P6, Safe. Sensible. Social. The Government’s Alcohol Strategy (2008) – UK Government

<sup>35</sup> P2, Accessing treatment for problem alcohol users: Why the delay?, Gloucester Research Unit

<sup>36</sup> P17, Accessing treatment for problem alcohol users: Why the delay?, Gloucester Research Unit

<sup>37</sup> Ibid

<sup>38</sup> P49, Safe. Sensible. Social. The Government’s Alcohol Strategy (2008) – UK Government

<sup>39</sup> P16, Thinking It Through Toolkit, Adfam and AVA, 2011

<sup>40</sup> Ibid, P7

There are also circumstances where survivors of domestic violence have alcohol problems rather than, or as well as, the perpetrators. Research has indicated that abused women are 15 times more likely to use alcohol and nine times more likely to use drugs than non-abused women<sup>41</sup>. Violence within the home might also discourage children or other family members from seeking support, worrying that they might themselves become victims, or that the mother could be punished by the perpetrator.

#### **4. Conclusions**

As might be expected, the factors that aid or prohibit families from successfully seeking support are many and varied. This review brings together and offers evidence for some of the most evident ones – it would be possible to devote a larger piece of work to digging deeper and unearthing more factors and more evidence. Although there is a lack of literature devoted specifically to the topic in question, it has proved possible to draw out facts and testimonies from related material that illuminates the matter. The experiences shared by families in consultation with Adfam, whether in person or online, provide evidence of the lack of adequate support that is compelling in its honesty and directness. It compliments well the findings of the researchers, policymakers and academics who have examined the challenges and suffering of these families so badly in need of help.

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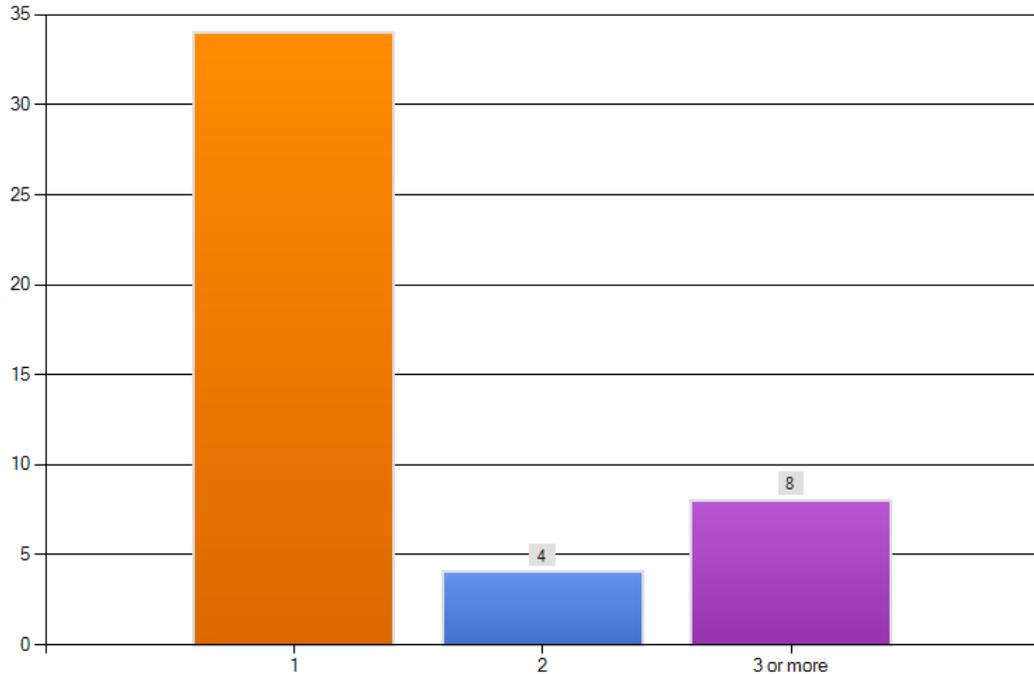
<sup>41</sup> Cited in Barron, J. (2004) Struggle to Survive: Challenges for delivering services on mental health, substance misuse and domestic violence, Women's Aid Federation England

