**Behind Closed Doors**



**Sunderland Area Parent Support**

**Peer Led Research Team**

With Sharyn Smiles and Victoria Smiles

**SAPS Peer Research Team**

SAPS Peer Research Team are a group of peer led researchers whom all care or have cared for someone with a substance misuse issues. This is the first piece of research undertaken by the group which we hope will be the first of many, with plans for annual reviews already being planned.

The SAPS Peer Research Team was formed through educational funding from Adult and Community Learning, as students were trained in research techniques and enabling them to interview other people who had similar experiences. The group has a passion for highlighting the voices of some of the most vulnerable and unrecognised members of our society. The group aim to improve the lives of carers throughout the city highlighting key areas such as health and housing as barriers to social and economic stability.

The research seeks to inform local policy makers and those with an interest in issues facing carers of substance mis-users in decision making and thinking.

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**Acknowledgements**

The Peer Led Research Team would like to express their heartfelt thanks to everyone who took part in the research without you this report would not be possible.

**Important Notes**

The names of respondents have been changed to protect their identities.

Substance misuse is used to refer to both drugs and or alcohol misuse and does not seek to differentiate the drug unless otherwise stated.

**The Authors**

Sharyn Smiles has worked in the field of substance misuse for over ten years and has experience of conducting research into aspects of addiction. As well as being a full time mum Sharyn is a volunteer for SAPS.

Victoria Smiles is a member of the Peer Led Research Team. She is currently studying Community and Youth Studies at the University of Sunderland.

**Foreword**

Dear Reader,

I am delighted to provide the foreword to this Behind Closed Doors Research, drugs and alcohol can damage individuals, families and communities and we have invested significant time and resources in seeking to prevent and reduce the stress for families affected by substance misuse.

In recent years the number and range of services for families affected by drug use have increased considerably. However, there is more work to be done if all families who are in need of family support services are to receive the help they need.

This research contains the voices of the families and I would like to thank all those who contributed their experiences. I greatly appreciate and respect the commitment and energy of those family members and others, who have contributed to this piece of research.

With great thanks to Family Adult and Community Learning, who have funded this piece of research to enable SAPS to highlight the issues encountered by families affected by a loved one’s addiction.

We would also like to thank Gentoo for the funding received for the printing of the report.

Last but not least I would like to say a massive thank you to the researchers of Behind Closed Doors, Sharyn Smiles and Victoria Smiles they have worked tirelessly on the research and have produced an outstanding piece of work.

Susan Leigh

Project Manager

**Executive Summary**

* Students of ‘Research Training’ course funded by Family Adult and Community Learning trained in methodology, ethics, questionnaire design and research techniques.
* 100 respondents interviewed using snowball sampling to find carers both in and out of carer services.

**Housing**

* 89% of those residents in social or privately rented properties had problems with their housing due to their loved ones addiction.
* 83% said that their loved one was homeless or facing homelessness as it was not possible for them to reside in the family home.
* Homeowners felt more secure in their property but came out worse in terms of feeling more socially isolated and stigmatised.

**Stigma and Isolation**

* 94% of participants felt isolated
* 85% of respondents had distanced themselves from all or parts of their families whilst 90% had distanced themselves from friends to protect their loved one and attempt to conceal the addiction.
* 81% were scared to leave their home as they worried about what would happen while they were out.
* 34% felt blamed for their loved ones addiction.

**Employment**

* 47% were unemployed and several had to leave work due to their caring role and serious incidents occurring whilst they were at work.
* 34% were in employment but were having difficulties holding down their job due to their caring role.

**Physical Health**

* 24% had been threatened with violence by the person they care for and 19% had actually been assaulted.
* 17% classed themselves as a victim of domestic violence.
* 49% consumed more alcohol and 37% had used over the counter medications (primarily codeine) to cope at the peak of their loved ones addiction. While 49% had consumed more alcohol.

**Mental Health**

* Depression was reported by 74% and 62% were prescribed anti-depressants.
* 59% if carers had suffered from panic attacks
* Shockingly 12% of carers had attempted suicide.

**Family Unit**

* On average 5.6 family members were affected by one person’s substance misuse
* 49% had experienced some family relationship breakdown
* 83% had argued with their partner about their loved ones addiction
* 93% of siblings had been affected by their brother / sisters substance misuse in various ways.

**Crime, Courts and Prison**

* Only 42% of respondents saw themselves as a victim of crime whilst 78% said they had things stolen from them.
* 74% had inadvertently became involved with the police due to their loved ones behaviour.
* 16% had to have their loved ones arrested due to their behaviour.

**Drug Treatment**

* 62% of the sample had physically accompanied their loved ones to their local G.P practice while only 32% that the G.P understood addiction.
* 93% had phoned a drug service for help or advice for their loved one.
* 83% physically accompanied their loved one to a drug treatment centre.

**Contents**

Pages

SAPS Research Team 1

Acknowledgments 2

Authors 3

Foreword 4

Executive Summary 5 – 6

Introduction 8 – 9

Housing 10 – 14

Stigma and Isolation 15 -19

Employment 20 -23

Physical Health 24 – 29

Mental Health 30 – 34

The Family Unit 35 – 38

Crime, Courts and Prisons 39 – 45

Drug and Alcohol Treatment 46 – 49

Bibliography 50 - 51

**Introduction**

This research has been conducted by carers of substance mis-users whose lives have been deeply affected by their loved ones drug and or alcohol problems.

It is hard to estimate how many people in the United Kingdom are affected by substance misuse, some UK estimates suggest that as many as 17% of the population are family members of drug and alcohol mis-users affected by their loved ones addiction. This estimate includes the 8% – 12% of children affected by parental misuse. (Vellerman and Templeton, 2005 a, b).

Within Sunderland the estimated population of problematic drug users is 1179 (Glasgow University 2009), ADFAM (2005) estimate for every one drug user three family members are affected; bringing the total of family members affected by their loved ones heroin or crack cocaine addiction to a staggering 3573 in the Sunderland area alone. However, if we include family members affected by problematic alcohol misuse and the problematic use of other substances including cannabis that number using Vellerman’s estimates this number rises to an incredible 47,736[[1]](#footnote-1) .

The impact of substance misuse on family members is devastating. Many family members feel anger, shame, embarrassment, hurt, despair and confusion it is rare they seek support (Copello, et al, 2005. Velleman, 2007). Within the focus groups we found that family members waited on average 3.1 years to access provision. Key themes were identified and we found that respondents often found it difficult to find help or there was a great reluctance to reveal the extent or true nature of the addiction to ‘outsiders’.

Based on caseload reviews and respondents answers we have found that 98% of cases included at least one co-existing problem such as mental health problems, isolation, deprivation, unemployment and psychological or physical abuse.

Families accessing SAPS felt they did not know how to cope, or were unsure as to how to respond to their loved ones addiction. The families found that the impact of coping with a family members drug problem has had severe negative effects on their lives, which is documented in the case studies throughout this report, in addition this well documented by national researchers such as Sims (2002).

We have found through interviews and case studies that the severe negative effects have had significant consequences on both physical and mental health commonly developing symptoms such as anxiety and panic attacks and increased blood pressure; this is documented in national research (Vellerman and Templeton, 2003; 108). These issues will be further outlined in case studies in the physical and mental health section.

Not only does substance misuse have negative consequence on the nuclear family it is well evidenced that the impact on local communities can be devastating (Copello et al, 2005, NTA, 2008). Our findings are reflective of this particularly with regards to anti-social behaviour.

The Peer Led Research Team have found this to be an exciting and challenging piece of work, it has been heart breaking and fulfilling and we hope that others can learn from our findings and gain insight into the forgotten lives of those caring for someone with substance misuse problems.

**Housing**

The main aims of the housing section of Behind Closed Doors are to:

1. To establish the scale of housing problems for carers and the effect it has on their lives
2. To highlight the barriers to suitable housing provision including those accessing private accommodation.
3. To consider how SAPS could further assist carers at risk of losing their tenancies

**Overview**

Very little research has been conducted the extent and effects of housing problems with direct regard to the lives of substance misuse carers; primary research is surrounding the housing needs of problematic substance mis-users themselves and tends to neglect the impact on the family unit and their housing needs.

The University of York found that 66% of ex-offenders who are released from custody without suitable accommodation are likely to re-offend in the first year compared to only 26% of those with suitable accommodation (1996). Whilst Hagan and McCarthy found that homeless young people are more likely to be involved in offending than young people living at home (1991 and 1992)

Case Study Elizabeth

Elizabeth lives with her grandson John who has problems with substance misuse. John was recently arrested and told Elizabeth that this was for carrying a knife whilst walking the dog. As John had been in trouble with the police and is resident with Elizabeth in a social property, Elizabeth was informed by housing that her tenancy was at risk.

