

Meeting the needs of people with Korsakoff's Syndrome in Ireland: Identifying treatment pathways and specialist services.



DISCUSSION DOCUMENT

INTEREST GROUP ON
KORSAKOFF'S SYNDROME

Bloomfield Mental Health Services

Bloomfield Mental Health Services is a charity providing treatment, care, and support to adults with severe and enduring mental health needs, including a range of neuropsychiatric conditions and specialist services for Huntington's disease.

Founded in 1812 by Quakers in Ireland, Bloomfield Mental Health Services provides care that is rooted in the principle of honouring the dignity of every person who comes through its doors.

The services provided at Bloomfield bridge the neurological and psychiatric disciplines. This joint approach is one aspect of what sets Bloomfield apart. Specialist mental health assessment, treatment, and support services are all provided from a purpose-built facility in Rathfarnham. Adults with a range of serious and enduring mental health issues and neuropsychiatric disorders are treated, such as those with Alzheimer's disease, schizophrenia, Parkinson's disease, Korsakoff's Syndrome and Huntington's disease.

More information at: Bloomfield.ie

Neurological Alliance of Ireland

The Neurological Alliance of Ireland (NAI) brings together 30 non-profit organisations to advocate for the rights of 800,000 people in Ireland living with a neurological condition.

Neurological conditions affect the brain and spinal cord. They are the leading cause of disability throughout the world and include many common conditions such as stroke, dementia, migraine, epilepsy and acquired brain injury as well as rare and genetic conditions.

Founded in 2003, the NAI advocates for the development of quality services for people with neurological conditions. Our campaigns are rooted in the experience of our members and the people and families with whom they work. We provide a united and expert voice on neurological care through research, advocacy, policy development, and education.

Further information is available at Neurological Alliance of Ireland nai.ie

Alcohol Action Ireland

Alcohol Action Ireland (AAI) was established in 2003 and is the national independent advocate for reducing alcohol harm.

AAI campaigns for the burden of alcohol harm to be lifted from the individual, community and State, and have a strong track record in campaigning, advocacy, research and information provision.

AAI's work involves providing information on alcohol-related issues, creating awareness of alcohol-related harm and offering policy solutions with the potential to reduce that harm.

Further information is available at Alcoholireland.ie

These three organisations formed a special interest group in 2020 to examine concerns about the unique needs of those living with Korsakoff's Syndrome, including the lack of specific services in Ireland and the current policy context. This report highlights some of the issues raised in our interactions with a range of stakeholders. It is presented as a discussion document with the hope that it will help stimulate consideration of how Ireland can best address the needs of this Forgotten Population.

December 2021

For more information about this report, contact: advocacy@nai.ie

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Membership of Interest Group on Korsakoff's Syndrome

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- Dr. Sheila Gilheany, CEO Alcohol Action Ireland
- Ms. Mags Rogers, Director, Neurological Alliance of Ireland and Chair of Interest Group on Korsakoff's Syndrome
- Ms. Nicole Cassidy, Project Assistant

Ms. Marie Lynch was contracted as an Independent Consultant, by the Interest Group on Korsakoff's Syndrome, to support the work of project and prepare this report.

Foreword

My report, "Wasted Lives", highlighted the number of people under 65 who were inappropriately living in nursing homes. The people concerned included those with alcohol related brain injuries including Korsakoff's syndrome. The report concluded that not only were individuals denied opportunities to live valued and engaged lives within their communities, but that they were also often unable to access the care and treatment they might need.

This new report on the situation facing people with Korsakoff's syndrome in Ireland gives a more fine grained analysis of their particular issues. It clearly sets out the lack of focussed services, leading to an over-reliance on inappropriate models of care, or a complete lack of any services. Whether people are in nursing homes, using homelessness services or simply failing to access any service at all, it is evident that the quality of their lives falls far short of what it could and should be.

The report also highlights the fact that rehabilitation is possible, and that with appropriate support, people can become more independent and live fuller lives. The report identifies international models of best practice, which could inform the development of specialist services in Ireland.

