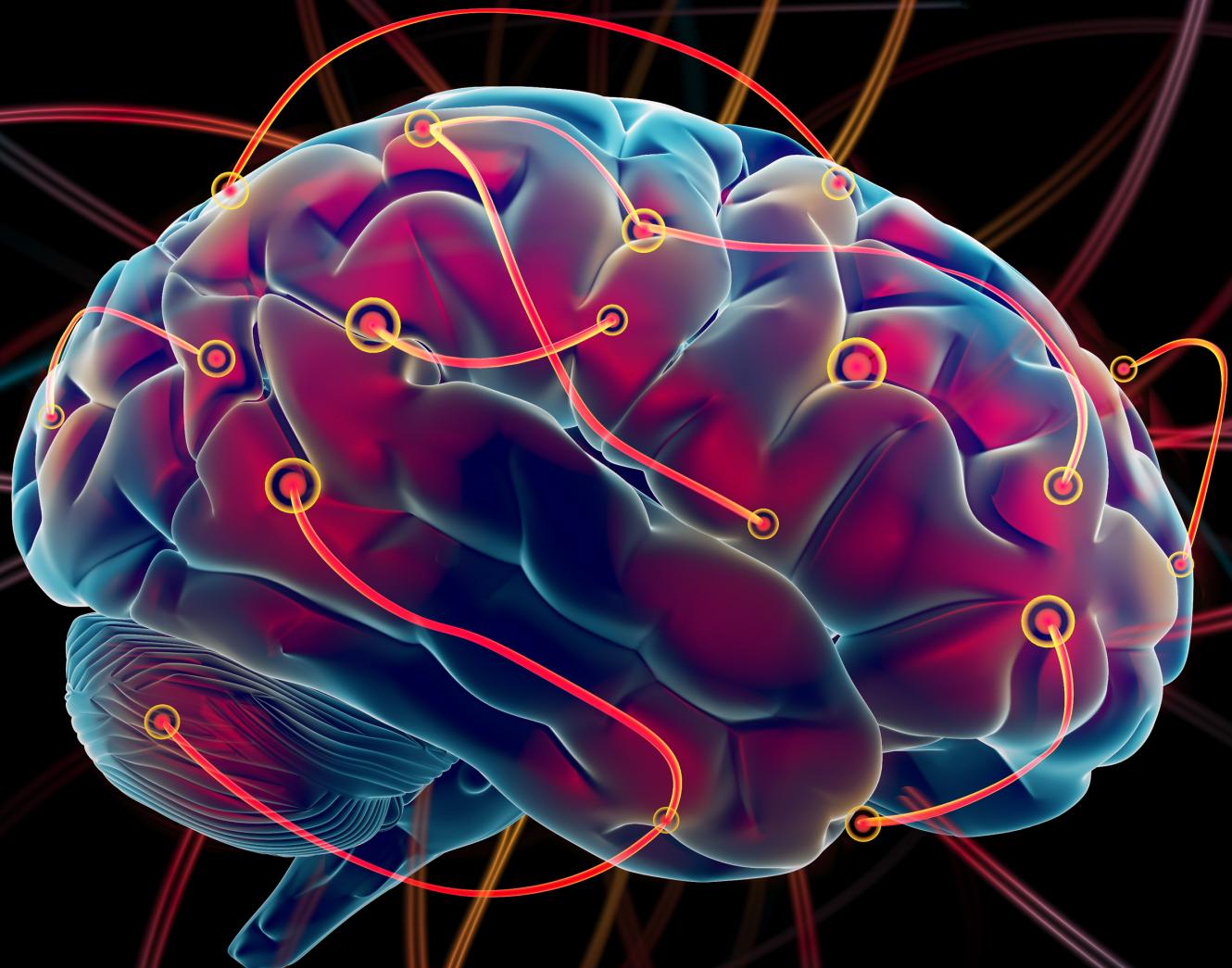


EDITION 5, SPRING/ SUMMER 2021

SPARKING CHANGE

A Newsletter from Alcohol Forum Ireland



ALCOHOL AND BRAIN HEALTH

Spring/Summer 2021

INTRODUCTION FROM THE CEO



ALCOHOL AND BRAIN HEALTH INCREASINGLY A 'CRADLE TO GRAVE ISSUE'

As Ireland's older population continues to grow, the maintenance of brain health is increasingly viewed as a key component of positive ageing and public health.