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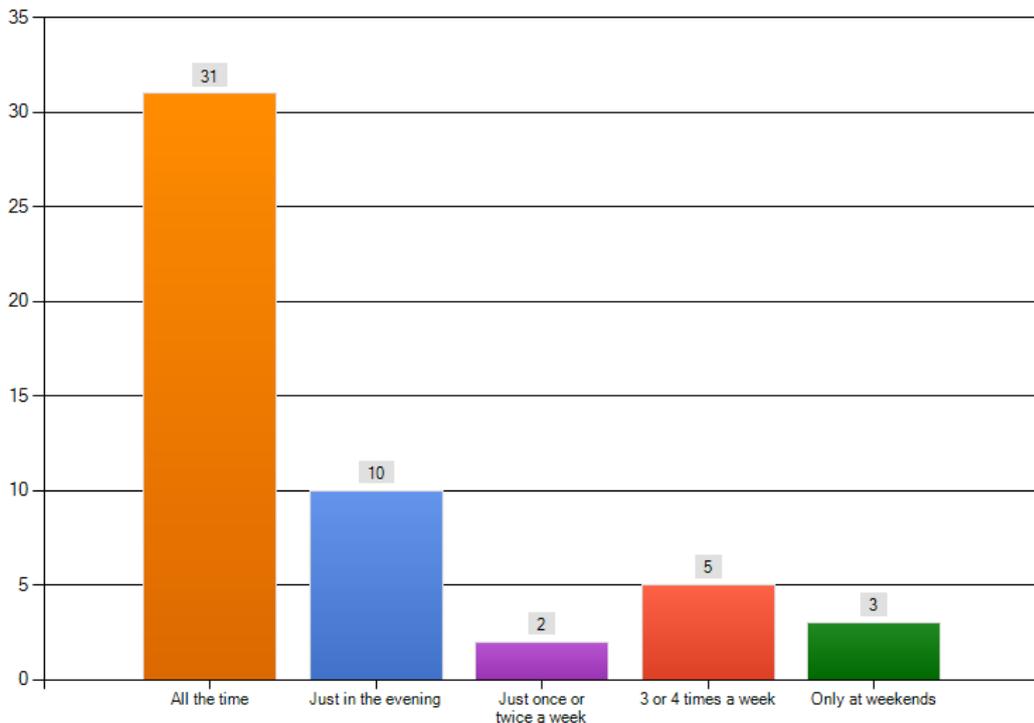
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- ✓ [Adfam’s manifesto for families](#) (pdf) (2010) – Adfam
- ✓ [Alcohol consumption and family life](#) (pdf) (2010) – Joseph Rowntree Foundation
- ✓ [Bottling it up – The effects of alcohol misuse on children, parents and families](#) (pdf) (2006) – Turning Point
- ✓ [Knowledge set three: Families and Carers](#) (pdf) (2011) – Alcohol Concern
- ✓ Psychological interventions with families of alcohol misusers: a systematic review (2001) – C Russell, Lorna Templeton and Richard Velleman
- ✓ Setting up a family support group (2009) - Adfam
- ✓ [Service provision for the children and families of alcohol misusers: a qualitative study](#) (pdf) (2004) - Sarah Zohhadi, Lorna Templeton and Richard Velleman
- ✓ [Supporting the supporters: Families of Drug misusers](#) (pdf) – UK Drug Policy Commission
- ✓ [Why do individuals delay accessing treatment for alcohol concerns? A pilot study](#) (pdf) (2008) – The Alcohol Education and Research Council
- ✓ [Working with Family Members in Specialist Drug and Alcohol Services: Findings from a Feasibility Study](#) (pdf) - Lorna Templeton, Sarah Zohhadi and Richard Velleman
- ✓ [Working with the children and families of problem alcohol users: A Toolkit](#) - Sarah Zohhadi, Lorna Templeton and Richard Velleman

## Appendix B: Online survey: questions and results

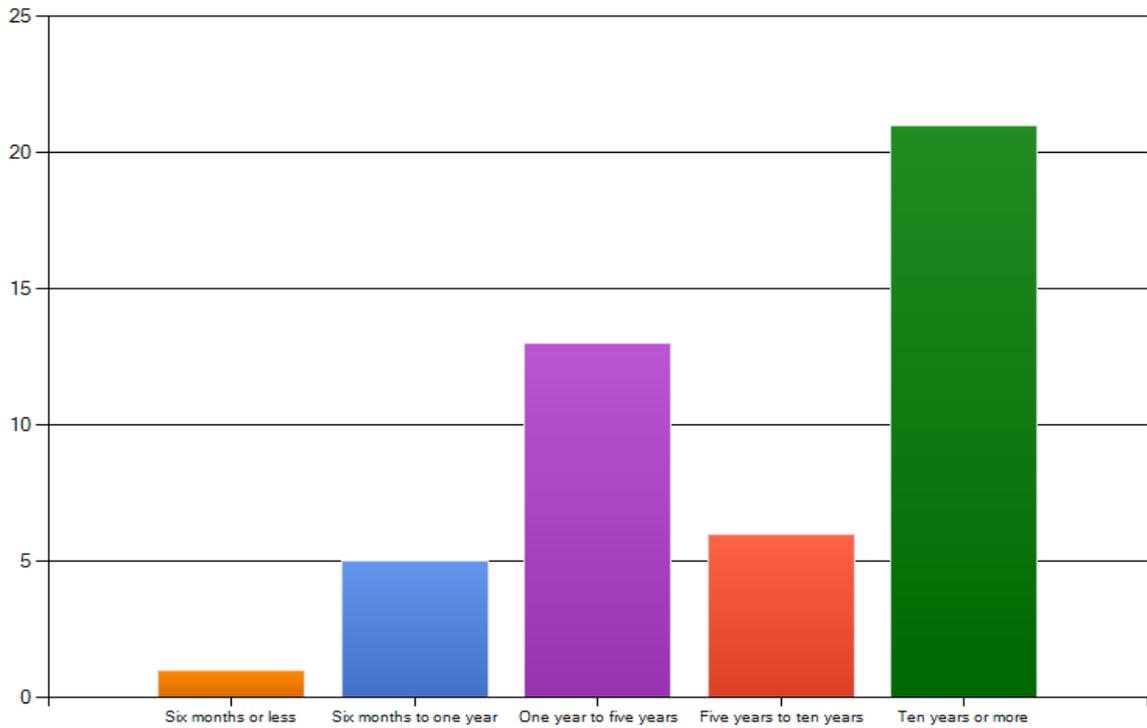
How many problematic drinkers are or were there in your family? Please note: if you have or had more than one problem drinker in your family please complete the survey according to your experiences of the most problematic.