By highlighting the failures of our current services, and identifying what future models could achieve, the report can stand as a call to action. I hope that it will contribute to the growing understanding that simply providing institutional models of care deprives people of their rights and the quality of life to which they should be entitled. I look forward to seeing new services emerge so that the lives of people living with Korsakoff's syndrome in Ireland can be transformed.

Peter Tyndall
Ombudsman

December 2021

Summary - key points

This report is focused on the need to identify treatment pathways and specialist services for people living with Korsakoff's Syndrome in Ireland, with the intention that its findings will give the necessary impetus for further attention to overall management and prevention of Korsakoff's Syndrome in Ireland.

Korsakoff's Syndrome is a long-term neurological condition that significantly impacts people's ability to form new memories and can also lead to other difficulties with aspects of higher-level thinking and behavioural control. Most people develop Korsakoff's Syndrome as a result of alcohol use combined with poor nutritional intake. People who develop this condition are generally unable to care for themselves, are often alienated from family supports, and frequently find themselves inappropriately and terminally placed in nursing homes, long-stay psychiatric institutions or availing of homeless services due to the lack of specialist treatment services or pathways.

The Irish prevalence rates are unclear due to limited research, however conservative estimates indicate a figure of 3,780 people in Ireland living with Korsakoff's Syndrome. Clinical staff who contributed to this report indicated people with Korsakoff's Syndrome who were accessing their services were aged between 20 – 60, with a 2:1 ratio of male to female. The contributors also noted that the condition was not always accurately diagnosed or appropriately treated due to lack of awareness.

People living with Korsakoff's Syndrome require a combined package of services from Disability, Mental Health Services, Older People and Primary Care. However, the relevant HSE Clinical Programmes currently do not provide direction or guidance as to how services for people with Korsakoff's Syndrome should be provided. In the absence of a strategic or coordinated approach, there is an inequity of service provision. This *ad-hoc* approach results in people with Korsakoff's Syndrome frequently falling between the service gaps and variably slotted into existing services that cannot meet their unique needs.

The report draws on contributions from people with Korsakoff's Syndrome and their families, which gives some insight into the complexity of care and support required to support someone with Korsakoff's Syndrome and their family. It also captures some of the anguish, distress and isolation experienced as a result of this condition.

The impact of the full enactment of the Assisted Decision-Making (Capacity) Act 2015 will have a bearing on those living with Korsakoff's Syndrome. In the meantime, there are clinical reports of a number of people with Korsakoff's Syndrome that are involuntarily detained in mental health hospitals in Ireland, most likely due to an absence of appropriate services or active treatment. To conclude, the report notes that in order for specialist services and treatment pathways to be developed there is a need to clarify clinical governance and leadership roles, increase clarity and awareness of the condition, the data and research gap, and ensure input from service users and their families in all the initiatives.

1. Introduction

Korsakoff's Syndrome is a long-term neurological condition that significantly impacts people's ability to form new memories and can also lead to other difficulties with aspects of higher-level thinking and behavioural control. In contrast to those with more classic dementia, Korsakoff's Syndrome is not a degenerative condition. In essence those with a diagnosis of Korsakoff's Syndrome rapidly forget new information; they will have no memory for conversations or other events occurring just short periods before, and have often lost memories for months or even years prior to the onset of the condition. Korsakoff's Syndrome is the long-term sequelae for those who survive an acute neurological emergency known as Wernicke's Encephalopathy, and arises when this acute condition is not sufficiently treated in time. Wernicke's Encephalopathy is, itself, caused by the effect of severe thiamine deficiency in the brain (Vitamin B1). This is most often the result of alcohol use combined with poor nutritional intake. Alcohol seeking behaviour usually, but not always, ceases at this time. It is estimated conservatively that there are around 3,780 people living in Ireland with Korsakoff's Syndrome. However, in contrast to other forms of dementia such as Alzheimer's disease, with appropriate interventions significant improvements can be made such that a large degree of independent living can be achieved for people with Korsakoff's Syndrome.