Alcohol-Related Brain Harm is an invisible but growing problem – ranging from early childhood years to older age – and is the source of decades of disability and lost potential in Ireland.

In this edition we account for the evidence that alcohol consumption plays a large role in brain health across the lifespan and demonstrate some of our responses in this area. At Alcohol Forum Ireland, we believe that future brain health strategies, either nationally or on a European basis must be inclusive of alcohol as a significant contributor to population brain health. We are also calling for brain health to be used to inform government policies and public health measures aimed at reducing population level alcohol consumption. There also needs to be greater cross sectoral collaboration in responding to conditions such as FASD, Alcohol-Related Brain Injury, TBI and Dementias that focus on implementing research, developing strategies for prevention, early detection, diagnosis and ongoing support frameworks.

We outline some of our work in responding to Alcohol-Related Brain Injury – sharing the experiences of family members supporting a loved one affected by this condition – and demonstrate that support can make a difference, but much more investment is needed to meet their needs.

Kieran Doherty
Chief Executive



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Connecting the Dots

Working together to improve psychosocial care for all people with cognitive impairments

“

Our ongoing experience at Alcohol Forum Ireland consistently shows that public awareness of alcohol-related brain harm is disproportionately low

”

WORLD BRAIN DAY



Maintaining a healthy brain is increasingly considered one of the most important goals in pursuing population health. On World Brain Day, we put forward that alcohol is a lifespan brain-health issue globally. From Fetal Alcohol Spectrum Disorder (a lifelong brain-based condition resulting from the use of alcohol during pregnancy) to Dementia in older age - alcohol and brain harm is an ageless concern affecting all groups across society.

Dr Helen McMonagle
Alcohol and Brain Health
Programme
ARBI Rehabilitation Coordinator

Recognising the life-course impact of alcohol on the brain enables us to prevent and control brain harm at key stages during our lifetime. It is simply not enough to respond when harm has occurred – the decades of disability caused by these conditions makes this unacceptable.



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The 2030 Sustainable Development Goals (SDGs) promote a commitment to “ensure healthy lives and promote well-being for all, at all ages”. A life-course perspective on alcohol-related brain harm supports the formulation of policy and public health interventions aimed at reducing risky alcohol use at all ages. Such an approach recognises the potential to protect all generations from disability.

This needs to begin at the earliest point in life - pregnancy - and follow through to interventions aimed at young people, adults and the elderly.

The reduction of alcohol-related brain harm requires coordinated support across governments, research communities and our health/social care sectors. In the past seven years, a number of large scale brain health initiatives have been launched in several countries across the globe. They aim to promote the development of neuroscience and strategies to enable population protection from brain harm. Despite this, most of these initiatives have remained silent on the issue of alcohol.

On the following pages, we document a devastating array of brain-based conditions caused by alcohol in our communities and focus on one condition (ARBI) to tell the lived experiences of those affected. Alcohol Forum Ireland emphasizes the need for primary prevention, a community and population approach, and an explicit commitment to eliminate disparities in personal health and health care for those that are impacted by alcohol-related brain harm. We are calling for alcohol to be recognised as a central tenant of population brain health research, strategic planning and policy.

WHAT'S THE HARM?