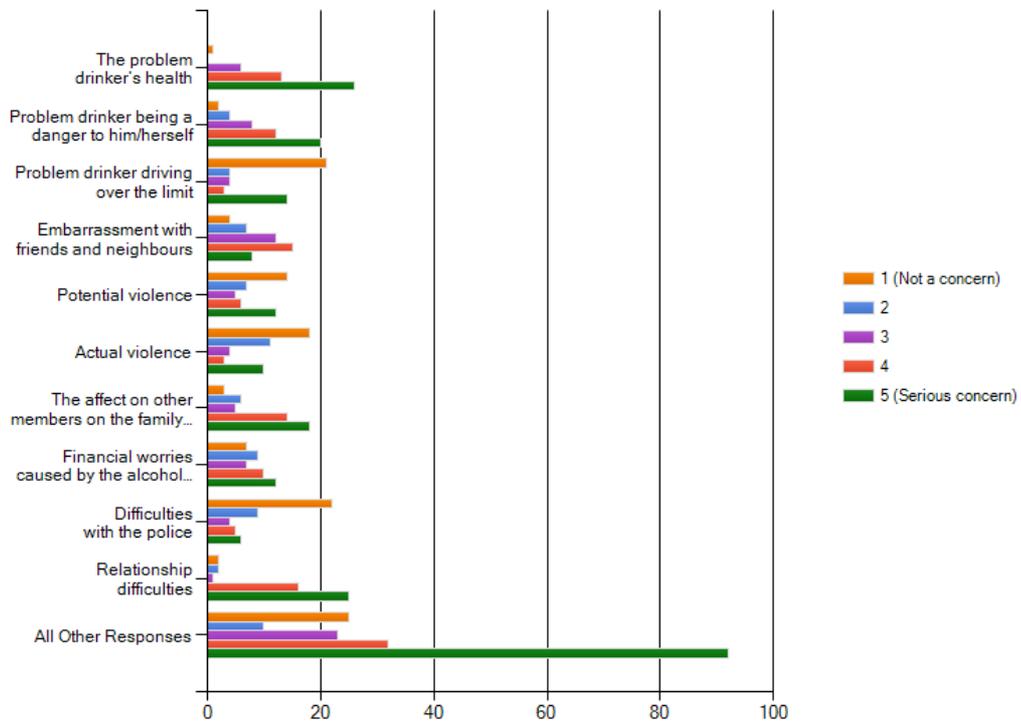
Does or did your relative problematically drink? (Tick all that apply)



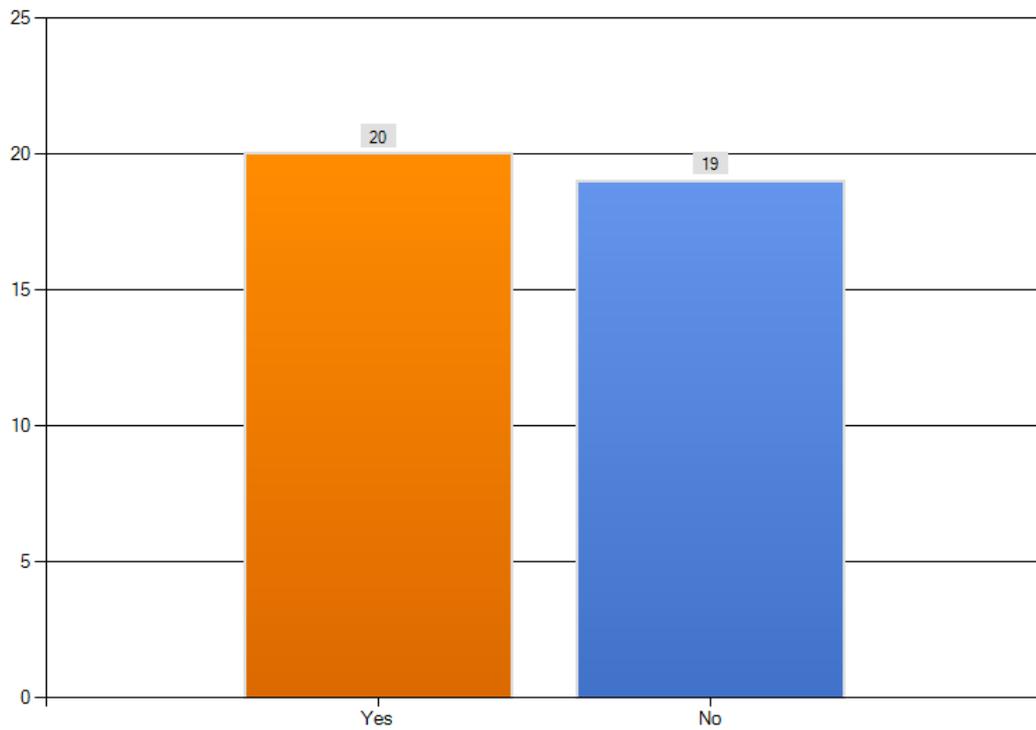
**How long have you known that your relative has (or had) been drinking problematically?**



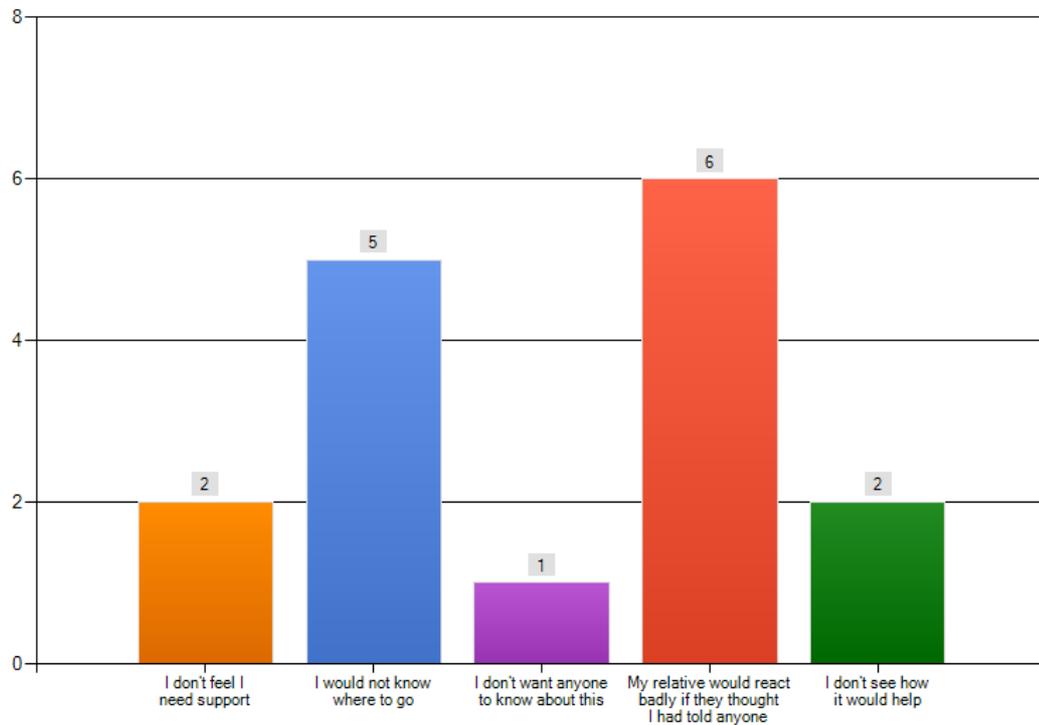
**How concerned were you about the following?**



