Making the connection

A report on how Alcohol Related Brain Damage affected socially isolated people during the Covid-19 pandemic
Tracey Stewart started CARDS in 2010 while she was working at Thorntree St., Rowan Alba’s homes-for-life for former street homeless men aged 50 and over. Since 2004 Rowan Alba has provided Scottish Assured tenancies and compassionate, individually tailored support in social environment.

The healthy relationships CARDS provides are the vehicle for positive health outcomes. This is empowering for service users as the informal discussions around mental health, addiction, recovery, and general health allows CARDS’ service users to make better informed decisions. This has also given service users the confidence to start conversations with family, friends and medical professionals about things they were once too anxious to approach. Creating opportunities for our service users to increase the number of supportive people they have in their lives is vital, especially when most of our clients never had an example of this for some time.

The relationship with alcohol took over, but CARDS helps to bring a little balance back to their lives.

The sensible and pragmatic approach of tackling a big issue like addiction, with the simplicity of CARDS support, is what makes CARDS successful.

One service user shared how much of an impact CARDS has had on their life:
“I had barely been over my door for years because of anxiety. I was referred to CARDS by my doctor after a stint in hospital. I would walk down my stair 4 or 5 times a day and not make it on to the street. Rebecca the volunteer chummed me to the corner shop. We had 34 failed attempts before that. This is where it started. Almost nine years ago. Since then, I have had 8 different volunteers, only 2 short lived relapses and have never seen the inside of the A & E room since. I was what they called a frequent flyer. Not any more, thanks to the knock at my door once a week.”

We hope that this ARBD Report helps those understand the seriousness of alcohol harm and the profound need our community has for more safe places for people who live with addiction.

This report would not be possible without Rowan Alba, the sponsorship from RS Macdonald and the consultancy work provided by Befriending Networks UK. We have deep gratitude for our wonderful clients, volunteers, staff and third sector partners who agreed to participate in this report. A special thank you to Michaela Devlin for sharing her story in the hopes of helping others.

If you would like to learn more about CARDS or would like to collaborate with us, please contact cards@rowanalba.org for more information.

Foreword

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Tracey Stewart
Rowan Alba CARDS Service Leader
1. Introduction

The COVID-19 pandemic has affected all of us in many ways. It has especially affected our service users of CARDS (Community Alcohol Related Damage Services). We knew that our clients would face many challenges with the added stress of lockdown, and it was important for us to make our presence known to them during this time more than ever before.

The Scottish Government reported that 2020 saw a 26-year low in alcohol sales because of the restrictions incurred by the national lockdowns due to COVID-19. Despite these numbers, people across the country struggled with managing their addictions over the past 18 months. Through a commissioned report by Befriending Networks, Rowan Alba’s CARDS found out how vital social and community engagement is for people who live with an addiction. Additionally, the report examines how Alcohol Related Brain Damage (ARBD) affects CARDS services users and, subsequently, how those results can be helpful in changing the way problematic alcohol use is approached by the community at large.

Our partners

This report has been made possible through the support and partnership of RS Macdonald, Befriending Networks and NHS Lothian.

Areas for growth highlighted by this report

With this report, CARDS has been able to identify the following areas for growth and education to support those that experience alcohol addiction:

1. More robust offerings of community-based peer support
2. Ending the social stigma of alcohol addiction
3. Bridging the gap between mental health and addiction services

We believe that strengthening these pillars, along with engaging people during their initial hospital admissions and providing more accessible rehabilitation options for those with alcohol addictions, we can continue to reach more people who need our help. Rowan Alba and CARDS believe that if these pillars are acted upon by government and private sector organisations, it would be possible to make a significant impact on the community.

2. Background to this report

People across Scotland have struggled to manage their addictions since the start of the Covid-19 pandemic. This report aims to highlight the combined effects of social/community isolation and ARBD on the CARDS client base.
2.1 Defining ARBD

ARBD refers to the damage that the brain incurs due to long-term excessive alcohol consumption.

In Scotland this is defined as consuming 50 or more units of alcohol per week in men and 35 or more units of alcohol per week in women. The brain damage can manifest in different ways, including memory loss and difficulties with problem solving and decision making. ARBD tends to affect people in their 40s and 50s, with females presenting a decade younger than males. Because of this, ARBD is often misdiagnosed as dementia or other cognitive degenerative diseases due to the similarities of the symptoms.