ALCOHOL AND BRAIN HEALTH

Fetal Alcohol Spectrum Disorder

Pre-natal alcohol exposure is the leading cause of preventable intellectual disability in the world. It is a brain-based impairment resulting from pre-natal alcohol exposure that affects one million babies born across the globe every year. Ireland is one of the five countries with the highest prevalence of Fetal Alcohol Syndrome (the most severe end of the FASD spectrum). It is estimated that 600 babies are born with Fetal Alcohol Syndrome each year in Ireland and 40,000 Irish persons are living with the condition. Children and adults with FASD can experience behavioural deficits, difficulties with regulation of mood or behaviour, cognitive deficits and impaired executive functioning that represent life long disability.



Adolescent Brain Development

The adolescent brain has a different and largely greater sensitivity to alcohol than the adult brain. There is emerging evidence that suggests a likely causal association between alcohol use in adolescence and structural changes to the brain, particularly structural hippocampal changes (memory) and grey matter development (information processing).



Dementia

Alcohol use disorders have been recently found to be a major risk factor for the onset of all types of dementia, and especially early onset dementia.



Traumatic Brain Injury

Intoxication is a factor in 24-50% of traumatic brain injuries globally.



Alcohol-Related Brain Injury

Alcohol-Related Brain Injury (ARBI) describes a clinical syndrome due to structural and functional brain changes which occur as a consequence of chronic, heavy alcohol use. There is no single cause of ARBI, which usually results from a combination of factors - these include the toxic effects of alcohol on brain cells and vitamin and nutritional deficiencies. ARBI can interfere with memory, attention, planning, judgement, processing new information and problem solving skills. 25% of people who develop this condition may not recover.

WHAT'S THE HARM?

ALCOHOL AND BRAIN HEALTH

Marchiafava-Bignami Disease

MBD is a rare progressive neurological disease resulting from demyelination of the corpus callosum - it is most commonly seen in chronic alcohol dependency. Features include : progressive intellectual deterioration, emotional disturbances, confusion, hallucinations, tremor, rigidity, seizures and ataxia . Prognosis is poor and can progress to coma and death in a few months.

Epilepsy

Alcohol is associated with different aspects of epilepsy, ranging from the development of the condition in chronic harmful drinkers and dependent individuals to an increased number of seizures in people already with the condition.



Delirium Tremens

When a person suddenly ceases dependent alcohol consumption, they are at risk of developing alcohol withdrawal syndrome or delirium tremens. Life threatening symptoms can develop including severe confusion or delirium, physical tremors, extreme agitation and irritability, stupor, seizures or convulsions.

Central Pontine Myelinolysis

This condition belongs to the spectrum of osmotic demyelination syndromes (ODS) and is frequently associated with chronic alcohol dependency. Osmotic stress, endothelial dysfunction, and blood-brain barrier damage are the key pathogenetic steps in the development of demyelination in ODS and may be influenced at multiple levels by alcohol-related pathogenetic mechanisms. The clinical presentation and outcome in ODS can be extremely variable - from asymptomatic cases to severe neurological deterioration with a considerable morbidity and mortality.

**“ PRIORITIES NEED TO BE
IDENTIFIED FOR THE ACTIONS
NEEDED TO
DEAL WITH NEUROLOGICAL
DISORDERS ASSOCIATED
WITH THE INGESTION OF TOXIC
COMPOUNDS ,”**

**WORLD HEALTH ORGANISATION,
NEUROLOGICAL DISORDERS PUBLIC HEALTH
CHALLENGES**

NEWS

No Safe Level of Alcohol Use for Brain

A recent Oxford University study of over 25,000 brain scans of people in the UK indicated there was 'no safe level of alcohol use for brain health'. The study (currently being peer reviewed) suggests that the more alcohol is consumed, the lower brain volume becomes, particularly grey matter density. The impact of alcohol on brain health was shown to be four times greater than the impact of either smoking or BMI.

Topiwala, A., Ebmeier, K. P., Maullin-Sapey, T., & Nichols, T. E. (2021). No safe level of alcohol consumption for brain health: observational cohort study of 25,378 UK Biobank participants. medRxiv.