‘*The first thing I knew about it was when the housing knocked on my door, I nearly died, I’m at my wits end I just don’t know what to do anymore’.*

Deeply anxious she contacted the probation service where John attends, probation tried on numerous occasions to get in touch with the housing officer and to date has not had their calls returned.

To add to the frustration, the police, probation and John’s solicitor would not discuss the reason for arrest with Elizabeth. On meeting with the Housing Officer she informed Elizabeth that John had been arrested for Robbery whilst being armed with a knife. Elizabeth is still shocked and uncertain and does not know what is going to happen to her tenancy.

*‘The housing wouldn’t say that I had to make Ian homeless but they certainly said that if he lived with me that they would be going to court to seek possession of the house I have live in for 32 years. I have looked after Ian since he was 6 because his mam is an alcoholic and left him with me, she turns up every now and again and messes his head up. He’s 17 now, got in with the wrong crowd and started to use drugs. It’s not that he’s a bad kid at all, he’s just had it a bit hard’.*

*‘Ian got sent to a young offenders institute and was there for 5 months, when he got out I hoped he would change but it just got worse. At least he was at home at night and I knew where he was and was getting some warm food inside him and a good night’s sleep. The last time he went to prison was when I had all of the carry on with housing; he had to move into a hostel in Gateshead, miles away from me. I know and truly believe in my heart that this is not the answer. I know that he is a problem for them but instead of dealing with it it’s just made to disappear. He would be much better off at home with his family instead of being stuck in that place with no support’.*

The focus group members felt that there was a general mistrust between housing services and carers of drug and alcohol users. There was a very strong feeling that tenancies were too easily threatened despite that fact that this could just be because family members in trouble with the police are only visiting the property.

Focus group members were worried at the ‘not knowing’ and compared it to being like a child being quiet at bedtime hoping their parents will forget that they are there! Not wanting to make an appointment but not knowing what proceedings were going on in the background.

Members were frustrated that information would not be shared with them about the person they cared for yet it was them who were risking eviction, this leads to the carer going through additional stresses.

The questions which will be used in Behind Closed Doors are derived from experiences from the focus group and by using these questions we hope to capture some current real life events of carers throughout the city.

**Findings**

40% of respondents were resident in social housing, 21% private landlords and 39% were home owners. Of those resident in social and privately rented properties 89% (n54) said that they had had a problem relating to their housing provider and dealing with their loved ones addictions.

We asked respondents what the problems were;

*‘My grandson is a heroin addict and got in trouble with the police, he put my address down so he could get bail from the police station, the next thing I know housing are at my door with a notice of seeking possession and I had to go to court to fight it. I was so frightened of becoming homeless I had never experienced anything like this before’*

*‘I got myself a one bed roomed flat and didn’t tell my son where I lived because I was scared of what he would do and he was always in trouble with the police, in the end he found out by following me home he moved himself in and said he wouldn’t go I didn’t phone the police because he would have been sent to prison and he said it’s not a nice place to be, his girlfriend turned up with her friend and they moved in because they were homeless, they took over my flat and kicked me out my bed. I had to sleep on the floor’*

*It’s just a constant worry it’s always at the back of my mind that I could end up with no where to live, I can see it from housings view that they want a quiet life but they need to see it from my view... so do I! The worry and stress of the whole thing is making me ill’.*

Furthermore, respondents said that they had numerous issues with housing as detailed below;

*‘I got the shock of my life when Group 4 knocked on my door with an electronic box to make sure my daughter was in the house. I didn’t agree knowing that once again I would have housing on my back. I told them they couldn’t wire it to my house but the court said that they had been ordered to put it in. What am I supposed to do?’*

*‘I had to put on my son on the street or I was going to lose my house, he had nowhere to go, he’s addicted to drugs and needs help not to make his problems a thousand times worse’*

*‘(Housing providers name) moved me to a much worse area it’s horrible because of my daughters ASBO. Out of the frying pan into the fire, my daughters behaviour has became much worse as I live in a street with the worst of the worst toe rags’*

*‘He takes what money he wants for his drugs and drink, then with what’s left I pay the rent and the bills, sometimes there’s enough sometimes there is not. I don’t sleep worrying about it’*

With regards to those resident in privately rented properties people were equally affected by the issues listed in the section above as well as having additional stresses such as more rent to pay on a low income and some ‘unprofessional’ landlords who have issued threats of violence and immediate eviction.

*‘The landlord came round with his heavies, basically he said he was would beat my ‘smack head’ son up if he ever saw him come anywhere near the house. I would rather have a notice of seeking possession from the council at least then it can be sorted out through the courts and stuff. I’ve got nowhere to turn with my landlord, he’s a bully, nothing more and nothing less’.*

Homeowners came out best in terms of feeling safe in their agreements with mortgage providers but worse in terms of isolation and stigma. Some homeowners said that they had been behind with some payments due to their house being burgled by their loved one, money being stolen and the money being used to purchase illicit drugs or alcohol.

*I bought my house from (housing providers name) because I knew what was going to happen, my son was getting worse and worse and ending up at home more and more often. I took a mortgage I really couldn’t afford and there have been loads of times where the mortgage money has paid for a private detox, drugs, drug debts and all kinds of other bits of trouble he has gotten himself into. What is it they say... out of the frying pan into the fire’.*

In conclusion, the respondents and focus groups felt that the way forward in supporting carers with housing issues is to; with housing providers is to;

1. SAPS and other carer agencies have a single point of contact within social housing providers. The single point of contact could champion and raise issues surrounding carers and the barriers they face.
2. The focus group thought that a meeting with the anti social team from the council to explain their procedures would help and offer housing a unique opportunity to see things from a carers point of view.
3. For SAPS and similar carer services to work more closely with housing providers to share information to ensure the carer can get sound advice and knows where they stand legally.
4. For SAPS and other carer agencies to offer training to housing providers to highlight the issues detailed in this report.

**Stigma and Isolation**

The aims of the stigma and isolation section of Behind Closed Doors are to:

1. To establish the scale of stigma and isolation in the lives of carers
2. To highlight the effects of stigma and isolation
3. To consider how SAPS could assist carers who are socially excluded

**Overview**

Goffman (1963) used the term stigma to ‘refer to an attribute that is deeply discrediting’ (p3) or something that is deemed by different and detrimental by society (Schur, 1971).

Literature around stigma and isolation amongst carers of drug users barely exists, however the findings of our research suggest that it would be naive to assume that the families of substance users are untouched by stigma. Concern and worry for a family member with substance misuse problem is likely to create struggles within the family and between the family and the outside world [O’Farrell and Cowles, 1989; Birenbaum, 1970].

Stigma for a carer can be difficult to accept as they are not engaging in drug and alcohol misuse which initiated the stigma, and as such, the family member is part of the ‘normal’ social world of the non-stigmatised yet on the other hand, the family member shares the stigma of his/her loved one. Birenbaum noted, families of stigmatized people are seen as ‘normal’ yet ‘different’ (1970, p 196).

Stigma can severely limit the individual’s ability to fully participate in the everyday life of society, such as holding a job, having a home, getting access to statutory and health services and enjoying mutually supportive relationships with family and friends. We have found that this has profound implications on the carers life significantly decreases social enjoyment, wellbeing and social capital.

**Case Study Alison**

Many parents and carers feel isolated, one particular carer Allison who cares for her partner of 21years who is a chronic alcoholic said she felt she had lost herself through her partners addiction. She had lost friends and family over the years but more importantly she felt she had lost herself and had forgotten who she was.