According to the Scottish Health Survey 2018: revised 2020, around 24% of adults drank at hazardous or harmful levels, with men being twice as likely as women to drink at hazardous or harmful levels. Among men the highest prevalence of harmful drinking was found in those aged 55 – 64, while in women this prevalence was in those aged 45 – 54. These are the ages at which ARBD develops within men and women.

People with ARBD are often overlooked and stigmatised because their condition was brought on by alcoholism. They can be perceived by medical and support staff as difficult to help, and there may be a judgement from others because it’s perceived that their problems are self-inflicted. People who live with alcoholism often become estranged from their families and can be socially isolated. When this is compounded by the effects of ARBD, there can be no one around to help.

According to the Mental Welfare Commission, 75% of people with ARBD do improve with proper rehabilitation and social support. The issue lies with receiving that proper care.

Building positive social relationships and developing structure and routine have been demonstrated to improve outcomes in the context of long-term rehabilitation.

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2.2 Research Aims

The overall aim of this report was to assess the impact of ARBD on the lives of CARDS clients pre Covid-19 and during the lockdown period between 2020 and 2021.

This report also aims to qualify the impact of the service offered by CARDS. Finally, this report was created to identify any changes in the support needs of clients during this period, and recommendations for future service planning.

2.3 Methodology

Data was collated through interviews, an online survey and email correspondence. In addition to the one-to-one interviews, a group discussion was held with members of the CARDS staff.

A total of 47 participants involved in research for this report:

<table>
<thead>
<tr>
<th>Audience group/setting</th>
<th>Number of participants</th>
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<tbody>
<tr>
<td>CARDS Clients - Informal discussion</td>
<td>20</td>
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<tr>
<td>CARDS Clients - Formal interviews</td>
<td>8</td>
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<tr>
<td>CARDS Staff / Locums - Interviewed</td>
<td>9</td>
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<tr>
<td>Professionals from referral organisations including NHS Alcohol Liaison Team</td>
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<tr>
<td>Professionals from Alcohol Industry</td>
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At the start of this project, COVID-19 restrictions were easing and, as a result, the initial interviews were carried out face to face with some of the clients. Since the tightening of restrictions in late 2020, all interviews took place by telephone or using an online platform such as Microsoft Teams and Zoom.

Names that where mentioned have been changed to protect the identities of those involved.
2.4 Public Health Scotland report on Alcohol sales & harm in Scotland during the COVID-19 pandemic

In February 2022, Public Health Scotland released an extensive report on the public health impacts related to alcohol during the Covid-19 pandemic.

While it was not possible for Rowan Alba CARDS to have considered that report during the compilation of this report, it’s findings confirmed some trends we saw from our communities.

“Of concern is the potential that groups with high levels of alcohol consumption before the pandemic may have increased their alcohol consumption, had reduced access to hospital treatment for alcohol-related conditions, and potentially experienced higher rates of mortality as a consequence.” 7

Although the report recorded a drop in alcohol-related hospital admissions and a fall in On-sale alcohol sales, those results are set against a rise in Off Sales of alcohol and ultimately a sharp rise of alcohol-specific deaths of men aged 45-66.

Key findings of the report

- On-trade alcohol sales were 66% lower in 2020 than the 2017–19 annual average, and 95% lower between January and May 2021 than the average for the same period of 2017–19.

- Over the same time period, alcohol sales for consumption off the premises (supermarkets and shops; off-trade) increased by 13% in 2020 and 15% in 2021 (January to May), compared with the average for 2017–19.

- Following the start of the pandemic, there were fewer hospital stays involving a diagnosis entirely attributable to alcohol (‘alcohol-related hospital stays’) than average. Rates were 7.3% (95% CI: 5.9% to 8.6%) lower in 2020 than the 2017–19 average.

- Alcohol-related hospital stays fell by the largest amount during the periods when the most stringent COVID-19 restrictions were in place.

- Rates of alcohol-related hospital stays decreased most for males, those aged over 45 years, and those living in deprivation quintiles 1 (most deprived), 2 and 4. In general, these groups had the highest rates of alcohol-related stays in 2017–19.

- Deaths from causes wholly attributable to alcohol (‘alcohol-specific deaths’) increased following the start of the pandemic. This was driven primarily by an increase in alcohol-specific death rates among males and those aged 45 to 64 years.

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7 Alcohol sales and harm in Scotland during the COVID-19 pandemic
Elizabeth Richardson, Lucie Giles, Catriona Fraser February 2022

David Milne
CARDS Peer Support & Community Engagement Co-Ordinator
3. Findings

In this section we look at the unique personal insights gathered by CARDS during the creation of this report.
3.1 Impact of ARBD on CARDS Clients

The reported impacts of ARBD from the client participants ranged from physical, mental, and emotional.