The profound amnesia that occurs in those with Korsakoff's Syndrome, coupled with the lack of awareness that the person has about their own limitations and behavioural challenges that can result, has extensive implications for their ability to function within society and live independent lives. Young, and working-age people who develop this condition are unable to care for themselves. They are so often alienated from family supports that are stretched to capacity where they are available. They frequently find themselves in homeless services or inappropriately and terminally placed in nursing homes or long-stay psychiatric institutions, with few to no onward options available to them. These settings, while providing the containment, supervision and safety the person needs are wholly unsuited to providing the rehabilitation required in order to optimise the person's ability to participate in society, and overall quality of life. (1, 2)

Those living with Korsakoff's Syndrome in Ireland are, in essence, a forgotten population.

Appropriate services are required to meet the needs of this unique group who are truly living 'wasted lives'. (3)

This document is the culmination of a process that began over three years ago, arising out of the frustration of clinicians, and the patients they work with, at the lack of appropriate or specialised services to support those living with Korsakoff's Syndrome in Ireland. Due to the absence of data in relation to this group in the Irish context, those who find themselves supporting people with Korsakoff's Syndrome are left with anecdote, and anecdote would tell us what is known to be true from clinical experience: that this group fall between a number of service stools. Neither neurology, psychiatry, dementia nor neurorehabilitation services readily support this group for whom doors tend to close, or indeed are locked behind them.

2. Rationale

There is a limited amount of research on Korsakoff's Syndrome in Ireland and the prevalence rate is unclear though there have been some studies in both Ireland and Northern Ireland which looked at this and suggest that the incidence is likely underestimated. (4,5,6)

Internationally, post-mortem studies estimate the whole-population prevalence to be 1%-2% (7), which is comparable to that of Alzheimer's dementia or schizophrenia. It is likely that certain sections of the population such as those experiencing homelessness will have a higher prevalence.

Some reports suggest that approximately 35% of dependent drinkers have Alcohol Related Brain Injury (8), of which approximately 12% have Korsakoff's Syndrome (9). A recent report from the Health Research Board (10) found that 14.8% of the population had an Alcohol Use Disorder with 3.1% having a severe Alcohol Use Disorder - approximately 90,000 people. This very conservatively suggests a possible figure of 3,780 people in Ireland living with Korsakoff's Syndrome.

In 2020, the Neurological Alliance of Ireland, Bloomfield Health Services and Alcohol Action Ireland established an Interest Group on Korsakoff's Syndrome, following an identification of unmet need by clinicians working with this client group, who struggled to provide or source appropriate, person-centred and rehabilitation-focused care for a group who present with specific needs and were seen to largely fall between services. See Appendix 1 for list of Interest Group members.

In the absence of data, anecdote from clinical experience suggested that this group, who were frequently of working age, often found themselves in facilities that were unsuitable to their needs, and likely associated with poor outcomes.

Objectives

In response to this unmet need, the Interest Group on Korsakoff's Syndrome set out the following objectives in the initial phase of its work:

- a) Establish interest amongst relevant stakeholders in developing services for people living with Korsakoff's Syndrome in Ireland.
- b) Become informed on models of care for people with Korsakoff's Syndrome in other countries.
- c) Consult with Irish healthcare practitioners and service users/families on the gaps and challenges in service provision for people with Korsakoff's Syndrome.
- d) Identify a potential range of actions to improve services for people with Korsakoff's Syndrome living in Ireland.
- e) Prepare a discussion document on the findings from this initial phase.

Scope

The scope of this phase has been limited to identifying potential treatment pathways and specialist services for people living with Korsakoff's Syndrome in Ireland. The Interest Group on Korsakoff's Syndrome acknowledges that significant attention is also needed to introduce a range of measures to reduce the prevalence of Korsakoff's Syndrome, including the crucial role of acute management of Wernicke's Encephalopathy and the introduction of detoxification protocols, as a means of prevention of development of Korsakoff's Syndrome. a public health campaign to highlight the neurological consequences of excess alcohol intake would also be key here.

It is hoped that this discussion document will provide the impetus for this necessary work so a holistic approach to the management and prevention of Korsakoff's Syndrome can be achieved, as well as greater understanding of the treatment pathways and range of trajectories that people with Korsakoff's Syndrome experience.