*‘I feel I have wasted 21 years trying to save my partner, I really don’t know who I am any more. I was always a bubbly lively lass with loads of mates, over the years those mates have vanished. I have become isolated in every sense of the word, my son has moved away and is*

*doing really well in university which has made me feel more isolated as he was the only person who made me feel I was important at home’. ‘I am so proud of my son, he is the only good thing in my life, I just wish when he came home in the holidays his Dad would try to stay sober, even if it was for just one day’.*

She then went on to explain that any type of social gathering is a thing of the past:

*‘I would love to have a garden party, a barbecue in the garden with some close friends and family, this just isn’t possible because you can guarantee Micky will spoil it. He would get so drunk and become aggressive with company or he would embarrass me further by getting so drunk he can’t stand up and walk to the toilet and just p\*ss or sh\*t himself, or sometimes both. I am the one left standing with the red face making excuses for him and I am the one always left to pick up the pieces and clean up his mess. I just want my life back’.*

**Case Study Tina**

Tina who was caring for her son Mark was interviewed and asked how addiction had affected her life:

“*When Mark was in the thick of his addiction I would lock myself away in my bedroom with my younger son Luke. We would spend days in my bedroom, I just felt like I couldn’t face the world and wanted to hide away forever or until the problems went away. I hardly ever went out as I didn’t want to face anyone, I would wait for the rain to come then maybe pop to the shop feeling I would be ok as I had my umbrella to hide behind’.*

*‘My home became my prison. To try and stop my son going out to score, I had every window in my home screwed down and I would sleep with Marks shoes under my pillow. Sometimes I wouldn’t go across the doors at all for weeks at a time, relying on the bairn to pop to the shops for the bare necessities such as milk and bread’.*

*‘I really can’t explain how isolated I became, I don’t know how to put it into words. They were the darkest days of my life, the sun could be cracking the pavements and I would still lock myself away in my bedroom’.*

Within the general discussion of the focus groups all of the carers agreed that they had suffered from the effects of stigma and had either been isolated by their families, friends or even by themselves choosing not to partake in day to day activities with the fear of being judged. Some carers shared about how they had hidden in the garage so her family thought she wasn’t there but she could keep an eye on the family home whilst another shared how she had hidden in her wardrobe so the person she cared for wouldn’t know she was there.

**Findings**

We asked respondents about stigma and isolation and how it affected them in their daily lives. Perhaps no surprise to the respondents is that all of them at some have felt they were socially isolated and been a victim of stigma in various shapes and forms.

From this chart we can see that 94% of respondents felt more isolated than before the addiction had occurred;

*‘I isolate myself by staying in the house all of the time. I daren’t go out the fear of what will happen. I don’t know if my house will be there by the time I get back’*

Whilst 34% felt they were blamed for their loved ones addiction. Of the respondents who had previously had dealings with the police 96% (n74) felt that they had been judged as two of the respondents stated;

*‘The police would bring my husband home and speak to me like it was my fault he was in that state, they spoke down to me, like an idiot actually, I overheard one of them saying once that he would drink too if he had a nagging wife like me. Talk about kicking someone when they’re down!’*

*‘I felt judged by the police when they came to search my house for stolen goods that my daughter pinched. My son was terrified he’s only 11 and they were searching his bedroom and asking where he got his computer games from. The whole family has been judged by this and now no one in the street will even speak to us’.*

85% said that they had been distanced from their families whilst 90% said that they had been distanced from their friends;

*‘I couldn’t be honest with anyone I felt ashamed and like I was the only person in the world who had experienced this type of thing. I didn’t want to lie to them so it was easier just to avoid everyone all together’*

*‘The whole thing cause a massive family fall out, the family is divided right down the middle and I’m the one stuck between the two. It’s a horrible horrible place to be’*

*‘I lock myself away from my family I am so ashamed of his addiction, I felt like it was my fault. I isolated myself I felt judged and that everyone was talking about me’*

We also found that 98% felt they were ‘not part of things’ whilst 93% felt that they were judged by their neighbours and 81% felt too afraid to leave home;

*‘My partner says if I go out he will use because he gets lonely and bored, I know it’s blackmail and I know that he will use anyway but it works I have not got any friends left’*

*‘I started college but I now I have to study at home, well if I can, I’m scared to go out anywhere because my mam has overdosed six times in the last eighteen months. I am scared I will find her dead.’*

**Recommendations**

The focus group would like to make the following recommendations based on their collective experiences and the research findings;

1. SAPS and similar agencies to work with the press to raise awareness amongst the general public about caring for someone who misuses substances.
2. SAPS and similar agencies to work with both statutory and third sector to raise awareness of the issues highlighted and to promote best practise whilst working with family members and loved ones.
3. For SAPS and similar agencies to continue to provide social and learning opportunities.
4. For SAPS and similar agencies to continue to provide out of hours off site appointments for support as and when required.

**Employment**

The main aims of the employment section of Behind Closed Doors are to:

1. To establish the scale of issues carers face whilst in applying for employment
2. To understand the difficulties carers face in maintaining employment
3. To consider how SAPS could further assist carers in being work ready and those who are in employment.

**Overview**

Unfortunately we have not been able to locate any published research into employment and caring for substance mis-users. However, what we do know is that carers of substance misusers are not afforded the same rights as those caring for someone with a disability; For instance those in employment are not entitled to apply for flexible working hours, in addition to this they are not afforded the same benefits for example only a very small minority may be eligible for carers allowance.

Within this section we will separate into two sections one for the 34% of those in employment and the 66% of those who are not.

**In Employment**

During this research we found that the 34% of carers who are in employment felt additional stresses in trying to keep their jobs and remain focused. Just over half of the carers in this section said they felt constantly on edge not knowing what was going to happen next or what their loved one was up to. Margaret explains;

*‘I’ve still got my job but only just, my daughter turns up at work and demands food and money, my boss said if she comes again he will have to sack me, it’s so humiliating, I hate going to work and am excluded from everything, all the girls have a natter and stuff and leave me out, they think it’s my fault’*

Whilst other carers in employment felt that work was a physical refuge in that they felt safe and the only ‘time off’ life they have as Bill explains;

*‘I look forward to going to work, all the other lads on the site moan and say they want to be at home or on holiday, you can tell that they are not looking after their alcoholic wife, I’m so grateful for my job, it’s the only respite I get, I dread bank holidays.’*

**Case Study Ellen**

Ellen is a carer to her two sons Mark and Jordan, she works full time and is solely responsible for the mortgage on her family home. Here she shares her experiences of how difficult she felt it was to hold down a job whilst caring for her two sons who both have problematic substance issues:

*‘I go to work as I have a mortgage and bills to pay, it’s really hard. There have been times when I have had the police ring me at work telling me I need to go home as they have a warrant to search my home, not only is this highly stressful and worrying it’s highly embarrassing, I mean come on it’s not like I can tell my work colleagues ‘right girls I’m off home now, my son has been burgling houses and guess what the police have turned up to search my home’*

*‘Sometimes I go to work and I am so distracted because I’m so worried about leaving the lads at home. I’ve made so many mistakes with money I’m surprised I’ve still got a job, which is another worry because if I didn’t work God knows what would happen. I really wish I could afford not to work. One of my sons couldn’t function one day when he had drugs and fell asleep with a cigarette which caused a fire in my house. I worry one day I will find them dead, I worry I am not going to have a home to go home to. It’s like living in some awful nightmare’*

Ellen was asked what she thought might help to resolve her problems, her reply was:

*‘Nothing, the only thing that would help is if I won the lottery or a small fortune, just enough to pay off my mortgage then I wouldn’t need to work, so I could stay at home hide from the world and guard my house’*

**Unemployment**

With regards to those who are not in employment 81% (n54) said they felt they could not work due to the stresses of caring for someone with a substance misuse issue. The remaining 19% (n12) did not work due to medical reasons or retirement.

‘*I had to leave work, I had no choice. I couldn’t trust my partner to turn up and pick my son up from school. Half the time he would be out stealing and buying drugs and the other half of the time he would be incapable of walking he was so off his head on drugs. Work wouldn’t let me change my hours so I had to quit’.* Lisa

**Case Study Sandra**

Sandra cares for her daughter who is a heroin addict and is often involved in criminal activity, Sandra doesn’t work and feels she could not manage a job because of all the problems with her daughter she becomes very depressed:

*‘I get hounded off the dole every fortnight, I’ve tried to explain to them how difficult things are at home and there’s no way I could work, sometimes I can’t even get out of bed on a morning never mind go to work, I am usually up all hours of the night wondering where she is, what she’s doing if she’s dead or alive’.*

*‘I broke down in tears one day in the jobcentre because of the pressure; I just can’t take anymore, the pressure to find a job was the straw that broke the camel’s back. People just don’t understand it’s a living I just couldn’t handle the pressure and some of the staff are really horrible, I’d like to see them step into my shoes for a day and see if they find it easy. Trying to explain to people how hard it is impossible, every time I go out I worry I will go home to find her dead’.*

**Case Study Sonia**

Sonia who cares for her daughter Stacy told us how she had to give up a good job with prospects of promotion and her pension. In reality she had given up her security for the future:

