

Appendix 14: experience of care - personal accounts and thematic analysis

Personal accounts from service users

The writers of the personal accounts from people with alcohol problems were contacted through representatives on the GDG and through various agencies that had access to people with alcohol problems. The people who were approached to write the accounts were asked to consider a number of questions when composing their narratives. These included:

- When did you first seek help for your alcohol problem and whom did you contact? (Please describe this first contact.)
- What helped or did not help you gain access to services? Did a friend or family member help you gain access to these services?
- Do you think that any life experiences led to the onset of the problem? If so, please describe if you feel able to do so.
- In what ways has the alcohol problem affected your everyday life (such as education, employment and making relationships) and the lives of those close to you?
- What possible treatments were discussed with you?
- What treatment(s) did you receive? Please describe any drug treatment and/or psychological therapy.
- Was the treatment(s) helpful? (Please describe what worked for you and what didn't work for you.)
- How would you describe your relationship with your practitioner(s) (for example, your GP, alcohol service worker or other)
- Did you use any other approaches to help your alcohol problem in addition to those provided by NHS services, for example private treatment? If so please describe what was helpful and not helpful.
- Do you have any language support needs, including needing help with reading or speaking English? If so, did this have an impact on your understanding of the alcohol problem or on receiving treatment?
- Did you attend a support group and was this helpful? Did family and friends close to you or people in your community help and support you?
- How has the nature of the problem changed over time?
- How do you feel now?
- If your alcohol problem has improved, do you use any strategies to help you to stay well? If so, please describe these strategies.

Each author signed a consent form allowing the account to be reproduced in this guideline. Three personal accounts from people with alcohol problems (one woman and two men) were received in total.

Personal account A

It was in 2001: I was 48 years old and standing outside a shopping centre when a fellow alcoholic walked towards me. I said 'hello' and he just stabbed me in the stomach. I was taken to hospital and treated as an inpatient for 10 days. In the morning I woke up with the DTs. A nurse came by and said I was suffering from shock and I answered that it was the DTs and that I was an alcoholic.

I took my first drink in a pub at 14 years old; I then had a successful 25-year career with a brewery and was always a heavy drinker. The drinking became a serious problem when my career and marriage ended in 1993, by which time, in hindsight, I would say I was an alcoholic.

In hospital doctors began to treat me for alcohol dependency, which consisted only of medication (daily doses of Librium), and on my release from hospital referred me to an alcohol treatment centre for assessment to decide which type/level of treatment I needed. It was the first time I had ever admitted that I had a problem, even to myself.

When I was released from hospital I returned to my YMCA hostel and resumed where I left off – drinking cider 24/7 in my room, breaking the rules at the hostel. While in the streets with my 'friends', I totally disregarded my referral to the treatment centre and went on my merry way towards oblivion.

When I returned to the hostel the staff were constantly on my case to get help. I was searched on my way in and my room was searched on an ad hoc basis to ensure I wasn't drinking or taking drugs (a minor pastime I had developed) on the premises. I began to feel persecuted and quite bitter, and I showed my anger at my hostel key working sessions. However, when I was sober enough, which was very rare, I did admit to needing help.

So in January 2002 I went to the alcohol treatment centre and was assessed. They informed me I would need medical detoxification and they would help to get a place; I was offered weekly key working sessions and advice in the meantime.

I had to wait 10 months to get a detox placement at a psychiatric hospital. During that time I had to go to my weekly sessions, which I nearly gave up on quite a few times but the hostel staff kept on encouraging me to go, no matter how drunk I was, until I took up my placement.

Detox was really hard for me despite the medication – I was disorientated, nauseous, shaking all the time, and I heard things almost constantly; I also couldn't hold a knife and fork so I could not eat hot food. On top of this, I had to attend two group sessions a day in the morning and evening, plus daily key working sessions,

and have a daily injection of vitamin B plus my medication four times a day. However, after 2 weeks, even though I was still quite shaky, I was at last functioning and through the group sessions I began to realise what I had been doing to my body and my mind.

Towards the end of my time in the detox ward I contacted my keyworker at the YMCA hostel with a view to returning but after discussion we decided, as I was not in receipt of funding and had no care/social worker to help with any further support to recover, that I would attend an alcohol rehabilitation centre run by the YMCA for 6 months. This enabled me to have continuous YMCA residency, which also meant I would be able to return to the hostel after the 6 months.

The rehabilitation centre was really good for me; the staff were professional, tolerant and understanding. I learnt that my style of recovery there was eclectic and made up of the centre's own ideas plus bits of 12 step, CBT and holistic therapies plus transactional analysis. Group sessions took place daily in the morning followed by a staff and group lunch cooked by residents nominated for that day; cleaning and gardening were also chores for the residents so that we could learn our life skills again. We also went shopping so we could learn how to budget (that is, live within our means and not rely on shoplifting or some other kind of theft or fraud). The group sessions were varied, covering relapse prevention, life stories, self-esteem, self-confidence and triggers. Other topics, which were linked to recovery, were art therapy and open groups where we could talk about anything that affected us. I seemed to do OK and after 6 months I returned to the YMCA hostel a sober man for the first time in 15 years.

I did not think I needed anymore support or treatment. I felt really fit both physically and mentally, and so resumed my previous friendships/relationships within the hostel feeling I was strong enough to stay clear of alcohol and drugs, but I was wrong.

In hindsight I think I planned my relapse. I left the rehab centre on a Monday and took my first drink (a can of cider), 4 days later on the Friday with the other drinkers at a park bench thinking I could leave it at that, but by the end of the day I was totally drunk. I woke up next morning with a 3 litre bottle at the side of the bed and instinctively reached down for the first drink of the day, and, as soon as that was gone and feeling quite ill, I made my way to the off-licence and was back to square one. The relapse hit me very hard. All I could do was hide away from any family who would talk to me (only one son) and everyone who had supported my recovery. My denial was total and as I got worse so did the shoplifting and begging.

It was whilst I was trying to outrun two security guards after stealing a three litre bottle of cider and a bottle of vodka that I had my first heart attack. I was taken to hospital and treated, but as soon as I was well enough the police arrested me for theft. Two days later I had a mild stroke and was strongly advised by my consultant to go back into recovery, but on my release I reasoned it hadn't worked the first time

so why should it now? So I just traded on whatever sympathy I could get and just carried on as before.