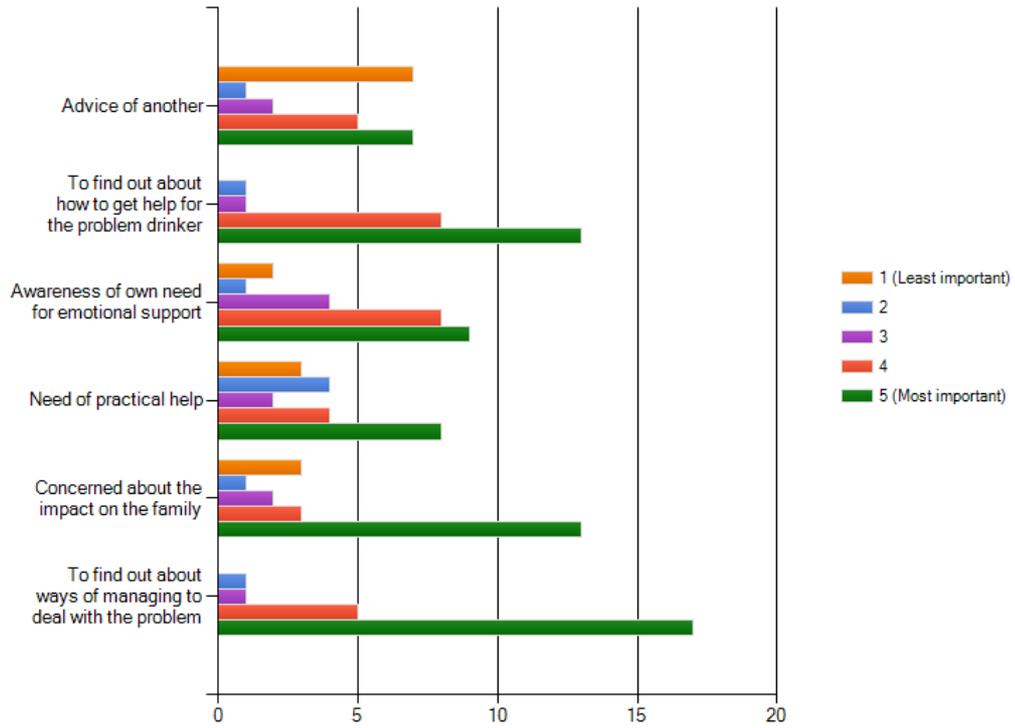
**Have you sought help or support for yourself regarding your family member's drinking?**



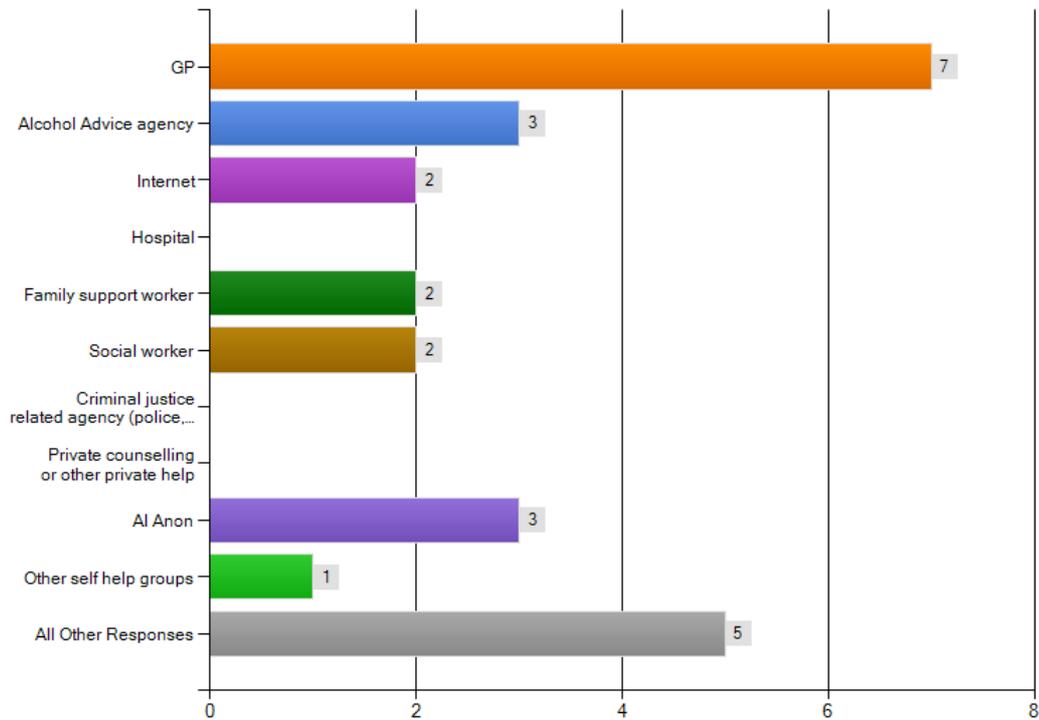
**If not, why not? (Tick all that apply)**