*‘I watched my own mum struggle in dead end jobs to keep us all in clothes and shoes as a kid, I was determined as I grew older this would never happen to me. I left school and went on to college then onto university and gained a degree in nursing. This was the beginning of a bright future, I went on to get married and have 2 children and my life was just perfect as I had planned. My career didn’t really start until I was 25 and both the kids were in full time education, this was now perfect a lovely husband good jobs, two lovely kids and a nice home. My daughter reached the age of sixteen and began to experiment with drugs, this is when my perfect life became a living nightmare’.*

*‘Before Stacy became involved with drugs my life couldn’t have been happier, unfortunately because of the strain of everything that was happening, arguments began and my husband and I ended up divorcing. I felt abandoned, hurt and lonely but my job kept me going, as stressful as it sometimes was it was my sanctuary and placer of peace. However things became a lot worse and Stacy was completely out of control, I had police at my door on a regular basis’.*

*‘Just when things got bad and you thought they couldn’t have gotten any worse, they got worse, something else that you couldn’t have imagined would happen. My work began to suffer, I was no longer a confident nurse, I was handing out drugs and at times was so tiered and stressed I had to lie and get someone else to give the patients drugs, I began to make mistakes and knew things were coming to an end’.*

*‘One night Stacy turned up on the ward I worked on, screaming and demanding money saying that she was in withdrawal saying it was my fault that she was on drugs. All of the patients, colleagues and friends heard it, it was horrendous and my world literally fell apart. I left work that night, went on the sick with stress and eventually left on medical grounds. I did get a small pay out but money never went far as I bailed Stacy out of so many sticky situations to pay off fines, drug dealers and three attempts of treatment in private clinics’*

*‘Heroin has completely ruined my daughter’s life, as well as her brothers and her dad’s. I hold out hope that one day she will get off drugs, but even if she does it will be too late for me, I feel like I have lost everything and I just can’t see where my little girl went, I think drugs have done so much damage I don’t know if she will ever come back’.*

In conclusion, the respondents and focus groups felt that the way forward with regards to employment service and employers was to;

1. SAPS and other carer agencies to offer co-ordinated awareness training with staff at the job centre detailing the pressures of caring for someone with a substance misuse issue.
2. SAPS to continue to provide education and work experience opportunities to prepare the carer for work as stability is restored within the family – to liaise with the job centre and other training providers as and when required.
3. For SAPS and similar agencies to raise awareness of problematic substance misuse and the effects on family members amongst local employers.
4. To raise awareness and campaign for rights equivalent to those who care for the elderly or those with disabilities.

**Physical Health**

The main aims of the physical health section are to;

1. To explore the effects of caring for someone with drug and alcohol problems on the carers physical health.
2. To ascertain what if anything SAPS can do to support carers in ensuring their health needs are met.

**Overview**

There is little specific research surrounding the issue of a carer of a substance mis-users physical health, most research relates directly to those caring for the elderly and back strains for carers. We have searched literature relating directly to the effects of stress on physical health as all of our respondents had suffered from stress at some point in their caring career. We also looked at literature surrounding domestic violence and physical health.

It has been reported that long term stress can have massive repercussions on a person’s health and well being. There are many illnesses which have been linked to stress such as high blood pressure, insomnia, migraines and strokes are just a few of many. Prolonged stress can also weaken the immune system leaving a person vulnerable to many coughs, colds and flu, chronic prolonged high levels of stress can also lead to serious illnesses like heart disease or cancer. Weight gain and weight loss are also symptoms of stress along with many others [[2]](#footnote-2).

In relation to domestic violence Stark and Flitcraft found that it is common in an environment surrounded by drugs or alcohol and can cause chronic health problems (et al 1996). 75% of reported domestic violence leads to physical injury or negative consequences on mental health (Home Office 2001) whilst the cost of treating physical health of victims of domestic violence alone is reported to be around £1,220,247 per year, with mental health treatment costing around £176,000,000 (Walby 2004). One incident of domestic violence per minute is reported to police (Stanko 2000) and it accounts for between 16% and 25% of all recorded violent crime. (Home Office 2004).

**Findings**

We asked carers a range of questions about their physical health and how they would rate different aspects of it. There have been several significant findings.

Quite shockingly 24% of the respondents had been threatened by the person that they care for and 19% had actually been physically harmed as Lilly explains;

*‘One night it got really bad, my son needed money for drugs, he was screaming and shouting the sweat was pouring out of him and I knew that he was seriously ill. I wanted to phone for an ambulance but he would let me and said he just needed £10 and everything would be ok, I didn’t have the money to give him he had already taken everything I had, he started to smash the house up so I phoned for the police, he pushed me up against the wall and had his hands on my throat. I have never been so scared in my life’.*

This experience is not uncommon as Judith tells a researcher;

*‘My husband has never actually spoken words to threaten me, that’s the worst bit about it, I know when he is going to beat me up because he goes quiet and sullen, he goes into himself. Sometimes I wish he would just hit me and get it over and done with because waiting for something to happen is much worse than it actually happening’.*

17% of respondents said that they had been a victim of domestic violence, although having spoken to the focus group they feel that this number is not reflective of the true situation in that carers are often victim of violence but do not consider it to be domestic violence, for instance Lorna said;

*‘Well my son sometimes comes in off his head and hits me and threatens his dad, but that’s not domestic violence is it?’*

Others shared their experiences of domestic violence;

*‘I knew Dave before he started drinking, well before it got out of control, honestly you couldn’t have wished to meet a nicer man, everyone liked him, he had loads of mates and a good social life. We would take the kids out for walks at the weekend and to the pictures or the park, not now, the kids would rather die than be seen out with him, they would be to embarrassed in case we bumped into any of their friends.*

*‘I think it got out of hand when he got made redundant, he started to drink more and more so I started getting onto him to stop drinking. One night things got out of hand and he hit me, he said he was sorry afterwards and was really depressed, that’s the way things are now, it’s a cycle, he drinks, I nag, he loses his temper and hits me, I threaten to leave, he says he’s sorry’.*

We have found that self esteem is severely affected by looking after someone with a substance misuse problem and have found that often the carer neglects their own needs put their loved one first. 72% of respondents said that they had neglected their appearance and 81% said that they don’t take care of themselves the way they would usually have done as Jennifer explains;

*‘Sometimes I stay in my P.J’s for days on end. I don’t bother getting ready and to be honest there’s no point. I used to wear makeup and like to wear nice clothes, my hair was always styled and everything matching and nice. Now I can’t be bothered, it feels like a big chore just to put some clothes on. All of my energy is spent worrying, arguing and fighting for help by the time I have done all of that I can’t be bothered anymore. It feels like I have lost hope’.*

Carers eating habits also changed in times of stress while 51% said that they felt like they couldn’t eat at the peak of their loved ones addiction 42% said that they ate more;

*‘I can’t stand the thought of food when I know she is out there on the streets getting up to God knows what, it’s a relief when I found out she has gone to prison’.*

*‘I go through phases sometimes I gorge on food to make myself ill, sometimes if I feel really ill it takes my mind off what Michael might be doing, if he’s dead or alive. Other times I can’t eat for days and days on end and the thought of food makes me feel sick. At those times I literally live off sugary coffee and cigarettes’*

*Sometimes it feels like it’s the only thing that I have control over, I can’t control my mam and her drugs and drinking and feel like my life is completely taken over, it’s then that food seems to be a problem for me, I can’t describe it but it’s all about control’.*

*‘I couldn’t eat or sleep my weight plummeted to 7stone, I’m 5ft 6 so my appearance was shocking, people thought I was actually on drugs sometimes I wish I was maybe then I could walk around high as a kite and not have a care in the world like my partner’.*

Worryingly 49% of respondents said that at some point in their time caring for someone with a substance misuse problem they had consumed more alcohol than usual to cope as Denise explains;

*‘I wouldn’t say it would have been a problem for the normal average person but being someone who rarely drinks I think it was bordering on it being a problem for me. The problem was is that I couldn’t sleep, I couldn’t relax or unwind and I couldn’t remember the last time I had laughed. My family had split down the middle and in a way I felt I should have held things together a bit better. It started just on a Saturday night I would have a glass of wine, it helped me to relax, I would look forward to the weekend, and then it started being Friday and Saturday then a long weekend and then every night I would have a glass of wine just to get to sleep. I knew what I was doing and I knew it was a problem.*

*‘I looked into it and the government said I could have 3 units per day and I was having my 3 units. In reality I knew I was lying to myself and I was going to end up needing a detox myself. I slowly cut down and came off it, but it made me realise how easy it would be to end up with a problem’.*

Nancy also told us;

*‘The first time my son went to prison I was a complete emotional wreck it got to the point where I couldn’t be by myself in the house anymore so I started going out to the bars day and night, I spent every penny I had it was the only time I wasn’t thinking about everything that happened. I did that for about 3 months before I stopped it. I did have to go through some withdrawals and it was really scary. I would tell any carer not to do what I did, it seemed better at the time but it made things 20 times worse and was hell’.*

Furthermore 37% of carers said that they had used over the counter pain killers to help them cope;

*‘It’s hard to describe to someone the pain you feel when you realised that your daughter loves drugs more than she loves you, when she would rather walk away with scum bag drug dealers than stay with her family who love her so much. The pain is deep, it cuts straight through your heart, it’s like a knife, a physical pain. I cannot describe it. I went to the chemist and bought some pain killers, codeine they were, and they helped, I would take handfuls at a time and they gave me a floating feeling like I could cope and it didn’t hurt as much’*.