A couple of months later I got into a drunken brawl followed by an altercation with the officers who were breaking it up and I suffered a more serious heart attack and again I ended up in hospital. But by now the doctors, police and the hostel were completely fed up with my antisocial behaviour as were the supermarkets, off-licences and just about everyone else. On my recovery I was arrested and in court I was given an ultimatum – either take treatment willingly myself or go to prison, which I did not want. So I again entered treatment, which the police insisted on as they were adamant I would return to my old behaviour.

My start in treatment was the same as the first time but much quicker – it began within 5 weeks at the alcohol treatment centre plus detox at the psychiatric hospital. This time I got funding for my rehabilitation which was at a different centre, but which offered a very similar style of treatment to where I was first treated. After 6 months I was offered the chance to extend my recovery period by entering a third-stage supported house, which was a semi-independent unit. I decided I needed this.

I had another stroke whilst at the supported house. After 14 months as a resident, and with the help and support of the staff of the rehabilitation centre, I got my own flat and have remained alcohol and drug free for the last 6 years. My physical health is still giving my consultants cause for concern but I am recovering slowly and as soon as I am fit enough to undergo surgery I am hoping one day to be fit enough to return to the workplace. However, my years of abuse have cost me a high price in terms of my career, home, marriage, family (four children whom I didn't see for 10 years) and my health.

I have to say I could not have achieved any of this without all the support I have received from the YMCA (the hostel and rehabilitation centre), the hospitals, the alcohol treatment centre, the rehabilitation centre who ran the supported house where I was a resident and, begrudgingly, the police who were really very good about things considering my atrocious antisocial behaviour.

I have worked hard to restore my relationships with my four children and two grandchildren, and have had considerable success. I had support throughout this process from my keyworker, to whom I will be forever grateful, and my ex-wife who I always thought, through my drunken years, hated my guts (she didn't – she just wanted me to get back to living again).

Now I feel fairly good about myself and what I have achieved. But I don't feel pride in myself and I will never forgive myself for the man I became nor for the hurt I have caused the people I love and the things I have done. Also I am afraid to get too close to people or commit to any relationship because I feel I can never completely trust myself again. But, having said that and having explained the reasons to my current girlfriend, who is understanding of my fears, I am making positive headway in 'trusting me'.

Personal account B

I am 55 and I started drinking heavily 2 years ago. I had been drinking for a long time before that and was dependent on alcohol, but I thought I was in control. For a while I went to work and no one noticed there was a problem. Alcoholics always say they can handle it and that is also what I thought. But then it did start to affect my ability to do my job and one day I lost it and drove a car into the building where I worked. So I lost my job and my licence, and my stepmother had also recently died and so I started drinking heavily after this. I was always being picked up by the police and I also tried to commit suicide at this point in my life.

When I was not drinking so much I tried to get help because my family wanted me to. I went to my GP first of all as he had always been helpful. He recommended I go to my local drug and alcohol service, and they sent me to a residential mental health hospital where I went on their detoxification programme on a voluntary basis. It was not a nice place at all, and the workers seemed far more concerned in getting people clean of heroin rather than helping people with alcohol problems. I was only there for 2 weeks and it did not help much. I went back to drinking when I got out.

But over the next few years I had to go back to that ward twice for a week at a time because of my mental health problems (I had acute depression and had attempted suicide) and I also had another detoxification. I hated the attitude of the staff--I was supposed to have a meeting with the special care workers three times a week but it never happened. The groups were mostly made up of young people and they were drinkers and drug users together, so this did not work for me. The door was always locked and I felt I was a prisoner. The people I met all went back to booze. They wanted me to go to a rehabilitation place in the country, but I wouldn't go because it was for a year and it meant I would not see my family.

When I was made to go to another hospital I saw a real difference in attitudes. The door was always open and one of the workers chatted to me for over an hour. I was only there for one night but if it had been longer I think it would have helped far more than the other hospital. They were there to help drinkers as much as drug users.

My family was there for me when I was drinking. They told me early on that I had a drink problem but I always denied it. I was stealing from them and one weekend I even stole my son's whisky, which he was keeping for a special occasion. I denied it but then I realised what was happening to me and tried to get help. I live with my Mum in her house with my son and I have two brothers with families and a sister in Australia. They always tried to get me to get help. My Dad was there for me too.

It was only earlier this year I realised I had a real problem and I needed help so I went back to hospital but I was barred because the last time I turned up and said I wanted help I was drunk. Their policy is that you can't turn up intoxicated.

I hit rock bottom when I was arrested for common assault in August 2009 and was sent to prison the next month. I went into detox on one of the wards. The staff were very good--they should swap jobs with staff in other services so other workers can see how it should be done when helping drinkers. I was always checked on, and I was able to talk to the officers and the therapists. I spent 2 weeks on this ward, and 2 weeks on another ward. Someone from Adfam came and saw me and kept in touch after I left. It helped to have someone in touch with the family and me. She is non-judgemental and says I can phone her when I need to talk.

I had a 3-month sentence but I only did a month because of good behaviour. I had no idea I was going out. They woke me up at 6.30 and said 'off you go' so I phoned my Mum. I was really shocked and at the beginning thought it was a joke. But going home clean made me and the family really happy.

I started going to AA and liked it because it was for alcoholics who were more my age. But it was on Saturdays which made it difficult to attend so I have not been recently.

I have cravings and triggers but I can control them. I think of something else and do something else like make myself a cup of tea. I still have good support from my GP who is a real family doctor and looks after my Mum. I really trust him. I am determined not to drink again.

When I was a drinker I hated the way people treated me. They judge you without knowing you because of what you look like as a drinker. I think it is harder to get off drink than drugs. It can kill you getting off alcohol and people do not know this--they think you can just stop. People seem to have more sympathy with drug addicts rather than alcoholics. People need to be educated about this, they just don't understand.

I think services should get people who have managed to stop drinking to talk to others to help them. Experience is really important.

Personal account C

From a very early age my lifestyle was somewhat alcohol-orientated in as much as I started work at 16 in the shipping industry where alcohol was available on board ship at any time of day or night. We seemed to accept that this was part of our working life, although I never felt at that time as if I was dependent upon drinking alcohol. Outside of work my sporting interests also involved much alcohol. It is clear to me now that alcoholism is a progressive illness and it was later in life that my dependency was determined.