Political commitment to ARBI service development

Launching their Community and Addiction Recovery Strategy on the 16th of June, Sinn Féin outlined their vision to establish a number of '*pilot projects that will fill gaps where vulnerable people often fall through the cracks*'. People with Alcohol-Related Brain Injury (ARBI) have not been named in any government policy or strategy – they exist in a policy vacuum which presents major barriers to the development or provision of services to meet their needs. Sinn Féin outlined their proposals for establishing a Working Group on ARBI and work with existing service providers to rollout a residential and community-based rehabilitation services commencing with a pilot programme.

https://www.sinnfein.ie/files/2021/Community_Addiction_and_Recovery_Strategy_.pdf

Leonard Cheshire Virtual Conference

Following their successful launch of a specialist residential rehabilitation centre in Belfast - Leonard Cheshire hosted a virtual conference on Alcohol-Related Brain Injury on 25-03-2021 . The theme of hope featured throughout with expert and service user input highlighting the potential and possibilities for recovery. Speakers included Dr Jenny Svanberg, Professor Kenneth Wilson, Grant Brand, Diane Wilson and Dr Anne Campbell. An interactive panel discussion was chaired by Dr Helen McMonagle and Sheila Gilheany (CEO, Alcohol Action Ireland) and centered on the need for the development of treatment pathways on the island of Ireland.

IN FOCUS: ALCOHOL-RELATED BRAIN INJURY

Alcohol-Related Brain Injury (ARBI) continues to be a growing concern in Ireland. Speaking at the government launch of Minimum Unit Pricing, Professor Siobhan MacHale, a consultant liaison psychiatrist at Beaumont Hospital cited a mother in her 40s with alcohol-related brain damage who did not recognise her 12-year-old child. “*This is not an isolated case*” says Dr Helen McMonagle - “*this condition is being seen across our hospitals and communities – a problem hidden in plain sight with little by way of support for people affected – it can result in decades of disability with no option of rehabilitation currently available in the Republic - this is a major area of concern involving vulnerable adults not getting the support they need*”

Like many other alcohol-related issues, the harm associated with ARBI extends beyond the individual. In this edition, we examine what families experience in the absence of accessible neurorehabilitation and structured community support services for people with ARBI.

Earlier this year, Alcohol Forum Ireland spoke to three families impacted by this condition to make their daily struggles visible. These interviews unveiled 4 key themes:

A lack of understanding of ARBI across various professional groups and among the general public.

A need to move away from older persons services

More dedicated core resources – OT, physio, respite – services provided within community services were often felt to be too generalised and non specific to meet the persons needs.

Lack of Parity with other conditions

“ He's not the right age, not the right disability, the right brain injury. They can help the elderly, they can help different disabilities but this doesn't seem to come under illness or disability – it doesn't fall under any category. It's a name they give you in the hospital and then that's it, it leads to nowhere. ”

NEED FOR MORE DEDICATED RESOURCES

FAMILY ONE

We got HSE physio and he gave him a list of exercises and you know that XXXX won't do them by himself.....he needs someone to do them with him – we got private physio for 60 euro a session and he was really good and proactive and enthusiastic.. talked about how important blood flow to the brain is and got all the physio done but we cant afford that all the time

Respite – "I worry about what would happen if something happened to me.....I was on a flight and they needed to make an emergency stop and a carer of this old man was taken by an ambulance and he was left on his tod...if that had been me and XXXXX god knows what would happen....theres little respite from being a carer.....there's worry about where he'd go and how he managed if I wasn't here.

FAMILY TWO

We saw a few other people once or twice but you've been the only person to show up at the door Where do you start - it seems like physio or an OT would be winning the lottery, very basic things like respite..... help at home would be life-changing, a support package that would help him be more independent in the house and outside the house, so many small things would make a big difference but they are not available as standard things for Korsakoffs and that needs to change.