In addition 67% of carers said that at times of stress when their loved ones addiction had peaked they had taken some form of sleeping tablet to enable them to get some rest.

*‘It came to the point where I was like a zombie, walking round in a trance like I wasn’t part of the human race, I was becoming delusional I hadn’t slept properly for that long. I went to the doctors and got some sleeping tablets, they didn’t work so he gave me some stronger ones. Thank God, sleep is my only respite’.*

*‘I used to look forward to 9.30pm that’s when I would take my sleeping tablets and go to bed. I used to pray that I wouldn’t wake up’.*

In conclusion we asked carers if there was anything else they would like to add about how they felt that their physical health had been affected;

*‘My blood pressure went through the roof at one point, I ended up in hospital for four days to bring it down. Doctors said I could have suffered a heart attack or stroke. I didn’t realise till then how dangerous high blood pressure can be, it took over one year to get it back to an acceptable level’.*

*‘My husband has suffered four angina attacks through the stress of his sister’s addiction’*

*‘I really worry about my mum, she had a heart bypass operation 6 months ago, I worry every day that my nephew will be the death of her. I help all I can and if I didn’t have two young babies to care for I’d take him off her hands but can’t afford to put my babies at risk’.*

**Recommendations**

The steering group would like to make the following recommendations;

1. SAPS and other similar agencies to work with G.P’s to highlight the stresses associated with caring for someone with an addiction.
2. SAPS and other similar agencies to provide confidential onsite health checks by a visiting medical professional.
3. SAPS and other similar agencies to provide valid and useful information to carers on different areas of health which can be affected by the stress of caring for a loved one.
4. SAPS and other similar agencies to inform and educate carers about domestic violence and how they can be protected by the law, statutory and third sector services.

**Mental Health**

The aims of the mental health section are;

1. Explore the effects of caring for someone on mental health.
2. Determine the extent of short and long term effects on the mental health
3. Understand how SAPS can assist carers in improving / maintaining good mental health.

**Overview**

There is little research into the mental health of those caring for people with substance misuse issues, however, in a more general sense there are many opinions of what can be the cause of mental distress, it is recognised in society today that any stressful, traumatic events or on-going struggles can sometimes be the trigger of mental disorders such as anxiety and depression. (Mind.org.uk) Severe anxiety and depression can also often lead to panic attacks which can also be triggered by environmental factors such as trauma and chronic high levels of stress; we have found this to be common in our research due to the stress of the caring role.

**Case study Janette**

Janette cares for her son Gareth who has a long history of heroin addiction, as a result of his addiction Janette became very depressed and was prescribed anti-depressants by her doctor. Janette has now been taking these tablets for more than ten years, although Gareth’s addiction is now under control, he has been stabilised and in treatment for over two years she still feels she needs to take her medication and would find it difficult to cope without it. She told us;

*‘I feel like my sons addiction led to another addiction my own I don’t feel ready to come off my medication, the thought of it actually scares me’*

Janette went onto explain about how low she got while her son was in the thick of his addiction;

*“At the lowest point of my whole life, feeling I couldn’t cope any more, I took an overdose of tablets. I didn’t think of the consequences, all I knew at that time was it would be easier if I never woke up again. There would be no more pain or suffering and I wouldn’t need to face up to the heartache of addiction.”*

**Case Study Terri**

Terri cares for her 18year old son James who was diagnosed with ADHD when he was 12 years old. He is dependent on alcohol and smokes cannabis daily. He is often in trouble with the police and has served 6 or 7 short custodial sentences since the age of 16 because of his persistent offending.

We asked Terri how these issues had affected her mental health;

*‘Honest to God I wouldn’t wish this life onto my worst enemy, there’s nobody understands how bad it can get unless they have been through it. I spent two years in bed and this is no exaggeration, I eventually went to the doctors and he gave me anti-depressants. I have been taking them for four years now, they have helped me a bit but I still have panic attacks’.*

*‘I am most frightened when my son kicks off or when the police come to search my house, I still go through stages where I can’t leave the house for days on end because my nerves are on edge and I’m frightened I might have a panic attack outside, which is much worse than having one at home.”*

**Findings**

Depression is something which was very prevalent amongst our respondents 74% said that they had suffered from depression and 62% said they had taken prescribed anti-depressants to treat this depression.

‘*Going to the doctors to ask for anti-depressants was one of the worst days of my life. I used to be so happy, I know that they help me and that’s why I take them, it’s the only thing that helps me cope’*.

*‘It’s hard for a man to admit that he can’t cope when I am supposed to be the head of the family and know what to do. I sometimes feel that it’s out of my hands, a dad is supposed to make everything right, I don’t know where my little girl went. I wouldn’t even admit to the majority of my family that I take anti depressants’*. Derek

Just over half of the respondents felt that at some point in their caring career felt like they were having a breakdown and 17% of the respondents believe they have had a complete mental breakdown;

‘*A breakdown is the only way I can describe it, I couldn’t cope, I used to sit and cry day and night, I couldn’t eat, I couldn’t concentrate, I couldn’t even watch the TV, I didn’t want to be in the house at the same time I didn’t want to go out, I couldn’t face my friends or family and completely shut myself off from the world. It really was my darkest hour’.*

*‘I was very nearly sectioned, I was at the end of years of sleeplessness nights, worry, anxiety I even started to have panic attacks. When I look back now I can see how crazy my thinking was I felt so guilty about everything. I talk to my psychiatrist now and I really do believe I made myself like that because I wanted to punish myself because of the guilt’*.

59% of respondents said that at some point they had suffered from panic attacks;

*‘I came out of court one day where my son had just been sent to jail, all of a sudden I felt that my chest was tight and that I couldn’t breathe, I didn’t know what was happening to me and I really believed I was going to die. The security guard phoned for an ambulance and I was taken to hospital, I told the doctor I thought I had had a heart attack. He said I had hyperventilated. I felt like a complete fool’.*

Very worryingly 12% of the sample said that they had actually attempted suicide as described in the first case study and as Michelle explains;

*‘Looking back I think thank God it didn’t work; I’m not usually a dramatic person, I used to live a very quiet life, I had a little job on the tills and managed to bring my two kids up by myself. My son James got in with the wrong crowd and started taking drugs, he changed overnight from a lovely young lad who was sport crazy to a horrible man who cared about nothing but himself. He would be rude, abusive, absolutely torture his brother stealing his computer games to sell, he had to put a lock on his bedroom door’.*

*‘Gareth left home and started university and when he went things with James got 100 times worse, he used to go mad at me for money and said over and over and over that I favoured his brother over him. It got to the point where I was scared of him, he took everything out of the house, I didn’t even have a television to watch. One night was really bad he was punching*

*holes in the walls shouting and swearing and the neighbour rang the police, the police came and arrested him.’*

*‘That night I thought I can’t do it anymore, that’s it I’ve had enough. I went down to the shops and bought myself a litre bottle of vodka and drank as much as I could with a load of paracetamol. Luckily the police came to drop James off later on and found me. I got sectioned and it took a long time for me to see that it was what I needed at that time. It gave Gareth a big wakeup call and he’s now in treatment and I am slowly but surely getting my life back together’.*

We asked carers if they were receiving any help for their mental health, apart from anti-depressants only 8% were getting any additional help;

*‘I pick my anti-depressants up but I have to go and see the doctors every 3 months. Last time I was there I had to fill a survey in so they could see how depressed I was, it doesn’t really do much good but last time I was there they did say they would refer me for counselling but there’s a long waiting list’*.