My problem in the early stages did not seem to have affected my education or professional life. Indeed I went on to be very successful in my profession. However I realise that latterly I was a 'working alcoholic'. It was at this time and as I retired that the lives of my wife and close family were badly affected. Although they initially supported me in seeking help I was not ready and really only paid 'lip service' to the

help available just to please them. I really had no thought about how I was tearing the lives of my family apart.

I denied any alcohol problem although I was told by my GP to stop drinking. However, my GP seemed to distance himself from the alcohol problem. In September 2001 I was diagnosed with severe depression and prescribed antidepressants. My GP also referred me to an antidepressant clinic, where I received individual counselling together with group therapy. I attended the clinic for a number of years – but I still drank.

At one stage I tried private treatment which consisted of a one-to-one consultation and a prescription of naltrexone which I was to take when I felt the desire to drink or was subjected to an alcoholic environment. This was supposed to reduce my urge to drink at that time. However this did not help me at all although the clinic claims a huge success rate.

In early 2005, even after attending the antidepressant clinics and seeking private treatment for heavy drinking, I was in a desperate state and contacted the Alcoholics Anonymous helpline. I attended AA meetings all that year.

On one occasion, while very much under the influence of drink, I was taken by my wife and daughter to the GP's surgery and saw the practice nurse who immediately referred me to the local psychiatric hospital where I stayed for about a week for detoxification before being discharged. I then attended an alcohol/drug centre which led to an interview with a local alcohol and drug agency. The agency gave me one-to-one counselling before I was introduced to the 12 step programme, which had strict rules of no alcohol intake and attendance at at least three AA meetings per week. After 3 weeks into the course, I was banned from attending AA meetings because I was under the influence of drink. I was also suspended from the agency.

I was nearly 70 years of age before I finally agreed to attend an interview at a rehabilitation centre. After then refusing to go to the first interview, with the encouragement of counsellors from the agency I entered a rehabilitation centre for primary rehabilitation. I was in primary rehabilitation for 6 weeks and completed steps one to five. I opted to continue into secondary rehabilitation for 12 weeks, completing steps six to twelve. I was given an intensive course of treatment consisting of one-to-one counselling and an in-depth understanding of the 12 step programme.

The treatment at the centre, and afterwards supported by the agency and AA, was incredible. The 12 step programme with the agency did not work for me as it was only one day per week and I did not have any self-control over my drinking for the other 6 days, whereas the intensive course in rehab gave me the concentration of mind I needed away from outside influences.

I still attend AA meetings which are an essential part in keeping me in sobriety and are helpful not just for me but others in recovery. The fact that it is anonymous enables us to talk frankly and open without fear. My family, especially my wife who

attends Al-Anon meetings, are very supportive. In the first 6 months of recovery I also attended aftercare sessions at the rehabilitation centre. Friends and community groups were also very supportive. Close friends and relations helped me considerably during the times when I was completely under the influence of alcohol, taking me to hospital, sitting and talking to me and generally supporting my wife and family. The community groups I belonged to supported me the best way they could and by not rejecting me. In recovery both friends and the community groups have supported me and welcomed me without reservation. Because of my heavy drinking I was not really aware of the support I received in those early days and it was some time before I really appreciated it.

The nature of my problem has changed in as much as I am still an alcoholic but I do not drink. Life now is 'beyond my dreams' - there has been such an incredible change in my life and the lives of my family. However, I am still an alcoholic and live with the fear of going back to those dreadful days. I also live with guilt, anger and resentment of the things that have happened and for what I inflicted on others during my years of drinking. I have to learn to control these feelings. It all takes time, as does the trust I have to regain from all whom I hurt and cheated. When it does come, and it comes slowly, it is the greatest gift. I am lucky that after years of abusing my body physically and mentally, now at the age of nearly 75 I am fit and well.

We all have our own ways of handling our lives in sobriety. However most of us acknowledge that talking to fellow alcoholics and close family is the best strategy for continuing in recovery. If we do not – and it does happen when we get into a 'comfort zone' – then it shows in the way we conduct ourselves. Even now after 4 years of sobriety I fail in this area, which causes problems with my close family, especially my wife. The one basic rule is not to take the first drink, day by day.

Personal accounts from carers

The methods used for obtaining the carers' accounts were the same as outlined above for service users but the questions included:

- In what way do you care for someone with an alcohol problem?
- How long have you been a carer of someone with an alcohol problem?
- In what ways has being a carer affected your everyday life (such as schooling, employment and making relationships) and the lives of those close to you?
- How involved are/were you in the treatment plans of the person with an alcohol problem?
- Were you offered support by the person's practitioners (for example, their GP, alcohol service worker, or other)?
- How would you describe your relationship with the person's practitioner(s)?
- Have you and your family been offered help or received assessment/treatment by a healthcare professional?

- Did you attend a support group and was this helpful?
- Did any people close to you help and support you in your role as a carer?

Carer account A

I remember very clearly the first time I felt I had become a carer of my youngest son, who was 16 at the time. It was around 9 p.m. one evening 13 years ago. This night would surely stay in my memory for ever. A young person who was completely out of control arrived home and brought mayhem to the family. He produced a large knife and I was standing at the other end of it in my kitchen not knowing what to do. Watching four policemen restrain my son and take him away shouting and screaming left us feeling numb with disbelief. This was the first time my son had got drunk and the 13 years since that first night have been a rollercoaster and have changed the lives of the whole family. It was when I seemed to begin to 'care for' instead of 'care about' my son. Over those years huge changes have taken place in my life and the lives of my husband and my older son. Many people in the local community have also been affected, and the devastation has been vast. I never saw myself as a carer, however my life took on a completely different meaning.

Living with someone with an alcohol addiction does not stop life going on in other areas. During this time, my Dad had a heart attack and died in front of me. My Mum got sick and I was told she was going to die. I moved in with her for the last 5 weeks of her life to care for her while my husband tried to cope at home. Each morning I would hear stories from my husband involving the police, ambulance service and so on, and of the horror of the evening before. This is just one example of how life does not stop because you have someone misusing alcohol. It became a huge balancing act.