Respite: The only respite I get is if I'm in hospital myself

FAMILY THREE

"Just terrible.....you think that having any condition would make services available but this one seems to close more doors than it opens (laughs) - I might laugh but not going to lie it has been hard and its helpful having someone to support ya in these battles, and there has been many many battles, but people don't understand that until you live with someone with this condition how hard that can be and then people not understanding and having to explain all the time to people that are supposed to be the professional - that's tough going full stop."

A NEED TO MOVE AWAY FROM OLDER PERSONS SERVICES

FAMILY ONE

"The Nursing Unit was very good and he came on a lot but there has to be something for people who are younger.... but some professionals in there have always been presenting things very negatively - you know what he couldn't do, what he'd never be able to do, always focusing on what couldn't be done what couldn't be achieved, told by the XXXXXXXX that he'd never be able to live independently EVER!"



FAMILY TWO

And the only options were a Nursing Home and we didn't want to do that – as much as we were angry we didn't want him in a Nursing Home with old people....because he's not old..... so we care for him and you think this is my loss, but what you don't understand how little is out there to support him and how demanding it is...you're just a carer, it takes over your whole life..... he still is aware of a lot of what is going on around him and it is very difficult to convince him to go into an elderly persons service facility where they are all over 80 and that's frustrating and you'd love to know what is going to through in his head, what about his its dignity

LACK OF UNDERSTANDING OF ARBI ACROSS PROFESSIONALS AND GENERAL PUBLIC

FAMILY ONE

"Yourselves have been the best in terms of in depth knowledge of it but people from the medical profession they know and they've heard of it but they probably lack direct experience of working with people with this condition and you see that whenever you have a doctors appointments they will ask him a lot of questions about things but he doesn't remember things and he'll guess or he'll give the wrong information and the doctor will assume that's true or the opposite they'll focus on their attention on me and ignore him and that annoys him – if you knew about Korsakoffs you might have more of a balance."

FAMILY TWO

"There is no services, you're the only service we have had and there are people in the medical profession that you speak to and they ask you what is Korsakoffs - its crazy, it's a diagnosis, and it's a diagnosis that nobody knows nothing about and a lot of ways its like caring for someone with dementia – you have to set your life to a routine for that person, its takes over your life, you are just a carer – but everybody knows about dementia and how demanding that can be but nobody knows anything about ARBI and it's a struggle."

FAMILY THREE

"Just terrible.....you think that having any condition would make services available but this one seems to close more doors than it opens (laughs) - I might laugh but not going to lie it has been hard and its helpful having someone to support ya in these battles, and there has been many many battles, but people don't understand that until you live with someone with this condition how hard that can be and then people not understanding and having to explain all the time to people that are supposed to be the professional - that's tough going full stop."

LACK OF PARITY WITH OTHER CONDITIONS

FAMILY ONE

"There's also that stigma and discrimination because of the cause of the condition and it doesn't have equal parity of treatment in comparison to other brain injuries or other conditions, and even not getting the full attention that people with alcohol problems get – there's treatment centres all around the country for alcohol or drugs or brain injury– where is the treatment centre or the rehabilitation for Korsakoffs – there's dedicated centres for drug problems"

FAMILY TWO

"They can help people with MS or spina bifida or dementia or any other disability but with this one, there just seems to be nothing out there for them....he's not the right age, not the right disability, the right brain injury..... They can help the elderly, they can help different disabilities but this doesn't seem to come under illness or disability – it doesn't fall under any category - it's a name they give you in the hospital and then that's it, it leads to no-where, it doesn't give you anything, that's the problem – its just doesn't slot in anywhere - its needs to be recognised for people to understand it – anyone that has supported me has never heard of it in their lives"

FAMILY THREE

"Its about supporting the person not just the condition - rather than bundling everything up in one care group and leaving out another - I've spent so much money myself on private services in different areas and across the border"

WHAT WAS THE MOST HELPFUL ASPECT OF THE SUPPORT YOU RECEIVED FROM ALCOHOL FORUM IRELAND?