These include, but are not limited to, poor memory, limited mobility, cognitive impairment, depression, anxiety and low self-esteem. Those impacts can be different for someone who has a strong relationship with a support network of family and friends. For individuals who do not have such connected support, the impacts can be even more severe. This observation from CARDS staff was apparent in interviews with different clients. Those who did not have close family relationships appeared to find their situation more challenging than those who had close and regular contact with their support network.

Stigma was discussed by every client who participated in interviews. In interviews, there is a sense that the public perception of alcoholism and ARBD being a ‘self-inflicted’ condition contributes to lack of care from professionals and loved ones. Public perception and trauma have influenced how greatly ARBD impacts on individuals, particularly those who had been involved with CARDS for some time. They all spoke about the impact of their condition and how they felt the support they received from CARDS had made a difference.

“I couldn’t go out. I had fallen out with my family and didn’t speak to them. I didn’t speak to anyone.”

Larry CARDS client
Larry, a CARDS client said, ‘Before I met (CARDS volunteer) I couldn’t go out. I had fallen out with my family and didn’t speak to them. I didn’t speak to anyone.’

Others spoke about memory problems, physical health issues and isolation. Before becoming CARDS clients, all the participants interviewed said they experienced increased anxiety when thinking about going outside. Whether it was due to physical comorbidities or emotional difficulties, it in turn led to an avoidance of going out altogether. However, since being a client, all participants reported they felt more confident about going out into the community on their own and 95% of participants attributed this success to the companionship of their CARDS volunteer. CARDS volunteer Molly stated, ‘My client has problems getting out because she doesn’t feel comfortable socialising on her own.’

Prior to joining CARDS, clients had difficulties with daily tasks because of the memory and cognitive impairments due to ARBD. After joining CARDS, 66% of clients stated that they were more aware of how their memory affects their lives. 80% of clients felt that using methods such as creating lists and keeping a diary, which they learned from CARDS, have helped manage their daily tasks. In addition, 73% of the participants felt that they had more confidence to discuss their ARBD symptoms with medical professionals, because of the education and encouragement provided by CARDS.

While some clients have regular and supportive contact with family members, others have lost touch with family or have difficult relationships with them. This can also contribute to poor mental health, social isolation, and loneliness.

Professionals from statutory and other voluntary sector services, who made referrals to CARDS, spoke of the tremendous impact ARBD can have on the lives of their patients and/or clients. ‘It affects their everyday lives, functioning, understanding, daily interactions.’, said one referrer.

The Edinburgh Royal Infirmary are one of the few hospitals that have dedicated specialised Alcohol Liaison Nurses. These nurses play a major role in identification and prevention of alcohol harm at an early stage.

The close communication CARDS have with the staff undoubtedly prevents re-admission and significantly increases chances of recovery or harm reduction. The development of the relationship between the alcohol liaison team and the CARDS team is our most vital strategic aim for the future.

Tracey Stewart CARDS Service Leader
I had a very long history of alcohol abuse, lived a chaotic lifestyle, and presented at hospitals on numerous occasions. Over the years I was prescribed Acamprosate and Antabuse and received numerous detoxes. I was often prescribed Thiamine, told it was very important that I take it, however I do not recall being told why. My daily life was so unmanageable I would often forget to take it or not have access to a steady supply.

As my alcohol abuse got progressively worse so did my health. I started to notice that I could not read properly, my eyes were unable to focus, and I could not see the words. I could not hold objects as I had no grip and I was unsteady on my feet, even when I was not particularly drunk. I struggled to walk downstairs, my legs were unsteady and felt like jelly and therefore would wobble terribly with each step. This was frightening and dangerous for me as well as embarrassing. I was extremely forgetful, and I could not form or hold a thought or piece together facts. At this stage I was unaware that I had alcohol related brain damage. Any medical advice I received at the time generally focused on liver damage and was consistently tested for my liver function. I do not recall ARBD ever being mentioned or receiving any cognitive function tests despite regularly attending hospital and addiction services.

3.2 ARBD Case Study

The following is an account from Michaela Devlin, a former CARDS volunteer and current staff member who shares her experience of alcohol addiction and ARBD.