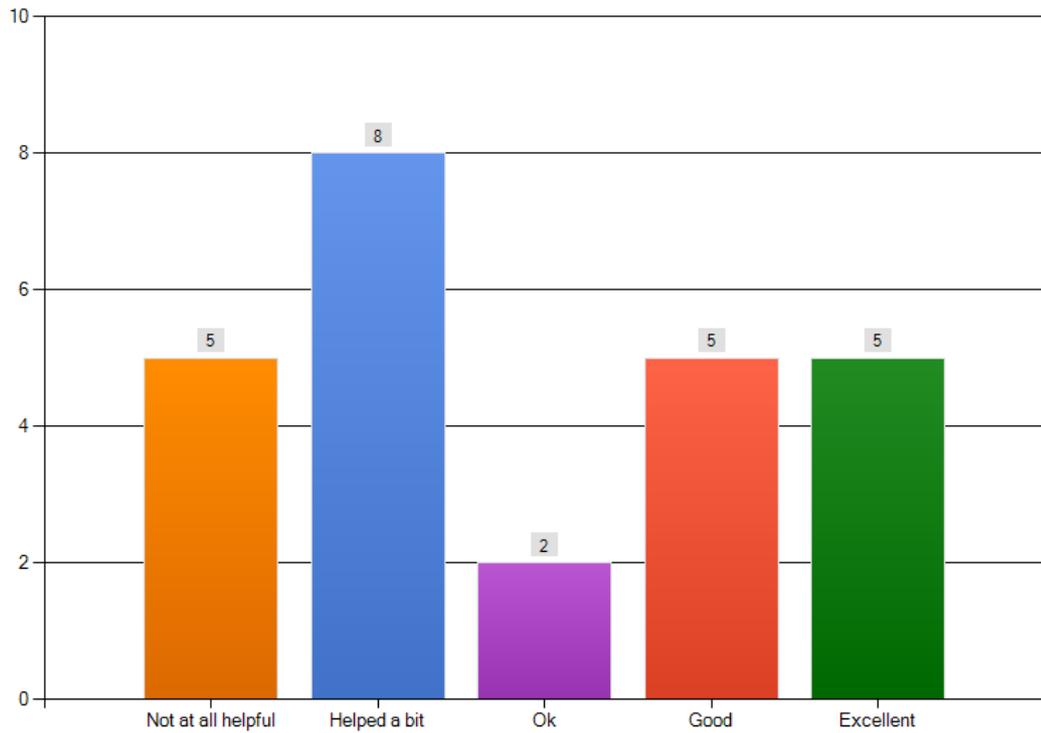
**If so what were the main triggers in deciding to try to get help?**



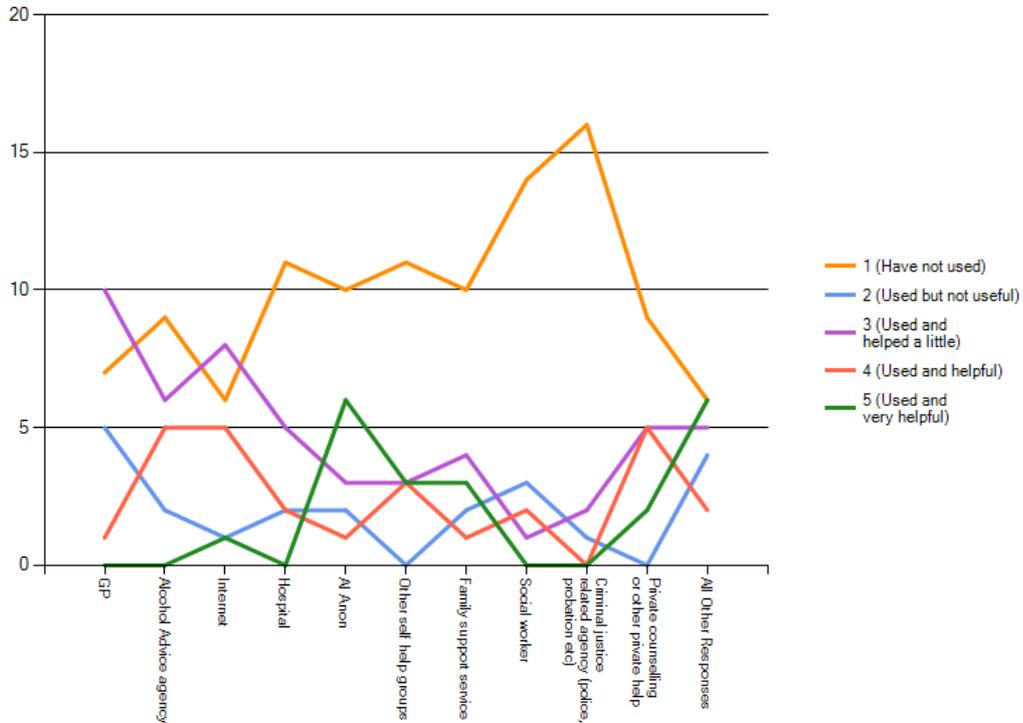
**Which of the following was the first place you went to?**