FAMILY ONE

“You've been the most in-depth support that we have gotten
– You've been the most – you've taken time to develop a rapport with him that has helped – you get these services and it's a different person every time and that doesn't work with Korsakoffs, you need to know them well – some services have been helpful but its so rigid its not personalised and it can't be used the way it needs to be“



FAMILY TWO

“We've only had you – the brain injury service was the only service we got any help or understanding from and your visits were always appreciated – we saw a few other people once or twice but you've been the only person to turn up at our door and ask how are things, do you need anything, how can I help. Just to have someone understand and ask how do we fix this, to have someone come in and give you an outside perspective and I'm looking at things everyday, it's harder you know, it's different from someone coming in and looking at things differently and you know 'he's not looking well today, maybe it's time for a review' the G.P you know those things that I might have missed and that's happened a few times you know when you've been in and then I knew we needed to do something – when you get excited about a brain injury service visit you know what I mean – other than that it like it's an unknown illness – they can help the elderly, they can help different disabilities but this doesn't seem to come under illness or disability – it doesn't fall under any category – it's a name they give you in the hospital and then that's it, it leads to nowhere, it doesn't give you anything, that's the problem – it's just doesn't slot in anywhere – it's needs to be recognised“



FAMILY THREE

“When you explained not to take it personally and to blame the brain injury and not the person and that sometimes the persons themselves might not even know what they are doing or saying and saying listen if this was dementia how would you react to that behaviour and that made us really see that it wasn't him, it wasn't all the alcohol or that he's lying, that it's his brain getting mixed up....we softened a bit after that and that helped us all to get used, I suppose respond better to things and him“

BRINGING STORIES TO LIFE

Alcohol Forum Ireland were delighted to support National Brain Awareness Week 2021, which continued our efforts to promote access to services for people living with Alcohol-Related Brain Injury.

Throughout the week, we documented the experiences of families, each day highlighting a different aspect of the family's journey, from the years leading up to their loved ones diagnosis, how people have responded, and what supports would make the most difference to them. Click picture to view.



Tom* tells of the difficulties he has encountered in getting support for his family member with Alcohol-Related Brain Injury and how this has affected both him and his loved one.



Mary* shares the years of turmoil her family experienced before her loved one developed an Alcohol-Related Brain Injury. Many families who are supporting someone with ARBI have also experienced the psychological trauma of watching a loved one decline over many years. This makes their support needs all the more important as they attempt to cope with both addiction and brain injury all at once.



Mary's Story Part Two: Everybody knows how demanding dementia is....but nobody knows anything about ARBI" - Mary tells us how dramatically her life has changed since supporting her loved one with Alcohol-Related Brain Injury.