3. Approach

The following methods were used to inform the content of this discussion document.

Webinar

The Interest Group on Korsakoff's Syndrome held the first dedicated webinar on Korsakoff's Syndrome in Ireland in November 2020. The webinar was entitled 'Challenges and Opportunities for a Forgotten Population', and attracted an audience of over 80 interested healthcare providers and interested groups. Further details on the webinar programme are contained in Appendix 1.

Structured Consultations

The structured consultation process, which took place between May and June 2021, sought to engage with a range of healthcare professionals and organisations that provide services accessed by people with Korsakoff's Syndrome and other acquired brain injuries in Ireland. This consultation process consisted of a survey, virtual focus-group consultation, and individual follow-up meetings where necessary. Views of people with Korsakoff's Syndrome and families of people living with Korsakoff's Syndrome were also sought.



Appendix 2 gives more detail on the process and range of contributors.

Feedback from the webinar and subsequent consultations highlighted a range of gaps and challenges for this population, which fall broadly into the themes of need for a clearer treatment pathway, need for specialist services to be developed and need for stronger advocacy for this patient cohort. These themes are discussed in more detail in Section 5 of this report.

Articles and reports

A number of articles and reports relevant to the issues at hand were identified, both by members of the Interest Group on Korsakoff's Syndrome, and those who contributed to the webinar and consultation. Relevant articles and reports are listed at the end of the report and also referenced in the text.

4. International Models and Reports

In addition to the material presented by Prof. Roy Kessels as part of the webinar on Korsakoff's Syndrome on the model of care in the Netherlands, a desktop review was carried out to establish what services were available for people with Korsakoff's Syndrome and gain insight into the models of care used. A brief description of the models identified are outlined below, with links for further information.

The Dutch Model

In 1989, under the guidance of Prof. Roy Kessels, the Centre of Excellence for the treatment of people with Korsakoff's Syndrome was established. The centre has academic links to Radboud University in The Netherlands, and is now a combination of national centres of expertise and regional care centres underpinned by scientific research (11).

The aims of the centres of excellence are to

- Assess cognitive (dys)function and everyday skills;
- Optimize the level of self-sustainability;
- Societal and cognitive rehabilitation;
- Reduce the extent of care use;
- Alcohol abstinence.

The Knowledge Centre supports a national network of nursing homes and psychiatric hospitals with education, guidelines, care standards and knowledge transfer and implementation, using an academic hub-and-spoke model of care. The societal and cognitive rehabilitation programmes are underpinned by evidence-based cognitive rehabilitation techniques (12,13,14).

An epidemiological study focusing on the city of The Hague, conducted by Blansjaar and colleagues in 1987, found 4.8 cases per 10,000 population (15). At the November webinar, Prof. Kessels reported that there were 5220 people known to services with Korsakoff's Syndrome in the Netherlands. Of these, 50% were living in the community, 25% were accessing community services, and 25% were in inpatient care.

Northern Ireland - Leonard Cheshire Model

In February 2020 Leonard Cheshire NI established a 14-bedded unit for people with Alcohol related Brain Injury (ARBI), catering for people with Korsakoff's Syndrome as well as other forms of ARBI. The service is funded by trusts on an individual contract basis, with seed funding from Leonard Cheshire. The model of care includes specialist rehabilitation with therapeutic interventions, development of new skills, rebuilding lost skills and preparation for independent living. Leonard Cheshire anticipates a 2-3 year stay for each client, and they are currently planning the development of a community-based outreach service as well as ensuring a sustainable funding model.

A two-year evaluation of the service has commenced in conjunction with Queen's University Belfast, which will address the impact on individuals as well as the cost-benefit/economic benefit.

Northern Ireland - Strategy to Tackle Harm from Substance Use

This recent publication: Preventing Harm, Empowering Recovery: A Strategic Framework to Tackle the Harm from Substance Use (2021-31) from the Department of Health in Northern Ireland, references Alcohol Related Brain Injury (ARBI) (16), including Korsakoff's Syndrome, and makes the following commitment for the NI Health and Social Care Board: 'The HSCB will review the need in relation to ARBI and will subsequently develop, as required, appropriate service models and pathways to support those impacted by ARBI to recover.' (p. 49).