My physical health suffered – I developed chronic fatigue syndrome and I went into a severe depression where I just felt I could not deal with life any longer. I remember clearly how close I came to taking my own life, but it really did seem to be the only way to escape the horrendous knock-on effect of watching my son getting sicker and sicker and slowly destroying his life. I had to give up work which led to financial implications and more stress for my husband. My relationship with my husband was affected hugely, and my relationship with my older son was also suffering. Any social life stopped when we became too afraid to leave the house, and holidays became non-existent. My whole day seemed to be geared towards trying to provide emotional and practical help to someone who just seemed to be going deeper and deeper into despair. I remember the evening we went out for 2 hours and came home to my son collapsed over the gas hob with two rings on and his arm inches away from the flame. Ten more minutes I am not sure we would have had a house to come home to or a son.

Over time we experienced violence towards ourselves, had many things smashed in the house, sat in police waiting rooms and court rooms, and found our son with both

arms slashed by a razor. On one occasion we went from visiting our eldest son at university, to going straight to a young offenders institute to see our youngest son. Being completely naive about prison we felt humiliated and ashamed and tried to hold back the tears when our young lad appeared with a swollen face and black eye. I spent the 70-mile journey home sobbing my heart out.

I sat by his bedside whilst he was on a drip after trying to take his own life for the second time; on the third occasion he insisted we did not call for help – we had to wait for him to be unconscious before doing so. Imagine how that felt when you knew it would be so easy to do nothing and hope that all the pain would stop, for him and for us. Only people who have been in this situation would know how we could even begin to think like this! It's so hard to believe it yourself, but the continuing despair and exhaustion just takes over.

Try living with the fear – every time the phone would ring or the door would knock would it be the news we all dreaded? I remember once when he was missing for 3 days, and I saw two police officers come up the drive. The difference this time was one of the officers was a police woman and I thought, 'this is it, they have sent a lady to give me the news'. Imagine living with fear on that level every day and night! Also came embarrassment, shame, guilt, anxiety, anger, isolation, despair and feeling powerless. I had lost both my parents and had no time to grieve; I was trying to keep the family together, trying to cope with my son's needs and the drinking, trying to get someone to really listen, trying to find the energy to get out of bed because of my own illness and it felt overwhelming every day.

Over the years my husband also suffered with depression and began to use alcohol to escape the problems. For 2 years I had to deal with both my son and husband, and eventually I had to leave my home, which did not feel secure, to stay with a friend. My marriage was in jeopardy after 31 years and my husband was on the edge of a complete breakdown. Thankfully, after I left, my husband decided to get help and stopped drinking. Four months later I returned back to my home.

My eldest son also had to receive treatment for depression; his life was affected enormously in a whole variety of ways and it's taken time to even begin to rebuild any of the relationships. It felt impossible to give him time and support and it was difficult to enjoy the good things happening in his life. One of my happiest and yet saddest memories was his wedding, when I stood at the front of the church and gave a reading about love. The loss I felt that my youngest son was not present will always be there. Many social occasions were cancelled, destroyed, or not even thought about. There was a complete loss of normality.

Was I a carer? My son's GP certainly did not see me as one – no information regarding any support services was ever given. Our relationship felt like a battleground. I had been taking my son to see different people since he has been 2 years old – if only someone had really listened to me regarding this. As a mother I had always known there was something not right and there were problems long before alcohol was introduced into my son's life. There were many times when my

son was not drinking when a comprehensive assessment that considered his previous medical history could have taken place. It took from the first incident to last year to find a person who would listen. My son felt the same. Everyone kept blaming the drinking. In court my son said: 'I have been seeing people all my life and people listen, but nobody has really heard what I am saying'.

Treatment for my son came first by a community programme, then residential treatment at the age of 19. As a Mum I never felt included in the process in any way and it would have been very valuable to have been given information and support in my own right even if my son had not wanted me to be involved with his treatment. Recovery needs to be for the whole family. Guidance around relapse would have been especially helpful. I felt elated when my son entered residential treatment for the first time, but then felt crushed when relapse came months later.

After a period of 8 years waiting for the second attempt at residential treatment, I again felt crushed when half way through things collapsed. It goes against everything as a Mum to say 'no' to requests from your son, especially for money for a place to stay and keep safe. Imagine how hard this is! Often it is the case that no advice is given to parents of children with alcohol problems, or the advice is conflicting and many are confused as to what they should be doing to support their child. We needed help for the whole family, not help to divide us. After 2 further years of chaos, I started to try again to find someone to listen.

It was only because the mental health team would not listen to me that I requested a Carers Assessment. I felt my son was at real risk of harm to self and others and I felt it was the only way to get this fear put down in black and white, to have evidence that I had told someone. The 'merry go round' of mental health services and alcohol services nearly tipped my own balance more than once. I had medical evidence that there were underlying problems long before the alcohol addiction took hold, and I felt this was essential for correct assessment. This was a complete failure in my eyes and later I was proved right. It did not help having a Carers Assessment worker who did not have any knowledge of addiction,

The biggest help and support has been through attending 12 step meetings. I have attended Families Anonymous and also attended Al Anon. The meetings helped me focus on myself, and gave me a support network in my own right. I was not judged and felt completely understood. It was a personal development of my own, helping me to understand that there were no guarantees that my son would stop drinking, but that I needed to take care of myself. It also taught me how to look at my role in my son's addiction and to support him in a more valuable way. To even begin to stand back when my son could die was the hardest thing to do. These meetings were a 40-mile round trip each time, so there was a large chunk of time and quite a cost involved.

I have also attended two other support groups which were not 12 step. Both of these were of different value, but I sometimes find it difficult when groups get into talking about the problems too much and focus on the other person. I needed to learn new

tools on how to cope with my situation. There were also many other things I needed to know, for example, how and where to go in an emergency, and finding out about these things was as hard for me as finding the correct services for my son. There was a lack of communication, a lack of information, battles around confidentiality, and a constant struggle.

I have a couple of very close friends who supported me the best they could. That might mean when I was walking the streets in desperation and depressed myself that I could find my way to their house and there was always an open door. Alcohol addiction brought family rows and sometimes, after my Mum died, I just felt I needed somewhere to go even for a short while before returning to the chaos. The people closest to me (for example, my husband and my eldest son) were also affected and found it difficult to support me. This was a 24-hour situation and my husband had to continue to work to support the whole family and my eldest son needed to pursue his own life somehow. The main thing to do was try and support myself in my role as a carer by my own self-care.