I started to notice that I could not read properly, my eyes were unable to focus, and I could not see the words.”
I eventually secured a place at an NHS Addiction Treatment Centre and began a programme of recovery for my alcoholism. Alongside therapy we received information on addiction in the form of talks and lectures. I was shocked to be told that alcoholism was an illness and though it was often fatal and progressive it could be treated. Up until then I had thought of myself as weak or bad; it never occurred to me that it was an illness. During one of our lectures, we learned about the effect alcohol has on the brain. We were shown slides of healthy brains and addicted brains. We were told that substances change the structure of the brain, the neural pathways and that damage is progressive. I recall a therapist telling us that all our brains were damaged and that it could take up to two years for this to improve, provided of course we remain abstinent and there was no lasting or irreparable damage. I found this to be a revelation, it explained why I could not read or write, my wobbly legs, my inability to form proper thoughts or to concentrate and my general clumsiness. It meant that I could recover, my overall quality of life would improve, and there was hope for me. I was also painfully aware of what was ahead of me if I did not remain abstinent.

I realise now how close I came to having permanent irreparable brain damage. One of the criteria for clinically diagnosing ARBD is drinking an average of 35 units (female) for a period of more than five years. It generally affects people in their 40s and 50s with females presenting a decade earlier. I was 46 when I entered the treatment centre and had been drinking at dangerous levels for well over a decade, yet my ARBD was never mentioned or investigated.

My overall recovery is simply down to luck in getting a place at the treatment centre and has involved a lot of support and hard work on my part. Unfortunately, the majority of those affected are not so lucky in finding treatment. I have been abstinent from alcohol over five years. My health is excellent considering what I have been through. I am aware of slight memory loss, an inability to record or recall facts and figures and forgetting certain words during conversations, however, I do manage to function well on a daily basis. I have various diplomas and degrees and a background in accounting, so I am painfully aware of the difference now in my overall brain function.

I was 46 when I entered the treatment centre and had been drinking at dangerous levels for well over a decade, yet my ARBD was never mentioned or investigated.

After volunteering for CARDS for several years, I am now a full-time employee. The care, dedication and support they provide to clients, volunteers and staff is outstanding. Their knowledge of ARBD and alcoholism, and especially their commitment to raising awareness of this condition, is what inspired me to volunteer with them in the first place.

ARBD has been described as a silent problem. Sadly, this will remain the case whilst it is misunderstood, stigmatised, under diagnosed and left untreated!
3.3 Impact of COVID-19 Lockdown

This report on experiences in lockdown had a wide range of results, including varying views and emotions identified.

Some clients said that they had not previously gone out a great deal and that, from that perspective, they had not noticed a real impact of lockdown. One volunteer spoke about her client, Annie, who has managed lockdown well. Annie was so used to being at home, for her that was her security as she found it difficult to leave her house before, as well as during, Covid-19. She was not socially isolated, having her partner and friendly neighbours in the same building. To some degree Annie felt that lockdown worked in her favour, as being at home was comforting to her.

The current situation almost gives some clients permission to do what they want. Many felt that it reduces social expectations. One client, Elsa, did feel that she should be trying to get out, but recognises that she copes with lockdown better than others might. Elsa felt that she is not the only one who is anxious, which made her feel better about the situation.

Some clients reported that they did not like to go out unless it was necessary. If anything, their anxiety about going out has increased. Will said, ‘I am still anxious about having to go to Tesco in the afternoon. I usually have to have a drink before I’m able to go out.’

“I’m finding it difficult because I like to get outside but I can’t go by myself”

Anna
CARDS Client
One client felt that when he couldn’t go out to the shops, that made it easier to not drink. When lockdown eased however, he started to drink again.

CARDS staff found that some clients could not get access to support and have been struggling along day to day. There is some uncertainty about how clients will cope when things return to some level of normality. Before Covid-19 most clients could go out for walks alone but were scared to go out. This has been exacerbated by Covid-19, preventing them for going outside altogether.

Several clients said they missed the company of their assigned CARDS volunteer. Most did still speak regularly on the phone and two were able to meet up outdoors during the better weather to go for a walk, but many reported missing the group activities and outings. Since the end of 2020 until May 2021, volunteers were unable to visit clients who were homebound and were limited to contact through phone. For clients, not having regular visits during lockdown has had a real impact. Lockdown, for some, been a very isolating experience. One client, Anna, explained that she and her volunteer went on weekly trips to a shopping centre before lockdown. Anna was missing the opportunity to get out to the shops and for a coffee and felt shut in. She said, ‘I’m finding it difficult because I like to get outside but can’t go by myself.’