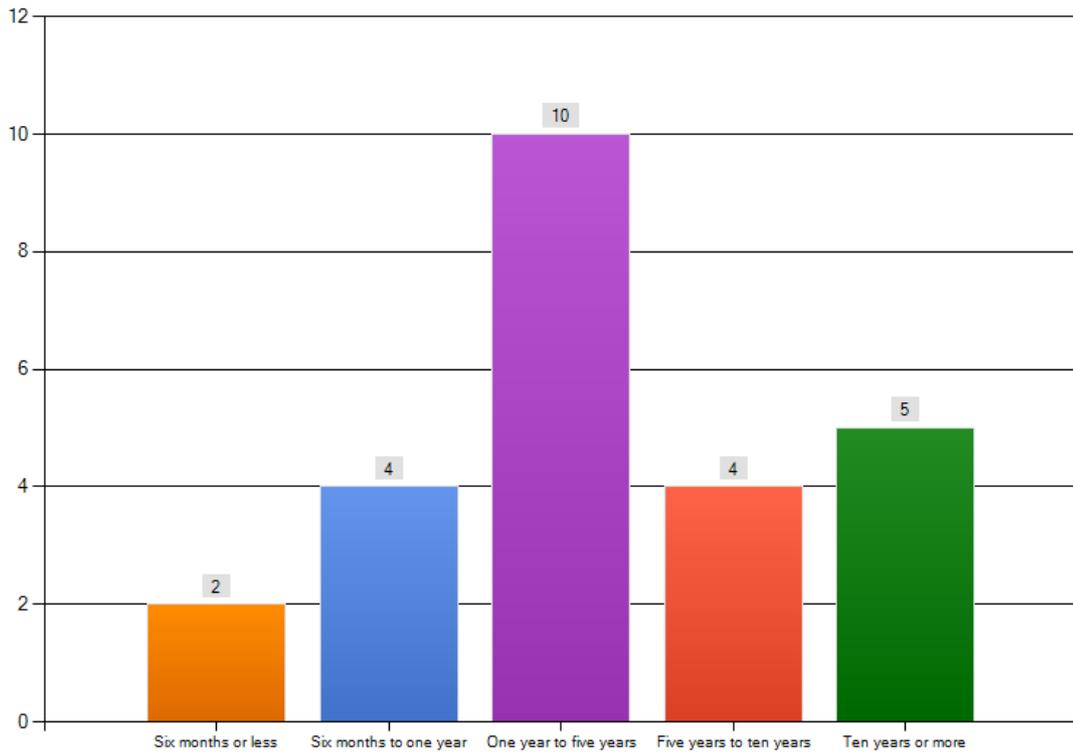
**How would you rate the response you received there?**



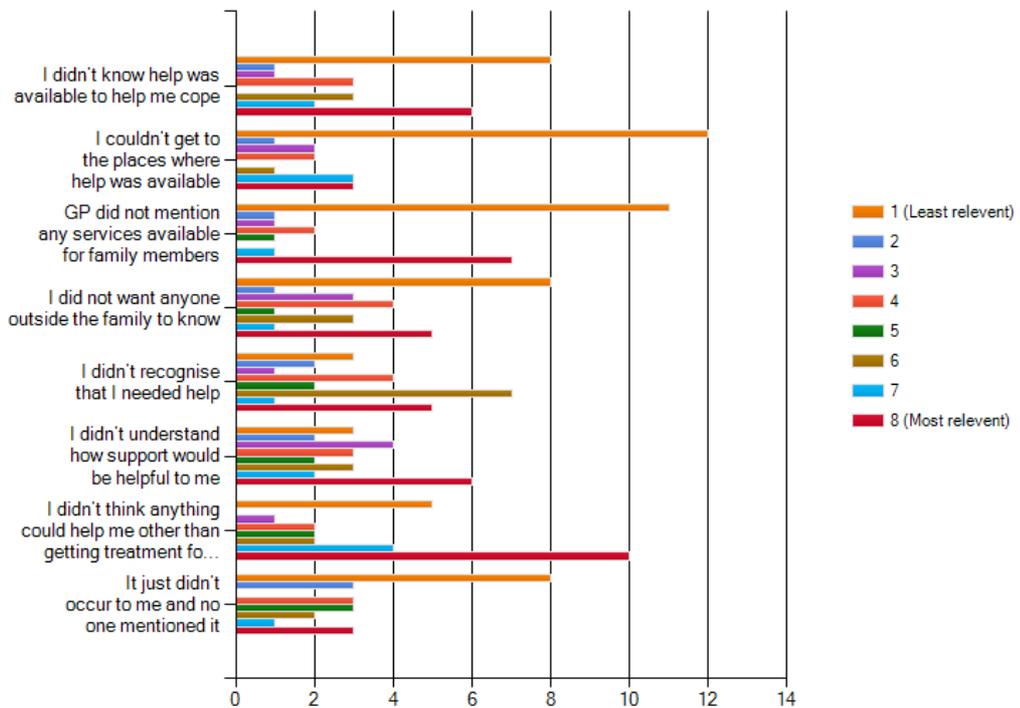
**Of all the sources of support how useful were they?**