I have attended two residential family programmes which were also very useful; however, they had to be funded by us and were costly. I attended my first family programme when my son entered treatment for the first time several years ago. I wanted to learn how to deal with the situation in a better way, and during the 3 days of the course, I was able to look at my own feelings and confirm that getting help for myself was extremely important. It also helped me to look at ways of supporting and loving my son but not to support his drinking in any way. I attended the programme alone. My second 5-day residential course was 5 years ago. It helped me learn more about addiction, look at my own self-care and understand my behaviours around my son. It helped me gain the courage to do some of the things I needed to do but were extremely difficult. I also attended this alone, whilst my husband was at work and continuing to support the family. However, one person changing can start the process of change amongst others.

Everything I have learnt and put into practice has helped me maintain my own emotional and physical health in a much more positive way today. It's taken a lot of work and courage. The biggest turning point for us all was the confirmation of underlying problems last year. My son can now understand his reasons for drinking when he does, which he has been trying to express for many years. Attitudes towards carers and family members need to change if people are to get well. You cannot have a relationship with the person's practitioner if that practitioner believes that only the person with the alcohol problem is involved. Our family spent years trying to get the right help for our son, which would have made such an enormous difference to not only his life but to all of our lives. There are no guarantees that he would still have not developed an addiction to alcohol; however, knowing that the underlying problems were real would have helped us all see things in a different light. These years are lost.

On New Year's Day this year we had our first family meal together for 10 years. Rebuilding relationships within the family is one of the main areas to restore. My

son is doing well at the moment – he is working and gaining huge insight into himself. Unfortunately when there are changes in our son, things for us can change overnight, but we just have to deal with this as and when it comes. At present he is living with us, but only because of a relationship ending. At times it can still be very difficult, but clear boundaries help us all.

Carer account B

My partner had always been a heavy drinker and in his teens and twenties had used heroin. He came from a background of regular social drinking and his parents run a pub where he lived and served in the bar. This set a pattern of daytime and evening drinking every day. At weekends he would often drink a great deal and would be completely immobilised for at least a day with very bad hangovers and sickness. He was diagnosed with hepatitis C which had damaged/is damaging his liver and this was probably the cause of his extreme reaction to alcohol.

Reacting to pleas from us, his family, he stopped drinking every evening in the local pub but we found out later that he was drinking after work and would also buy alcohol when he took the dog for a walk later in the evening. Over time, and coinciding with a change in family life with me taking up a high pressured and senior job and our children leaving home to go to university, he began to drink far more. His behaviour was dramatic and extremely upsetting as it was obvious that he was drinking to obliterate his misery and when he did drink like this he would become tearful and abusive dependent on his mood. He never drank at home but would go to parks or drink while walking around the area until he collapsed on benches or in the park and we had to go and find him. I made him go to the doctor who called out the local mental health team who put him on a high dosage of antidepressants, but things got worse not better and he then started to disappear overnight. As the GP said, the best thing he could do was to be arrested and dry out because he couldn't get help until he presented in a sober state. The police agreed but the nightmare of disappearances, us taking turns roaming the streets looking for him, trying to entice him home via phone calls, the muggings and beatings he got whilst collapsed on the streets, went on for years. He would go to AA to keep us quiet and also went to the GP every few weeks which, looking back, was the only indication that he wasn't trying to kill himself through drink. Friends tried to help and he was offered psychotherapist support by work but he would not go and he ignored friends. The only place he could go to whilst intoxicated was a drop-in centre which, for a while, successfully engaged him and allocated him a case worker. I tried to talk to the worker to find out how we could help or what was happening but because of stringent confidentiality issues I got no help or information at all. This did not happen when drugs came into the picture and I do feel that given my partner's drunkenness, he did not understand or was given no guidance on how to opt out of the confidentiality issue.

It was the downward spiral which completely takes over someone who is vulnerable and makes me wonder about the word 'carer'. You aren't caring for someone who is in this state except by trying to keep them from harm and trying to get them to eat

and sleep. Well, you start like that but by the end you are so furious that even that gets withdrawn – a useless threat really as my partner did not care if he did not eat or if he smelt or slept in the park. The family kept ourselves to ourselves and it was dreadful to watch the effect it had on my younger child who was more vulnerable and a teenager at the time. The anger and anguish in the house was there all the time although we often tried to pretend we were a normal family watching *EastEnders* together. But all the time we would be watching and waiting for him to turn up so we could relax a bit. We even tried locking him in – all these desperate tactics made no difference.

There was no one professionally who helped us in the first years and it was only when we found out by accident that my partner was back on heroin that any funded support for the family was offered. A local service for families of people with drug and alcohol problems helped us. We had a family meeting and were able to ring and talk to the key worker assigned to us. In meetings we wrote things down on flip charts and talked through lots of issues. This helped the children face up to their father and to write down their wishes for the future and their terms for us taking him back. But the support was not continued and we were led to believe that this was because he was being treated primarily as a drug user rather than as a dependent drinker and there was little funding for the latter.

I think that for my partner drink was far more pernicious than drugs. It nearly destroyed our family because of the extreme moods, the anger it caused in all of us, the tears and the disappearances. On drugs he could lead a sort of normal life – so much so that we did not even know he was taking heroin for months. He finally stopped drinking when my children and I said we had to leave or to get help. We did not realise that he had just swapped his addiction.

Families and friends find it far more difficult to deal with drink because it is so much part of our social makeup – and so available. It is impossible to stop someone drinking if they don't want to stop because they can get it at any time and it is relatively cheap. We tried a number of things but we had no support from professionals so we were sort of making it up as we went along. We made a lot of mistakes – like locking him in and attempting to forcibly remove cans and so on when he was on the streets – but we only found out why these were not useful tactics until later on. The web was informative but not personal and the family support group Al Anon was just not suitable for us, especially because the meetings were in the day time and I had a full-time job.

Eventually my partner reached rock bottom and was arrested for possession of Class A drugs. He was very drunk as well. From the moment of his arrest, all the help came pouring in – detox was arranged, community rehab set up, and a care manager appointed who worked with him on a care plan. We were also offered family therapy via these services. We did not take it up mainly because we felt we had gone through enough and we felt our coping skills and understanding of what to do next were stronger. We wanted him to go through rehab for himself. The 12-step therapy used by the rehab service helped him a lot and he started going to AA and NA

several times a week. He has not had a drink – except for a few pretty dreadful slips – for nearly 3 years and has not used heroin. But when you are involved like this with a user, you are always on the lookout for slips or lapses. Ironically it would be better if such a lapse was drug related as I am still not at all sure where we would get the same support if he started drinking again.