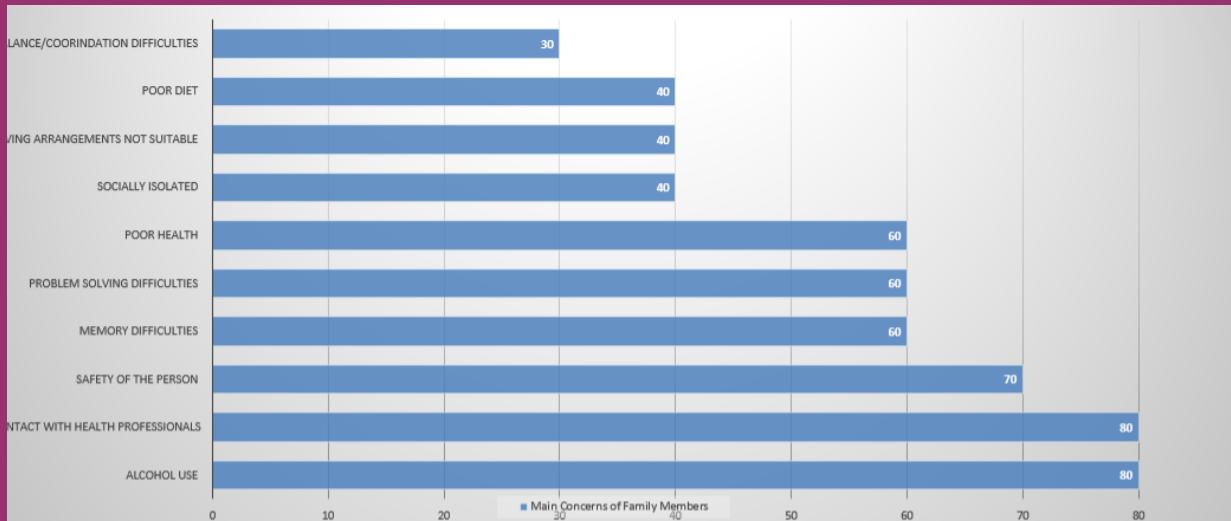


Mary's Story Part Three: "What you don't understand is just how little support he gets and how demanding it can be" - Mary bravely shares how little support she and her loved one receive and what would help the most.

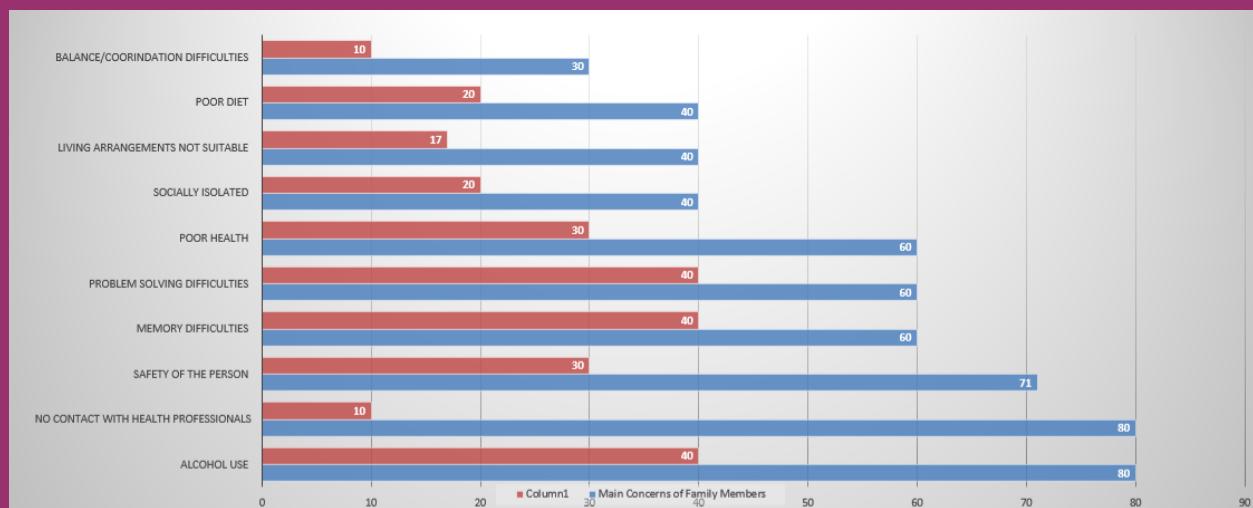
ARBI FAMILY EVALUATION (FAMILIES BETWEEN 2018-2019)



What were the main areas of concern about your family member with ARBI prior to referral to Alcohol Forum Ireland?



What are the main areas of concern about your family member with ARBI at the end of our input?



How long has your family member been supported by the Alcohol-Related Brain Injury Service



01.

IN WHAT WAYS DO YOU FEEL YOUR FAMILY MEMBER WITH ALCOHOL-RELATED BRAIN INJURY BENEFITED FROM THE SERVICE?