*‘I see a psychiatric nurse; she’s actually really good and is always at the end of the phone when I need to talk. Sometimes I feel like she is the only person I can talk to, someone who isn’t involved and separate from my normal life’*.

We also asked respondents ‘what help do you think could make a difference for your mental health’ 94% said that for their loved one to start or to continue receiving help would make a difference to their mental health in that if they didn’t have the pressures of caring and worrying that in itself would be a massive improvement.

**Recommendations**

The steering group would like to make the following recommendations;

1. SAPS and similar agencies to continue to work alongside G.P’s and mental health services to ensure the needs of individual carers are met.
2. SAPS and similar agencies to raise awareness through this report about the effects that the caring role has on an individual’s mental health.
3. SAPS and other similar agencies to continue to advocate on behalf of carers to enable them to have a full mental health check as and when required.

**The Family Unit**

The aims of ‘The Family Unit’ section of Behind Closed Doors are to:

1. To explore the effects of substance misuse on the family unit
2. To consider how SAPS could further assist carers in increasing resilience and strengthening the family unit.

**Overview**

The effects of problematic substance misuse on the family unit are devastating, described by one of our research participants as ‘*a tornado which has ripped our world apart*’. It is well documented that substance misuse does not simply affect the person misusing substances but also affects families, communities and society in general. Furthermore NIDA found that problematic substance misuse attributes to unresolved family conflict between parents, partners, siblings, grandparents and extended family members and chaotic living environments (NIDA, 2002).

National research has found that the effects of individual family members are vast and wide ranging and include a deterioration in family relationships, an increased likelihood of domestic violence, concealment of addiction and withdrawal from both the family and society (Bancroft, et al 2002), whilst the physical and mental health of family members is significantly affected as detailed in this report but also of significant note in research by Barnard (2005) is the personal struggle of family members to come to terms with and adapt with the effects of negative change.

Issues of kinship care in Sunderland are dealt with separately with independent research by Susan Robson.

Within the focus group we explored many issues relating to the family unit and how it is affected by substance misuse. We feel it is important to note that on average 5.6 family members were affected by one person’s substance misuse as opposed to the three members used as a guideline by ADFAM[[3]](#footnote-3)

**Case Study Rita**

Rita is a grandparent caring for her grandson Billy, Rita comes from a large family and feels isolated from her other children and grandchildren whom she rarely sees as they choose not visit her home where Billy is living. She explains the extent of the damage to her once close knit family.

*‘There are 17 members of my family affected; I never see my only son and his children. He won’t come to my house where Billy is and has told me to get rid of Billy a thousand times, I wish it was that easy but if Billy didn’t have me he would be left with absolutely no one and I really worry about what might happen to him’.*

*‘My daughter won’t even visit with my granddaughter even though Billy is her own son, it hurts me to think how close we all were and now there is a massive divide right throughout the family. I love all my children and grandchildren equally and I just wish the elder family members would realise how hard it is for me trying to cope with Billy, I need support not ridicule. I feel like I am fighting a battle every day totally on my own with no help from anyone’.*

*‘If I kick my grandson out onto the streets maybe I would get my family back, but no one understands that I just can’t bring myself to do it, he is my family to whether he uses drugs or not. If I don’t believe in him no one will’.*

Sadly Rita’s story is not in isolation, many of the carers who have been responded and 49% said that they had been separated from some part of their family unit due to substance mis-use, please also note that 85% said that they felt distanced from family members as detailed in the isolation section. Exclusion within the family is quite common for a parent or carer living with substance misuse as Denise’s case study details;

**Case Study Denise**

Denise who cares for her daughter Gemma feels she has suffered exclusion from family gatherings and various social events on many occasions because of her daughter’s unpredictable behaviour. Gemma fell in with ‘the wrong crowd’ when she was very young and has been in and out of custody since the age of 15. Denise feels she has only ever been included in family gatherings at times when her daughter has been held in custody.

She explained how hurt she felt when she was un-invited to a family members home for Boxing Day:

*‘Last Christmas I was invited over to my niece’s house for Boxing Day, this was arranged weeks before Christmas, I was looking forward to spending time with my niece and her family. Gemma was in jail at the time but I received a phone call from her about 10 days before Christmas, she had been given an earlier date for release. This was to be Christmas Eve she was really excited as this was to be her first Christmas at home for three years having spent the last two in custody. I rang my niece with the news only to be told we would no longer be welcome over on Boxing Day’*

*‘I was hurt and upset by this but to be honest I can’t blame them, she has spoiled so many family parties through her aggressive and drunken behaviour. I wouldn’t of enjoyed myself anyway as I’d of been waiting for her to kick off like she usually does’.*

We also noted that lot of respondents mentioned the addiction brings shame to many families; Joanne was a carer to her son Alex for a number of years while he was heavily addicted to heroin. Joanne felt so ashamed of Alex’s addiction and felt she could not tell anyone, Joanne isolated herself from her family and friends terrified they would find out her secret.

*‘When I found out Alex was using heroin I really couldn’t believe it, didn’t want to believe it and couldn’t bare the thought of my family and friends finding out, I distanced myself from everyone as I was so ashamed of his addiction’*

*‘I couldn’t even bring myself to tell my mam although we are really close, I was just too ashamed and felt like a failure and also wanted to protect her from the pain addiction inflicts onto families. I hid it for as long as I possibly could but eventually I had to tell my mam when Alex was sent to prison’.*

*‘I am one of the lucky ones, my son is now completely free of addiction but I will never forget the pain and heartache it caused to all of my family’.*

Joanne is now a fully trained mentor, helping other parents and carers to come to terms with addiction. In retrospect Joanne can see how her own behaviour influenced other family members and shares her experiences with others to help them change their thinking around substance misuse. From the respondents in this survey 61% of family members felt that their daily behaviours and routines had changed.

Siblings are often affected by substance misuse and of the parents in the survey who had children 93% (n29) said they had treated the non-using sibling differently to the substance misusing brother or sister.

One parent, Angie explained how her son was cruelly bullied because of his sister’s lifestyle choices;

*‘Bradley never went to school because of the name calling, people would shout at him ‘your sisters a smack head’ or call him a ‘smackrat’, it made me sick to my stomach I was terrified for him. He would beg me not to send him to school and even make himself sick so he didn’t have to go or he would be sent home’.*

*‘I went to the school about it against his will, it didn’t make much difference. One teacher even said to him ’you will never make anything of your life, you’ll end up in jail just like your sister’. They don’t understand Bradley is a lovely kid struggling to come to terms with what his sister does, he doesn’t tell me but I can hear him tossing and turning in his bed worried sick about her. I wish I could make people see what a lovely kid he actually is’.*

It will come as no surprise to any carer of a substance mis-user that all of our respondents had argued with their loved one about their addiction and 83% had argued with their partner about it. A further 92% said at some point or another they had defended their loved ones and their actions to others and 42% said that there had been jealously in the family due to the amount of attention addiction demands.

In conclusion, the following recommendations were made by the focus groups;

1. SAPS and similar organisations to provide awareness sessions for whole family units and continue to make available specialist sessions for young members of the family.
2. SAPS and similar agencies to provide services dealing with substance mis-users with information, advice and guidance as well as copies of this report to help people understand about the effects of caring for someone with drug and or alcohol problems.