ARBD focused model of care in Liverpool, Cheshire and Wirral Partnership.

This service has been developed by Prof. Ken Wilson (Consultant Psychiatrist) and his team, and includes people with Korsakoff's Syndrome within the service model. The model contains a useful template for cost-benefit analysis of treatment intervention. A clinical guidance manual for the rehabilitation of those presenting with severe alcohol-related brain damage (ARBD) was published by this team in 2020, and stresses the importance and value of psychosocial rehabilitation. They report on evidence that the majority of patients with ARBD will progress in terms of cognition, behaviour and socialisation through natural improvement in physical health as a result of abstinence.

16. In the UK, the terms Alcohol Related Brain Injury (ARBI) and Alcohol Related Brain Damage (ARBD) are used interchangeably and refer to the effects of changes to the structure and function of the brain resulting from long term consumption of alcohol; this includes people with Korsakoff's Syndrome.

Upstreet Project Canterbury Kent.

This residential service in Kent, England provides a first step for people diagnosed with ARBD including Korsakoff's Syndrome. Three residential homes offer specialised care and support depending on the needs of those who access the care. The website quotes weekly charges between £725 and £1,100 as a guideline.

Scotland

The Mental Welfare Commission Scotland published *Care and treatment for people with alcohol related brain damage in Scotland* in Sept 2021, which is a report based on visits to people and services across Scotland. In the foreword of the report the CEO of the Mental Welfare Commission notes that "Discriminatory perceptions of 'self-inflicted illnesses' can lead to people with a diagnosis of ARBD being extremely vulnerable, marginalised and socially isolated."

The report has four recommendations – the first is most pertinent to this discussion document in that it recommends that health and social care partnerships commission suitable, age appropriate, and where possible, specialist alcohol-related brain damage services.

Penumbra Mental Health Charity is one of Scotland's largest mental health charities with services in Edinburgh, Glasgow and Aberdeen. As part of their suite of services, they provide supported accommodation and supported living services to those living with ARBD, guided by person-centred and recovery-focused support plans. They work closely with the City Council, Health and Social Care bodies, and Mental Health and Addiction commissioning teams to identify and assess the suitability of potential referrals.

5. Policy, Service Provision and Legislation in Ireland

Prior to addressing the policy that underpins service provision for people with Korsakoff's Syndrome in Ireland, it is helpful to consider the 2021 report *Wasted Lives: Time for a better future for younger people in nursing homes: An investigation by the Ombudsman*. This report notes that the HSE provides health services based on assessed needs of the individual (including people with alcohol related brain injury) rather than diagnosis, and the clinical assessment will determine whether the service will be provided by Primary Care, Disability Services, Older People's Services or Mental Health Services. The report indicates how this approach allows for **"individuals to fall between gaps and seems to leave little scope for strategic planning on how to address the specific needs of people with alcohol related brain injury"** (p.152). It draws particular attention to the challenges that present when people with ARBI, which would include those living with Korsakoff's Syndrome, require a combined package of services from Disability Services, Mental Health Services, Older People's Services and Primary Care. The report findings highlight the lack of uniformity of approach and inequity for services for people with ARBI, and its recommendations seek to address the changes that are required.

From a policy perspective, the most recent direction for services for people with Korsakoff's Syndrome comes from the Department of Health *Sláintecare Implementation and Action Plan 2021 - 2023*, which refers to the Healthy Ireland Alcohol Policy and the Dept. of Health national strategy on drug and alcohol use, *Reducing Harm, Supporting Recovery 2017-2025*. The latter emphasises a health-led response to drug and alcohol use in Ireland, based on providing person-centred services that promote rehabilitation and recovery. However, there is no recognition in this strategy of ARBI including Korsakoff's Syndrome. The National Social Inclusion Office work with drug and alcohol services funded through HSE Section 39 funding.