MISSING CARDS TRIPS
Before the outbreak of Covid-19, CARDS had arranged several group trips, including going to the National Portrait Gallery, the Botanic Gardens and the National Museum. All clients who had joined in these outings had enjoyed them and were missing such opportunities. ‘I really miss group meetings. Someone would pick me up to get there. I was getting used to going out because I was anxious about going out but had got used to it and looked forward to it, when lockdown started. I feel depressed because I can’t do anything or go anywhere,’ said client Bob. Activities that have been established for clients during lockdown include photography and art projects. Materials were sent to clients with ideas for what they might do with their new circumstances. This has provided some real interest for clients, some of whom had not taken part in any art activity for many years, in some instances since schooldays.

MOBILITY ISSUES
The lockdown has created practical problems for clients with mobility issues. Two of the clients who took part in interviews had been assessed for mobility aids for their homes before the lockdown. Both are waiting for ramps and rails to be built to allow them easier access into and out of their homes. These seem to have been delayed now for at least a year.

A staff member from a referral agency reported on problems for a patient who had been working towards resolving some difficult personal issues. Lockdown and the pandemic have added to the problem, making resolution of these issues even more difficult than they had been.

PROFESSIONAL OPINIONS
Professionals have expressed concern about the impact of lockdown. One reported that, for many clients, the restrictions of lockdown mean their usual drinking places are not available and thus they are more isolated. Community connections are not possible and because of that there is no contact with others. People may be drinking more, and this will be missed by services that have not been active during lockdown restrictions. Also, fewer people are going to hospital due to anxiety about potential infection.

IMPACT ON SERVICES
One impact identified by a referrer is that due to the need for social distancing and requirements for comprehensive risk assessments, it has been more difficult for statutory and voluntary alcohol and addiction services to provide the levels of hands-on support they previously offered. In those circumstances there is a greater likelihood that people will be less able to cope. This can hinder development during the treatment and recovery pathway.
4. Looking Forward

All participants were asked about their thoughts on what Rowan Alba and CARDS should consider in terms of any future developments.

Clients, volunteers and referrers all felt that the service should be more widely available. The consensus was that the approach and ethos at the core of the service are what make it so valued and successful, and so it would be important to ensure that these essential elements were retained and built upon.

Recent research from Alcohol Change UK shows a strong need for services that support high risk drinkers in making positive changes to their drinking. Their study showed that between 60-70%* of apparently non-changing higher risk dependent drinkers want to make positive changes to their drinking. 40%* of higher risk dependent drinkers actually take action to try and change each year.

Michelle
CARDS NRI Hospital Liaison
Since January 2022 Michelle has been supporting specialised Alcohol Liaison Nurses to offer holistic community-based support to high-risk drinkers before they are discharged into the community.

Once discharged CARDS community support services begin regular visits to the clients, enabling them to make positive changes, in a supported and sustainable way.

Considerations for development, suggested by respondents, are as follows:

- Engagement beginning at the hospital: A CARDS volunteer to meet client before discharge. This would help reassure clients who might be reluctant or fearful about what they are being asked to engage with. With such a visit they would be more likely to engage.

- Increase CARDS visibility to Health & Social Care Teams and GP Practices to allow us to maintain our client relationships when their personal circumstances change.

- Grow Rowan Alba’s community projects such as our Art Project, Digital Literacy groups and CARDS Café groups. We aim to support wider development of peer support within all of our groups.

- Provide training and resources to Bar staff and Off-sales staff to enable them to identify vulnerable people who may have a problematic relationship with alcohol, at the point of sale. CARDS has developed a suite of these training and resources in collaboration with Alcohol Change UK.

- Continue to prioritise effective outreach. By assertively maintaining regular home visits we can focus on building healthy relationships with our clients. In time, this allows us to understand and support them holistically, including linking them with other vital services.

- Advocate for services to not be made available on condition of sobriety. The reason why CARDS is effective is that it uses a human-centred approach instead trying to force clients to fit into something that does not help in the long run.

*Source Alcohol Change UK
5. Conclusion

From this study, it is evident that ARBD can be combatted through emotional support that is provided by the CARDS service.

Community-based interventions are the future in helping those with alcoholism feel that they are not alone or being stigmatised. The impacts of the Covid-19 lockdowns illustrate how important these emotional bonds are in creating a sense of self, autonomy, and purpose for the clients. The pandemic has reminded us that we, as a society, need to focus on the person to solve a problem. Through more community outreach programmes around addiction and mental health, and more advocacy in accessible psychoeducation around these issues, it is possible to end the stigma around alcoholism and ARBD.

CARDS hopes to lead a conversation around creating more community outreach programmes with similar foundations to create positive change.
For more information about this report and the work CARDS does, please contact:

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