**Crime, Courts and Prison**

The main aims of the crime, courts and prison section is to;

1. Explore the extent of crime against carers
2. To understand how carers can become inadvertently involved with the police
3. To explore carers experiences in dealing with the police
4. To consider carer experiences of visiting courts and prisons
5. To understand how SAPS can better help carers involved with the criminal justice system

**Overview**

It is a well-documented fact that those involved with drug misuse invariably break the law due to the very nature of the substance they are obtaining and using and it is estimated that over half of acquisitive crime is committed by drug mis-users costing the UK approximate £2.5bn per year.[[4]](#footnote-4)

Over 2.6 million people in the UK drinking at least twice the recommended daily alcohol limit and alcohol related crime costs the taxpayer between £8bn - £13bn every year. There were 1,057,000 admissions to hospital for alcohol related incidents in 2009 and parental alcohol misuse has been identified as a factor in over 50% of child protection cases. [[5]](#footnote-5)

**Case Study Audrey**

*‘I was lying in bed one night when I heard someone rummaging around downstairs, I was terrified as I live alone, I phoned for the police but by the time they had arrived the burglar had gone, they had taken my handbag and some jewellery which had belonged to my late husband. It really shook me up, while the police were there they got a message on their walkie talkies asking what they had stolen as they had arrested a man with a handbag and thought it might be mine’.*

*‘I was delighted that I was going to get my things back, the police took a statement and off they went, they came back the next morning to tell me that the person they had arrested was my grandson, he admitted burglary and asked the magistrate to send him to prison because he wanted to get help for his drug problem’.*

‘*I’m glad that he is going to get some help but if I’m honest I don’t think that prison is the right environment if you want to stop committing crime and taking drugs. I hope he does get help. I want to be able to tell him one day how petrified I was that night. My home is now a house; I don’t feel comfortable there anymore’.*

**Case Study Jimmy**

‘*Me and my wife have good jobs, there is no one in my family who has ever been involved with the police, with drugs or with anything like that. We are a family of hard workers, I have taught my kids that crime doesn’t pay. My youngest son Aaron became involved with drugs at school, he started smoking cannabis and we found out as one of his friends mam’s had caught them. At the time it seemed like it was the worst thing that could ever of happened, now I realise it was the tip of the iceberg’.*

*‘Two years on and the whole families world has been turned upside down. He got drunk one night and him and his mates robbed an off licence, they beat the owner up and he got 6 months inside. He only did 2 months and came home with an electronic tag, he had promised that he was going to get a job and turn his life around. The day he got out I knew there was something terribly wrong, he wasn’t himself and he was irritable. He said he had to go out and his brother followed him he went to a drug service. I confronted him about it and he said he had started taking heroin in prison. Oh my God my son was on heroin’.*

*‘I looked on the internet and found out everything I could and decided it would be best if we supported him and tried to help. He said he didn’t want to go onto methadone and decided to cut down instead. I ended up keeping heroin for him in small tin foil packets and giving him one every morning and night, a smaller bit each time. He’s been free of drugs for 9 months now – touch wood – and things seem to be ok, he is at college and has got that sparkle back in his eye. I really hope that is it’.*

**Case Study Janice**

Janice is a carer to her son Gary; Janice explained what it was like visiting her son in prison on one particular occasion when he had been a victim of assault;

‘*Visiting your own child in a prison is the most upsetting thing in the world, well it was for me and his Dad. Every fortnight we would go and visit and it was just absolutely awful seeing him in there, I would look forward to seeing him but at the same time dread it. I found it one of the most upsetting and degrading parts of my journey through addiction’.*

*‘I will never forget the day we went and walked in to see him sitting there black and blue, I couldn’t believe my eyes. I can’t describe how I felt, I burst into tears at the sight of him his face was a mess he had been badly beaten. I couldn’t believe how this could happen in a prison, the only good thing about him going to prison was that I knew or I had thought that he was safe. After this visit I constantly worried about him every minute of every day until the day he was released I will never ever forget that day, it was one of the worst days of my life and I barely slept for weeks. The bruising and swelling took weeks to disappear but the memory will stay with me forever’.*

**Findings**

42% of respondents said that they had been a victim of crime, yet it is worthy of note that 78% said that their loved one had stolen from them whilst caring for them. We broached this subject with a focus group who told us that they thought this could be that the carer didn’t see themselves as a victim of crime but almost as a part and parcel of their caring role. One of the focus group explained;

*‘I said I wasn’t a victim of crime but I suppose I am when I think about it, I can’t begin to tell you about the thousands of pounds I have had stolen from me over the years by Derek. I didn’t think i was a victim, more like a fool for putting up with it’.*

We asked what kind of crimes the carers had been victim to; 13% said a house burglary, this is much higher than the national average of 2.2% (British Crime Survey 2010/2011. Pg 72) again, we asked the focus group why they thought that this could be to which they said they feel they are more prone to burglary as their loved ones are involved with criminal activity and suspect that they are being burgled by either their loved ones themselves or by their acquaintances.

*‘My house was burgled, I know for a fact it had something to do with James, I can’t prove it but deep down I know. I mean if someone burgled your house they would have to have a good rake about to find things, yet this ‘burglar’ knew everywhere that we had valuables without even looking!’*

Respondents were asked if they had ever been victim to anti-social behaviour and 31% said that they had been a victim and they believed was directly related to caring for their loved one;

‘*My car was scratched right the way up the side and it said ‘smack head’ now you can’t tell me that’s nothing to do with my daughter being addicted to heroin’.*

*‘I had some bloke come and kick my garden fence down, I went out and asked him what the hell he thought he was doing he said ‘this is for what Tommy did to Paul’ Well Tommy is my son who doesn’t live with me and God knows who Paul is, but what I know is that I’ve got a broken garden fence!’*

Furthermore 37% said they had been victim to abuse in the streets due to their loved ones actions;

‘*It’s not abuse as such but people will turn and stare, make sarcastic comments and not include me in anything. There was a street party when the Royal wedding was on and I was the only person in the street without an invite’.*

*‘I’ve been shouted at in the street by my neighbours; I just put my head down and walk away as quickly as I can. I want to tell them it’s not my fault I did my best, but there’s no point they wouldn’t listen’*.

With regards to the police 74% said at some point the police had been to their home. 12% had their family home raided as one carer explains;

*‘I once had 6 police officers raid my house; I thought my son had committed murder or something. They were looking for four cans of lager believe it or not, I couldn’t believe it my son younger son was petrified. They had a warrant and there was nothing I could do. I wouldn’t care but I had thrown him out of the house earlier that week, so he didn’t even live there*’.

*‘6 O’clock one morning my door got kicked in by the police looking for my daughter she had a warrant out for her. I nearly died; my little granddaughter is only 9 months old and was screaming. I think the police think that the whole family are criminals because had they just knocked I could have told them that she was actually in prison where they had put her a week previous. I really think that they should communicate more’.*

12% of respondents said that they had found stolen property, drugs or drug using paraphernalia in their home;

*I found 10 brand new pairs of jeans with the price tags on and everything in a bag in my shed. I threw them in the bin, Billy wasn’t happy but I don’t care I’m not having that kind of thing anywhere on my property’.*

‘

‘*Jenny got sent to prison and I thought I would clean her room out as it stunk. I have never seen anything like it, there were used syringes hidden under the mattress, cigarette burns in her duvet, bits of tin foil which looked like they had powder stuck on. There were even shoe laces with blood on them. It was horrific’.*

A further 16% said that they had called the police and had their loved ones arrested for a series of incidents including assault, theft, burglary and threats to kill.

‘*My uncle stole all of my husband’s wine and a bottle of whiskey out of the cupboard that was the end of helping him, it was the end of the line, I couldn’t justify helping him anymore. I phoned the police and we pressed charges. I’ve told him that when he gets himself some help I will be there for him, but you can’t help someone who won’t help themselves’*.

*‘My husband was so high one night he thought that I had been having an affair, he was paranoid, I don’t even know why he would have thought this considering I never left his side. Anyway this one night he locked me in the garden half naked after giving me a good hiding he said he was going to bury me in the garden, I had no choice but to phone the police. I have never been more humiliated’*.

With regards to courts we asked respondents if they had ever been to a court to support their loved one and how this felt. 35% said that they had been to court;

*‘It used to be embarrassing but now it’s just like an everyday thing, I used to be at the youth court every week. One of the magistrates even stopped me in the town one day to say hello she knew me that well. I have told my son I will be there for him and will support him at court, but the main reason I go now is just so I can see him alive because I don’t know how much longer he has got left’*.

*‘When I go to court* (with my loved one) *it almost feels like it is you who has done wrong, it is a horrible horrible place, even the waiting area of full of people boasting about what they have done or talking about crime and what they are going to do next. The language is disgusting’.*

We also asked carers if they had been to prison to visit their loved one. 14% said that they had. Here are some of the things that they said about visiting their loved ones;

*‘I hate taking my young granddaughter to see my daughter in jail, how do you explain to a three year old they can’t stay with mummy and mummy can’t come home yet’*

*‘My son went to prison a alcoholic and came out a class A drug addict. It done him no good at all; if anything it made him a hundred times worse’*

*‘I hate prison visits with my son, I have to sit there and have even seen people passing drugs over, I would never dare tell anyone. I worry my son might become worse his attitude is terrible. It would be good if they could try and help him. I mean he did do a painting and decorating course in there but what good is that when he is a raging crack addict?’*

*‘I go to see my dad as often as possible and take my baby son with me, I hate having to pass my baby over to be searched. What a way to start a life, thank God he won’t remember it as he gets older. I want him to have a granddad he can be proud of’*

In conclusion the focus groups would like to make the following recommendations;

1. SAPS and similar agencies to provide co-ordinated training to magistrates and police about the barriers that carers face.
2. SAPS and similar agencies to raise awareness with those working within criminal justice to include arrest referral and probation staff.