Being a ‘carer’ of a dependent drinker is lonely, frustrating and terribly tragic – tragic because the thing you learn is that you know if someone wants to drink and stay drunk, they can always find a way. Street culture becomes their family and the real family are left outside.

Thematic analysis of people with parents who have alcohol problems

Introduction

A qualitative analysis was conducted using transcripts from people with parents who have alcohol problems, accessed from the NACOA website.

Methods

Using all the personal experiences available from NACOA submitted from 2004 onwards, the review team analysed 46 accounts from people with parents who misuse alcohol, the large majority of whom were female. All accounts have been published on the website in their original form. The majority are written by people from the UK but there are also some from other countries, such as the US and Australia. Poems and letters were excluded from the analysis. Each transcript was read and re-read and sections of the text were collected under different headings using a qualitative software program (NVivo, 2010). Initially the text from the transcripts was divided into three broad headings that emerged from the data: impact of the parent’s alcohol problems on the child’s behaviour, thoughts and feelings; impact of the parent’s alcohol problems on the child’s psychological state/mental health; and support and services for the family and the child. Under these broad headings specific emergent themes identified separately by two researchers were extracted and regrouped under the subsections below.

Impact of parental alcohol problem on the child’s behaviour, thoughts and feelings

Avoidance and concealing the truth

In recounting the experiences, a common theme that emerged was fear, shame and embarrassment which led to avoidance, escapism and concealing the truth about their parent with the alcohol problem. These kinds of behaviours impinged on the child’s ability to enjoy simple activities, such as have a friend over to the house:

I became an expert at hiding my feelings ... I was scared to get a girlfriend because I was worried that she might find out. I never invited friends round to stay. I’d do anything to avoid going home ... I took a job after school that involved

working until 10 p.m. and I thought that was great because I had a really good excuse not to be at home.

[Participant 01]

As children we never invited anyone home, the embarrassment would have been too much to bear.

[Participant 18]

I wouldn't invite even my best friend round to my house, I couldn't bear for anyone to see my father. I was worried they would talk about me, worried about what they would think of me.

[Participant 24]

I dreaded events where parents could attend. If my dad came, he'd be drunk, sing loudly and make a fool of himself. I didn't want him there, didn't want to be different to everyone else – what child does?

[Participant 02]

Some people even described trying to hide the problem from themselves in order to cope:

I led a double life, hiding my feelings until I'd 'forgotten' I ever had any, saying I was 'fine, thank you' when I was falling apart and convincing myself that it 'wasn't that bad'.

[Participant 44]

I realised that I had kept all my feelings bottled inside me for so many years. So hidden that even I hadn't really noticed them.

[Participant 48]

Many also noted that they had no-one to talk to and very little support (see section 0), and concealing the truth made this even more difficult for others, such as teachers/friends, to recognise that there was a problem:

I couldn't talk about my dad's problem or my mum's illness to anyone, my school only found out she was ill 3 months before she died, when I ran out of a lesson in tears and had to explain to a teacher.

[Participant 38]

On the surface we were all terribly polite and we never spoke about the insanity and fear that lurked beneath the surface of our daily rituals... we were the best-mannered children in the world to strangers.

[Participant 43]

Others mentioned that when they tried to face the problem and discuss their worries directly with their parents, they were confronted with negative responses or abusive behaviour which prevented them from raising the issue again:

I told her I was worried she was an alcoholic. She hit me hard across the head and shouted, you don't know what that word means. It was the last time I tried to talk to her about her drinking until I was grown up and even then I daren't do it in a direct and open way.

[Participant 25]

I was the first one to mention that she may have an alcohol problem, when I was 15, following an argument between my parents... the encounter led to a period of ostracizement from the family home.

[Participant 22]

Relationships in childhood and later life

A prominent theme was the development of personal relationships and friendships in childhood and in later life. Many of the accounts reported that it was a challenge to form or maintain relationships with others. This was frequently attributed to a lack of trust:

I struggle to form relationships with people, it is ingrained into me that nobody can be trusted, and that all promises are false. When I do form relationships with people, I cling to them tightly because I am scared they will leave me and in the end frequently this obsession only serves to push them away. I find it difficult to talk to people, and open up. I think this is something I'll never be able to do.

[Participant 24]

The effect of my childhood has caused me to not trust people (although I trust 2 good friends now)...and to pursue unsuitable relationships with men (hardly surprising after all 4 of the men in my immediate family abused me).

[Participant 25]

Because of the struggle to form successful relationships, as well as the avoidance, many people described themselves as lonely and isolated:

I became a very serious, lonely teenager who was not able to trust anyone.

[Participant 29]

I feel negative about lots of things and have isolated myself from lots of people, know I should not be but it's so hard just now. I feel so different to other people and compare myself to my work colleagues who had a normal upbringing.

[Participant 26]

If anyone saw her drunk I was so ashamed. As a teenager, that made me feel different and isolated. I was lonely.

[Participant 25]

As adults, a number of people described wanting to find partners who were different from their parents, primarily people who did not have an alcohol problem. However, some did also say that they were attracted to others with similar experiences:

Having an alcoholic father made me determined never to get myself attached to a man with any kind of habit.

[Participant 38]

I chose my husband and father of my two children very carefully...he drank very little and had no change in personality when he did and did not obsess about where the next drink was coming from.

[Participant 13]

I'm in a good relationship, with another child of an alcoholic who shares a lot of the same understanding.

[Participant 22]

Triumph over adversity

People described many situations in which negative experiences and beliefs from their childhood were turned around in order to change current emotions, thoughts and behaviours into positive ones. For example, taking on different parenting skills to those of their own parents in order to be better parents, or trying to make the best of a situation:

I vowed, even as early as eight or nine, that I would never ever inflict this kind of torture – of being a child of an alcoholic parent – on a child myself

[Participant 26]

I had hoped that having a family of my own would help to fill the emptiness inside and provide some of the love, warmth and nurturing I had missed. In bringing them up we have completely turned my parent's philosophy on its head

[Participant 43]

I'd come to the conclusion that I was stronger than I thought I would ever be when faced with her eventual demise...I knew I had to find something positive to do with it; to have buried the experience along with her, would have been a crime.