From an operational perspective, guidance from the National Clinical Programmes (NCP) supports the design of models of care to ensure high quality, accessible and safe care that meets the needs of all the population and are aligned to the HSE priorities and to respond to the principles of Sláintecare. The NCPs should be the primary reference point for providing cross-service and cross-programme solutions in relation to:

- New models / pathways of care based on population need;
- Clinical components of community-based care expansion;
- Acute and unscheduled care development;
- Integrated end-to-end models of care.

Of the 31 clinical programmes, from the perspective of a person with Korsakoff's Syndrome, the following clinical programmes have particular relevance: Neurology, Disability, Mental Health and Rehabilitation Medicine. However, there is scant mention among the programmes of how services for people with ARBI, in particular Korsakoff's Syndrome, should be provided.

The Neurology Model of Care and The Strategy for Provision of Neuro-Rehabilitation Services in Ireland both refer to the sub-speciality of Neuropsychiatry to respond to complex disorders caused by brain dysfunction. In addition, the Neurology Model of Care specifically lists Korsakoff's Syndrome as a substance-related neuropsychiatric disorder (p 225). The Dementia Model of Care is currently under development and the Interest Group for Korsakoff's Syndrome have prepared a submission to the Clinical Programme highlighting the rationale for making reference to Alcohol-Related Dementia and Korsakoff's Syndrome in the document.

From a regulatory perspective, HIQA's Dementia Care Guidance on Dementia Care for Designated Centres for Older People (2017) makes reference to Korsakoff's Syndrome (p. 5).

5.1 Legal aspects to consider

The following Acts have a direct relevance to the care and treatment pathways for people with Korsakoff's Syndrome: The Mental Health Act (2001), the Lunacy Regulations Act (1871) and the Assisted Decision-Making (Capacity) Act 2015.

Although those with substance-dependence disorders are not subject to the Mental Health Act (2001), those who present with severe dementia (i.e. 'a deterioration of the brain of a person which significantly impairs the intellectual function of the person thereby affecting thought, comprehension and memory and which includes severe psychiatric or behavioural symptoms such as physical aggression') who, because of their dementia, are likely to be an immediate and serious risk to themselves or others, or whose condition will deteriorate without admission to an approved centre, are covered. Clinical experience tells us that it is under this Act, and under these conditions, that a number of people with Korsakoff's Syndrome are involuntarily detained in mental health hospitals in Ireland. Although regular formal reviews by mental health tribunals are a statutory part of this system, the nature of the difficulties encountered by those with Korsakoff's Syndrome (i.e. significant cognitive impairment, including memory and insight, as well as behavioural challenges) along with an absence of more appropriate services, mean detention orders can be renewed repeatedly over long periods of time, leading to distress for patients, but also for staff who have little to offer by way of active treatment in this healthcare setting.

The Ward of Court system enacted under the Lunacy Regulations Act (1871) continues to operate in Ireland while we await the full commencement of the Assisted Decision-Making (Capacity) Act 2015. Under the former Act, a person who is deemed unable to look after their affairs due to mental incapacity is made a Ward of Court and has someone appointed to do so on their behalf; the purpose of the wardship is to protect the person and their assets when they lack the capacity to do so for themselves. As with the Mental Health Act, this Act may also apply to those with Korsakoff's Syndrome who may be found to lack decision-making capacity, typically due to impairments in reasoning related to lack of insight, behavioural control and other higher-level thinking skills.

The Assisted Decision-Making (Capacity) Act 2015, when fully commenced, will repeal the Lunacy Regulations Act governing the Ward of Court system and will ensure that decision-making, which will be seen as issue- and time-specific, will be supported and a person's capacity to make decisions for themselves will be maximised. It is, as yet, unclear what the relationship between the Assisted Decision-Making (Capacity) Act 2015 and the Mental Health Act will be, or what implications this will have for those with a 'mental disorder' as defined by the Mental Health Act, who do have decision-making capacity. Regardless, the ADMA Act in and of itself will undoubtedly have a bearing on those with Korsakoff's Syndrome when it is commenced.