**Drug and Alcohol Treatment**

The main aims of this section are to:

1. Explore the benefits of early intervention not only for the user but also the carer and society as a whole.
2. To identify any barriers carers face in supporting the user in treatment
3. To identify any gaps in current provision
4. To determine how SAPS could further support carers to promote positive treatment outcomes for those in drug treatment

**Overview**

In 2009-2010 a total of 206,889 people were reported to be receiving treatment and help from drug services across Britain, as we have seen historically within service provision the majority are white males[[6]](#footnote-6), 38% of those in effective drug treatment were free of their drug of choice on discharge. It is estimated that 29% of problematic drug users within the north east are treatment naive.

Research suggests that it can be of great benefit to the service user if treatment is supported by family members. Copello found that it can increase retention and can speed up the treatment journey (et al 2005). Family support can have a positive effect on both treatment and social outcomes and there is evidence that family approaches can lead to improved outcomes for both drug and alcohol users. (Stanton and Shadish 1999). Whilst Liddle found that family based engagement strategies have a significant effect on retention and treatment outcomes of young people (2004)

**Case Study Andrea**

***‘****My son has been a heroin addict for 9 years, I feel like I’ve been through drug treatment the same amount of time as he has. There’s no doubt that it’s a million times better than it used to be and you don’t have to wait long to get in. I am so grateful that it is much easier for him now and I think they have learnt a lot but I really don’t think they know much about carers and how to handle them’.*

*‘Everyone is so tied up in confidentiality. I phone up to find out if he has been for his appointment or not ‘sorry can’t confirm this confidentiality’ it’s like a mantra for receptionists! I always explain that he has signed a form to say I can know about his treatment and they sometimes get back to me when they say they are going to phone. Things can be OK for a time if I get to know his key worker, but he has a new key worker at least every 2 months and then we start the whole rigmarole again’.*

*‘Sometimes I almost feel like a nagging mother phoning (service name) what they don’t realise is that it’s the only way I can find out if he is dead or alive, I don’t know if he will live or*

*die or whether the next person to knock on the door is the police to tell me he’s passed away. It’s a heart ache and a nightmare. If people could understand this I’m sure they would be more likely to help, the only time I feel any comfort is when I know he is in prison’.*

**Case Study Leanne**

*“Last year after six months of waiting I managed to get help for Phil my partner who has struggled with alcohol issues for well over 15years. I’d had enough and eventually told him if he didn’t get help with his problem I’d leave him. He attended appointments all over the place for weeks on end and finally got an assessment for detox’.*

*‘ The day I received the phone call to say there was a bed for a week in a drug and alcohol rehab centre, I was over the moon, Phil was excited too and we talked about our future and things were going to change, he was really motivated. Phil went into rehab on the Monday, he was scared and worried I tried to comfort him as best I could’.*

*‘I felt so relieved when he went into the rehab as I’ve have seen him have so many fits when we have not had the money to get his drink in or he’s tried to detox before. He was doing really well and I was in contact with him via telephone, he sounded bright and cheery the first few days. By the time Wednesday came he was becoming really anxious and worried that he hadn’t been in long enough for the treatment to work and that he would have to leave on the Friday, the centre rang his social worker and left a message for him to call’.*

*‘He must have rang me 20 times that day and the next if not more and with every phone call he became more desperate, in the end he was actually sobbing on the phone begging me to help him. He knew he needed longer, I promised him I’d try and help. My heart was aching listening to his sobs, my Phil doesn’t do tears so this was pure desperation from a grown man, my grown man and this was killing me. I phoned the rehab centre 3times and tried to explain that Phil wasn’t ready to come home and how upset he was, they said they were trying to get in touch with the funders. I phoned the social worker every hour for the next two days; I felt like I was banging my head against a brick wall. I am still waiting for the call back I was promised’.*

*‘Phil was discharged on the Friday afternoon and back on the drink by Friday night, I could hardly get angry with him knowing how desperately he’d pleaded for more time in detox. I feel totally let down by the services, people complain that treatment is a waste of taxpayer's money, I would usually argue this but on this occasion it really was. If he had just been given maybe an extra week our lives could have been so different now and worth every penny’.*

**Findings**

83% of respondents said they had physically accompanied their loved ones to find help for their substance misuse problem while a further 93% had called drug or alcohol services for help and advice. 62% had accompanied their loved ones to the family doctor. Angie shares her experiences;

*‘I took my nephew to his first ever appointment knowing he wouldn’t attend otherwise, it was to try and get him help and a prescription. My sister couldn’t cope and I stepped into help her. He was 19 at the time, we were made to wait where people come and get their scripts. I was shocked at how many people came in for their medication while I was sitting. One young woman actually thought I was waiting myself to see the doctor and seemed to pity me, another young lad tried to fool me into giving him his bus fare to get home. I felt a little degraded but I am so pleased my sister didn’t have to go through it; I think she has gone through enough already. I’m glad I went with him now as he has told me there’s no way he would have attended had I not been there. The only thing I would say is it would have been better if I felt a little more welcomed when I had been there’.*

The principle of involving the family and carers is now being recognised within the services, there are 4 levels of working with the families. The first level is to simply be family friendly, provide carers with plenty of information about drugs and friendly waiting environments. (Copello, 2005)

Of the 62% of carers accompanying their loved ones to the G.P just over half (n32) said that they felt the doctor didn’t understand drug and alcohol addiction. Tracey explained how upset and angry she became with her family G.P and has since changed surgeries;

*‘I took my daughter to the doctors for help with her drinking, she had been reading about antibuse and had asked the prison doctor for it, he said it wasn’t in their guidelines but that her own G.P should prescribe it. She had some blood tests and things done in prison and the prison faxed them to the doctors. She used to follow a pattern, get drunk for weeks on end, get arrested, go to prison, get out, get drunk and so on and so on’.*

*‘We went to the doctors full of hope and I think Lisa had her heart set on it, I think we thought it would be a miracle cure. When we spoke to the doctor I had never felt so judged in all of my life, he told her ‘you haven’t got a problem with alcohol, you haven’t drank for 8weeks whilst in custody, your problem is not being able to say no, you’re just being silly’ I became angry and upset as I felt he was judging my daughter and also me as a mother. He was very rude to me when I challenged him and tried to explain it isn’t that*

*easy for her, he said ‘there’s nothing difficult about saying no’. He did say he would put a referral in to an alcohol treatment service, she’s done 3 sentences since then and I’m still waiting to hear from them’.*

There is good evidence that family support networks can benefit the family unit as a whole. If one family member becomes involved with such support, the positive outcomes are not only confined to that single person but can usually be seen right across the family. (Copello et al 2005). 42% of respondents said they were involved with family support services which they said had greatly increased their understanding of drug treatment and how it works;

‘*It has made a massive difference to my life, I’m a happier person all round and with their help I have discovered lots of different coping strategies and find I tend not to lose my temper as much as I used to’*

‘*I really didn’t think getting help for me would be beneficial at all, I just wanted James to get sorted out and then there wouldn’t be a problem! I went against myself and got help and what a difference it has made, I have been going for two years now, I’ve learned so much and realised I can’t change the situation but I can change the way I think about it. I understand much more, they say knowledge is power and caring for James this is definitely true!’*

*“I have a much better understanding of my sons behaviour, I thought him getting methadone meant that he was just addicted to another drug but now I understand and know why it works, that helps me and his dad a lot’.*

In conclusion the focus group would like to make the following recommendations;

1. Drug services to regularly reproach the issue of confidentiality with the person in drug treatment actively encouraging family members to become part of their treatment journey.
2. Family members to become part of substance users ‘advanced directive’ in case of relapse instructing family on how they can best assist them.
3. SAPS and similar carer services to offer co-ordinated carer awareness sessions in drug services team meetings and G.P surgeries.
4. SAPS and similar carer services to continue to support G.P training and contribute to course materials.

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1. 47,736 is 17% of the population of Sunderland which has 280,300 residents (Office of National Statistics September 2009) [↑](#footnote-ref-1)
2. www.aboutstress.com [↑](#footnote-ref-2)
3. [www.adfam.org.uk](http://www.adfam.org.uk) [↑](#footnote-ref-3)
4. Drugscope [↑](#footnote-ref-4)
5. Alcohol Concern [↑](#footnote-ref-5)
6. Primary Care Trust [↑](#footnote-ref-6)