"Better housing, better health, no alcohol, less chaos"

"Having a structure and a worker who cares about him"

"He had a professional person to talk to on an ongoing basis and he listened to that person. He has stopped drinking and he is taking care of himself and is living a happy life now"

"Just somebody was always there for me. I did have a lot of stress with my son for near 2 years, help I got was wonderful"

"Having a worker was good for him and helping to organise more support for him"

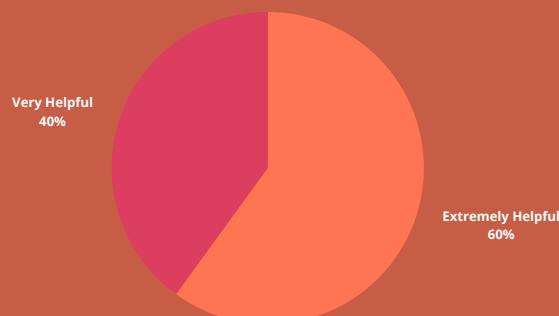
"Guidance and direction in life"

"He's more himself that he has been in a long time"

"A weekly home visit to make sure every is okay, & answering all his questions, & encouragement to keep going & food brought to the door for him & making phonecalls when needed"

04.

HOW HELPFUL HAS THE SERVICE BEEN IN SUPPORTING YOUR LOVED ONE?



02.

IN WHAT WAYS DO YOU FEEL YOUR FAMILY AS A WHOLE HAVE BENEFITED FROM THIS SERVICE, IF AT ALL?

""Less worried, less shame"

"We have a better understanding of him and his condition"

"Definitely less pressure on us as a family, we know someone is here to help and someone to call for advice."

"We don't worry about our brother as much as we used to"

"being a mother I always got a nice comforting voice at the end of the phone"

"Having advice about how to support him was very helpful"

"There was kindness towards us, we experienced little of that in our dealings with a lot of services"

"Your visit was the highlight of our week during the difficult times"

03.

WHAT WERE THE LEAST HELPFUL ASPECTS OF THE SERVICE?

""Appointments only once a week - occasions where more than this was probably needed"

"We only saw some services arranged once or twice (the nurse, the OT) "

CONNECTING THE DOTS: WORKING TOGETHER FOR THE PREVENTION AND SUPPORT OF ALL PEOPLE WITH COGNITIVE IMPAIRMENTS.

Alcohol-Related Brain Injury represents one of many alcohol-related brain conditions for which care and support pathways are significantly underdeveloped and under-resourced. Health and social care for these conditions require multisectoral and interdisciplinary collaborations with a holistic person-centered approach focused on promotion, prevention, treatment, care and rehabilitation and the active engagement of persons experiencing the conditions and their families or carers.

While policies are needed to protect population brain health and prevent these conditions from emerging, so too is cross sectoral collaboration in supporting those who have been impacted by them. Alcohol-Related Brain harm shares many commonalities with other neurological and neuropsychiatric conditions – with changes observed in memory, problem solving skills, behavioural difficulties and quality of life and social participation being impacted. They often act a barrier to full participation in society and can lead to decades of disability.

Regardless of the underlying cause, people affected by cognitive impairment in many cases have similar or overlapping support needs. For example, those with FASD share some commonality to those with Autism Spectrum Disorder and those with Alcohol-Related Brain injury share many similarities to those with other forms of Acquired brain injury. Even so, siloing of both support and intervention continues to persist - often leaving those with alcohol-related conditions excluded.

A closer examination of models of care however shows comparable interventions being used across different cognitive conditions. Many of these interventions focus on aiming to support people cope and compensate for cognitive difficulties either through self management, rehabilitation or environmental adaptation. Despite this, these interventions are often delivered by discrete or separate services with specific remits.

An approach outlined by Stiekema, van Heugten, de Vugt (2019) sets out a proposition for multi-sectoral joint working to improve psychosocial care for people with cognitive deficits across diagnoses using social health as a common framework. These inter and intra professional dialogues are much needed but particularly so for those with FASD, Alcohol-Related Brain Injury as well as dementias. An explicit commitment to eliminate disparities in personal health and health care for those that are impacted by alcohol-related brain harm is fundamental to drive heightened focus on research, prevention, early detection and diagnosis, as well as treatment, rehabilitation and support.



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