[Participant 14]

You know now that for every negative emotion there is an opposite positive...tears into laughter, fear into courage, co-dependency into mature friendship...shame into pride...lack of control into more control over your life, victim-hood into assertiveness

[Participant 42]

I learnt to channel my addictive tendencies into more positive things such as my great passion in life, surfing.

[Participant 01]

High levels of responsibility

Another theme that emerged was that of increased responsibility. Some felt that they were forced to grow up quickly through practical and emotional burdens which are not usually considered the responsibility of a child:

All my energy and time went into worrying about and saving my mother from her drunken dramas. It was extremely draining being the responsible one. I was not sleeping or eating properly, and constantly felt ill with headaches through stress.

[Participant 10]

I was forced into growing up too quickly and had to get on with things, doing my washing, making sure I had clean clothes for school or did my homework, getting myself a meal.

[Participant 38]

Without thinking about it I had denied huge parts of myself, learned to make myself invisible and to take care of myself. After all, nobody else was guaranteed to do it for me.

[Participant 37]

High levels of responsibility were commonly reported and often led to feelings of guilt and blame, as they felt that it was partly their fault that things had gone wrong

and that in retrospect they could have done more to help their parent with the alcohol problem. Some even felt that the problem was actually theirs through over-identification with their parent:

I always blamed myself for all the hurt my mum caused me thinking everything was my fault

[Participant 26]

I felt immense guilt, perhaps if I'd been to see him more often this would not have happened. Maybe I could have prevented his drinking.

[Participant 24]

It still feels like I'm 'carrying' her problem for her, because she never admitted she had one...I understood she had a problem; she didn't and so she thought it must be my problem.

[Participant 22]

I kind of treated her illness as my illness, as though we were both alcoholics and both had something to hide.

[Participant 01]

Other themes relating to impact on behaviour which were apparent but less prominent than those outlined above included: committing unlawful behaviours such as stealing; negative impacts on education and employment, such as failing exams or struggling to keep a job and experiencing a sense of relief at the death of the parent with the alcohol problem. Many also described suffering some form of abuse from family members or relations, which could have impacted on a variety of behavioural and cognitive outcomes.

Impact on psychological state/mental health

Fear, anxiety and worry

A theme that repeatedly appeared was that of fear, and anxiety and worry. People described feeling scared about coming home from school, worrying about bad things that may happen to their parent and generally being on edge:

Coming home from school was terrifying. I knew every floorboard that creaked, every door that squeaked and became expert at moving silently. I practised when he was out.

[Participant 36]

As a child I always knew something in my house was wrong. I had an anxious feeling most of the time and never really questioned it. I would lie awake worrying that we would get burgled and there was only me who could phone the police. My mind would go into overdrive with anxiety.

[Participant 25]

I do still worry about my mother, I do not think a part of me will ever rest about her drinking, until the day she dies.

[Participant 10]

Depression and feeling low

Another theme that emerged was the experience of depression, unhappiness and despair, both during childhood and continuing into later adulthood. Some people even talked about suicidal feelings:

I was 16 when I realised that I couldn't remember the last day that went by when I didn't cry and feel utterly miserable and unhappy. I overdosed out of depression for something to change, for someone to notice, for someone to help me.

[Participant 46]

I suffered low self-esteem, a lack of sense of self, self harm, an eating disorder, attempted suicide, anxiety, and depression and welcomed an abusive lover into my life.

[Participant 08]

I am convinced that these experiences have played a major role in allowing my life to be subsumed on occasions by misery, fear and despair.

[Participant 41]

You have to work at being 'happy', and fight off continually, the bogey of depression. You are constantly saddened, and unable to ignore great grief and suffering of anyone in the world, and absorb everyone's trauma like a sponge.

[Participant 35]

I'm suffering severe depression now and frequently think about taking my own life, have had counselling; maybe not enough of it.

[Participant 26]

Anger

Anger was another emotion that was frequently described in the experiences, although exact reasons underlying the anger were for the most part not described:

Forgiveness was vital for me as I had years of fear and unresolved anger.

[Participant 03]

I got angry with the people that looked on the bright side, 'always look on the bright side of life,' Rubbish. 'Things aren't as bad as what they seem.' Shut up. 'Things will get better, they always do.' Anger. I was confused, I did want to get better, but I didn't know how.

[Participant 08]

I have never ever forgiven myself for my behaviour towards her as a teenager. I'd slam doors, break things, scream, rant rave in frustration.

[Participant 02]

Own alcohol problems

Another theme that emerged was the development of their own alcohol problems, both in adolescence and adulthood:

Coming to terms with my mother's alcoholism took me on a rather circuitous route involving my own deep struggles with the substance, over many years. It was almost as if, despite vowing I would not end up like her, I had to experience it to understand it.

[Participant 25]

I was first drunk when I was 12 years old. I stayed drunk either in my head or physically, for the next 13 years it took away all the pain of being an object, OK it created so many other problems but killed the feelings when I was out my head.

[Participant 40]

Instead of breaking free from his restraints, I began drinking, just like he had!

[Participant 43]

They described how they accessed help for their own drinking problems and there were mixed views about whether talking to health professionals or attending self-help groups made a difference, however the majority did report a positive outcome:

I started to realise that my drinking was now problem drinking and sought help from a counsellor ... After talking to the counsellor, who explained the progressive nature of alcoholism, that my drinking was alcoholic and that there was only one cure: i.e. total abstinence, it all fell into place.

[Participant 02]

I sought treatment and found nightly doses of Amitriptyline to be helpful. I have also decided to take part in a course of psychotherapy. Though I look upon the drug as a temporary measure, I will not lose sight of the principle that whatever helps me to limit the impact of the most distressing and intrusive of my experience is a good thing. I have retained control in my purposeful dealings with medical and mental health professionals.

[Participant 41]

I was in AA, and although I needed them it took years to let anyone near me. When I get that old feeling I am still the same. I still feel that for an adult child AA is a hard place to be if they do not have some kind of support behind them.

[Participant 40]

My girlfriend knew that I was an alcoholic and she persuaded me to enter a treatment centre...I spent 12 weeks at the centre drying out and afterwards

received lots of support by joining Alcoholics Anonymous, the self-help group for recovering alcoholics. I would never have stayed sober without them but it's now been 10 years since I touched drink.