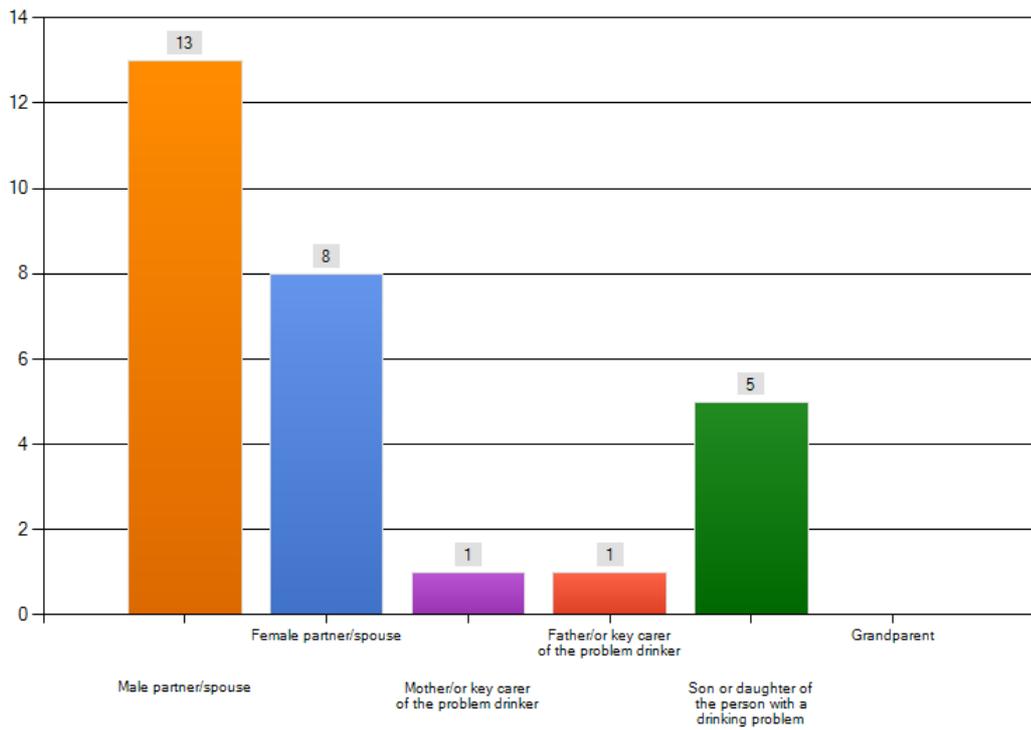
**How long had you been affected by the problem drinker before you sought help?**



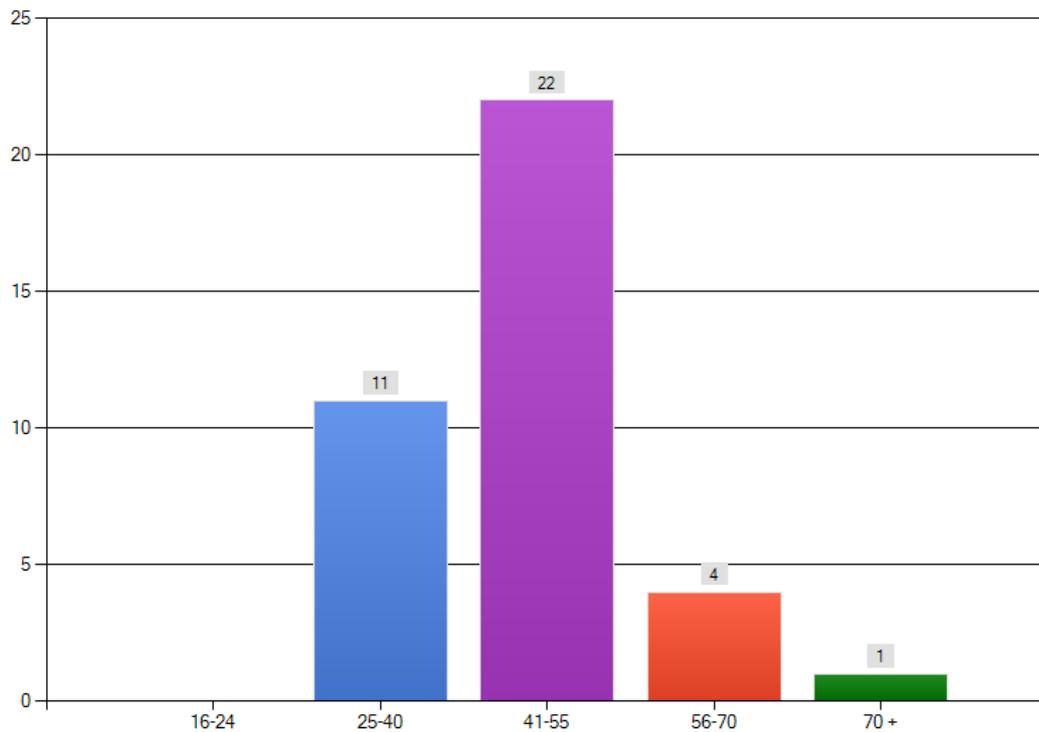
**What were the reasons for the delay before seeking help? (Rank in order of importance)**