[Participant 43]

Support and services for the family and children of parents who misuse alcohol

Talking to somebody

One of the most prominent themes that emerged when discussing help and support was the need to talk to somebody about what they were feeling and thinking. Many felt this was difficult to do, but once they did manage to talk to someone they felt relieved and found it helped to discuss their problems. A few people talked specifically about how having a supportive teacher to talk to was helpful:

The worst part was feeling alone and that I could ask no one for help. I used to dream about talking to someone and the relief that would bring but felt disloyal for even having the thought...I wish I had felt that talking to someone was an option. It never even occurred to me.

[Participant 25]

There is support – and although the pain, guilt and shame does come back sometimes, facing it with honesty and knowing that you are not alone, gives you the freedom to move on and build a purposeful life with meaningful relationships that help you to grow.

[Participant 44]

I finally realised that I needed to tell someone outside of my family, so I spoke to a teacher which helped a lot. I wish I had done that earlier. I now realise how much easier it would have been if people had known. Looking back I can see that I needed help. My teacher suggested ways in which she could help, and it sounded great, although sadly it was too late.

[Participant 01]

Another apparent theme was how having a strong parent (who did not have a drinking problem) who tried to maintain some sort of stability at home was helpful:

Despite all the problems alcohol caused, my Mother stood by us. She was torn apart but still put practical solutions in place.

[Participant 36]

My mother made enormous efforts to give us some normal family life but a lot of her attention was taken up with trying to keep my father calm and happy.

[Participant 43]

Talking to a professional and accessing treatment

Some gained help from mental health professionals, and others tried to find out more information for themselves, for example from self-help books. Most found it helpful to talk to a professional and understand more about alcohol problems:

Just to hear about the disease in a non-judgmental way and to be heard can end years of isolation and be profoundly healing. She (doctor) was fantastic and told me that she had once watched a woman patient drink herself to death and had no intention of letting that happen again and referred me to the psychological services. That was the best thing that could have happened to me as I began to learn to cope without drinking and talk a bit about the shame that had kept me closed for so long.

[Participant 25]

I began to devour self-help books and trawl websites aimed at people like me ... Initially just to experience the recognition was a relief. 'Yes, exactly' I'd say to myself. Then I began to ask 'why hasn't anyone told me this before?'

[Participant 37]

At college, my tutor organised counselling for me, I was really against the idea at first and went along determined not to take it seriously. But it really helped to have someone to talk to who wasn't involved in my life, who could see things from another perspective.

[Participant 38]

I have read all the self help books and I have to say if I hadn't read them to this day I don't think I would have ever understood why I'm like I am. Sadly it took me

nearly 20 years to realise the impact it had on me. I never realised until one day I sat in a counselling session.

[Participant 33]

However, the minority of people did mention negative experiences of accessing help:

Three years previously I had gone to AA and found the experience profoundly disturbing. I thought of my mother over and over again, listening to very familiar stories and knew that I had to deal with my feelings about her as well and the two problems were inextricably connected.

[Participant 25]

Even in therapy, only the people who were there with me know what it's really like – the pain, the terror, the blood, sweat and tears, the rage of helplessness and fear

[Participant 46]

Seeking help for the parent with an alcohol problem

Another reoccurring theme which emerged was the children and other family members trying to access help on behalf of the parent with the alcohol problem. A few people described how the family were in a situation in which they felt they needed to get the parent sectioned in order to get help:

We were desperate at this stage and tried to convince the doctors to section her. This would have meant forcing her to have treatment in a mental health hospital. The doctor said he couldn't and with that, I think her last chance went.

[Participant 01]

The only thing left we could do was to try and get him sectioned. The doctors agreed and were coming round the following day for him.

[Participant 09]

We had her sectioned with the thought that it would make her stop and realise what she was doing to her self and the people that cared about her. But she fell off

the wagon again, I called an ambulance for my mum and they had a go at me for wasting their time, my mum could have died, what was I supposed to do?!

[Participant 16]

We tried getting social services involved as she was physically and emotionally neglecting us all.

[Participant 23]

In March of this year I fought for an appointment for my father at the local rehab clinic and took him myself. He was admitted and diagnosed with Wernicke's Syndrome.

[Participant 24]

Others discussed trying to persuade their parent to access some form of help, but the majority reported an unsuccessful outcome:

I have tried every trick in the book to get my dad to go and get help. But right now, it seems I am at a dead end

[Participant 07]

The subject of my mothers drinking is occasionally mentioned around my mother but her reply is she knows she needs help. She never seeks it.

[Participant 18]

Summary of thematic analysis

There are some overarching themes experienced in childhood by people with parents who misuse alcohol. A dominant theme was that of avoidance and hiding the truth, which stemmed primarily from shame, fear and wanting a sense of normality. Concealing feelings and thoughts made approaching other people or services for support difficult, when most people just wanted to talk to somebody. This may have been exacerbated by feelings of anxiety and worry, in addition to a sense of guilt, self-blame and heightened responsibility towards the parent. When they did seek help on behalf of their parent, it seemed to occur in quite desperate circumstances, such as getting their parent sectioned. This suggests that children of

parents who misuse alcohol do not, or cannot, access the services and support they need easily.

There were also overarching themes experienced in adulthood that seemed to originate from childhood experience. Many people struggled to form stable relationships, which was often put down to lack of trust and self-isolation, and which impacted on work, social life and the ability to maintain a successful relationship with a partner. Such problems could have originated from not being able to form 'normal' friendships in childhood. Depression, and to some extent anxiety, emerged as longstanding psychological problems attributed to various childhood experiences as well as personal traits such as low self-esteem.

Development of own drinking problem was also a theme, in which alcohol was used to block out negative thoughts and experiences, or even used in an attempt to identify with the parent. There were also a range of common life choices that emerged, predominantly an impact on relationship choices and parenting skills. Some people also reported overcoming adversity by transferring the negative behaviours, thoughts and feelings into the positive ones.

There are some limitations to the qualitative analysis for this guideline. As the review team relied only on transcripts submitted to NACOA, information on other issues that could be particularly pertinent for children with parents who misuse alcohol may not have been identified. Moreover, people who have visited the NACOA website to submit their accounts may over-represent a help-seeking population. Finally, while some accounts are based on experiences that occurred recently, others occurred a long time ago; therefore there may be differences in attitudes, information and services available. For these reasons this analysis was not included in Chapter 4.