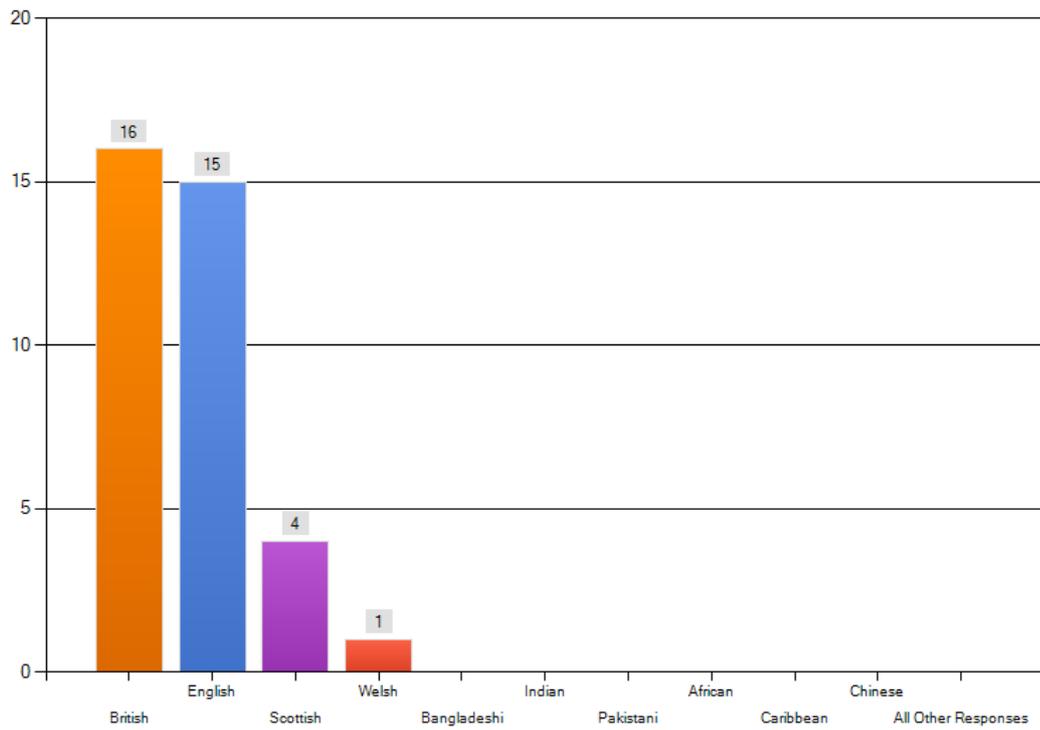
### What's your relationship with the drinker in your family?



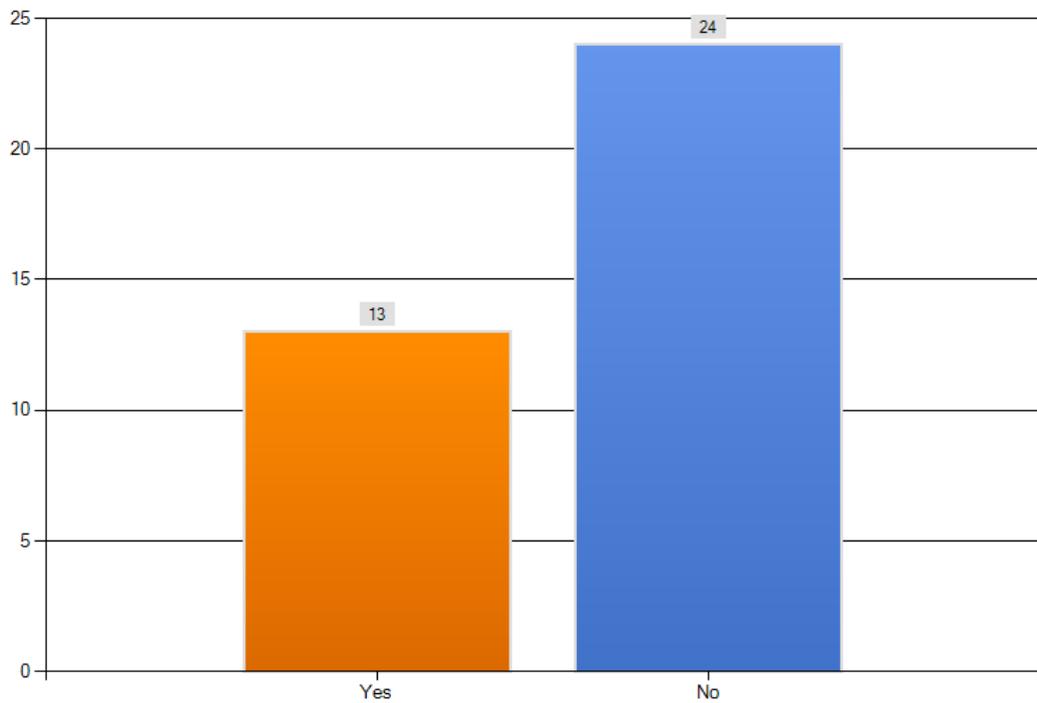
### What is your age?



### What is your ethnicity?



### Would you be willing for someone to ring you to discuss your experience of seeking help further?



## Appendix C: Interview guide (information for participants)

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Adfam, a national organisation working to support families affected by a member with an alcohol or drug problem, is examining issues concerned with how people affected by a family member's drinking go about seeking advice and support and what barriers they have to overcome in getting the right help. Much is known about the issues faced by families of drug misusers, but little about the needs of families of alcohol misusers – whether there are issues specific to them or whether they are the same.

I am undertaking a scoping study to inform what work is needed to promote better access to services for families affected by a loved one's alcohol problem, and am interviewing individuals by phone and in person in different parts of the country as well as carrying out a number of focus groups on this topic.

Participants will need to be a close relative (mother, father, son or daughter, grandparent or someone who is the principal carer) of a person whose problem is only alcohol (although if some minor drug use is present, but is a marginal issue, this would be fine). I do not need to collect any identifying information but it would be useful to be able to ask for a few details such as age and ethnicity.

The question areas are as follows:

- ✓ The time when interviewees became aware there was a problem
- ✓ How they reacted (initially, over time, experience of other members of the family, what they thought, what they did etc.)
- ✓ How long did it take before they sought any help of any kind (friends, family, helplines, books, internet, GP, specialist agencies, anyone else) exploring which sources were approached first, what enabled them to seek help, what held them back
- ✓ Issues around other family members – the degree to which the family could support each other, had different needs etc.
- ✓ How have they used any help available
- ✓ What is useful and what is not – what kinds of things have helped them come to understand the issues, learn how to deal with them, what their ongoing support needs are and how these could be addressed.

Face-to-face interviews will take between 45 minutes and one hour. Phone interviews will take approximately 30 minutes and focus groups will last a maximum of one hour 30 minutes.