6. Views on Current Service Provision in Ireland

There are no dedicated services or patient pathways for people with Korsakoff's Syndrome in Ireland. Based on input from the people who contributed to this discussion document, it is evident that an *ad-hoc* approach is in place to meet the needs of this vulnerable group, with people variably slotted into existing services that cannot meet their unique needs.

This section will first report on perspectives from service users and families and then outline the view of those who are involved in providing services to people with Korsakoff's Syndrome, based on the contributions to the stakeholder consultation.

6.1. Perspectives from Service Users and Family Members

This section gives three perspectives – the first is an outline case study of how a person with Korsakoff's Syndrome has successfully moved home following a lengthy rehabilitation period, the second perspective gives insights and recommendations for actions for services from a family member of person with Korsakoff's Syndrome, and the final piece is a letter from a person with Korsakoff's Syndrome who is currently detained in a residential care setting under the Mental Health Act.

a) At the November Webinar, a case study was presented by Headway Ireland of how a person with Korsakoff's Syndrome eventually managed to move back home after a lengthy period of rehabilitation involving a wide range of stakeholders, and a lot of 'red tape'. Whilst this case is exceptional in that most people with the syndrome remain in residential care, it does demonstrate that when the right structures and supports are in place, people with Korsakoff's Syndrome can be supported to achieve a better quality of life.



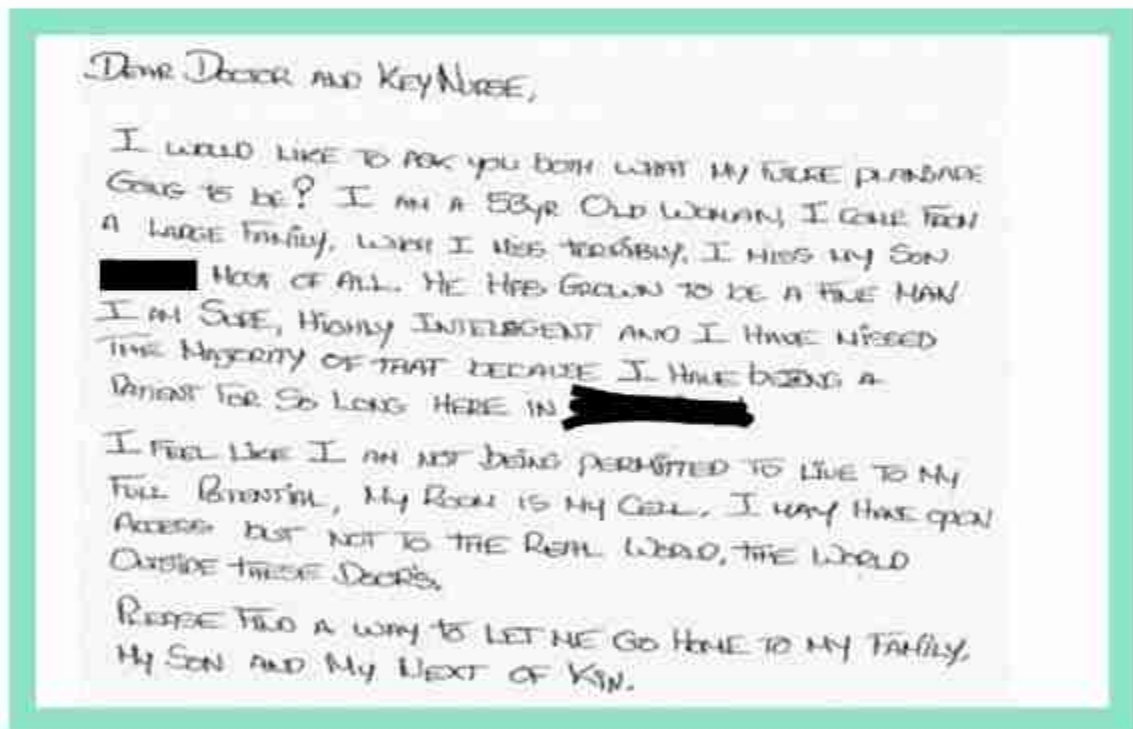
b) A family member of a 57-year-old male with Korsakoff's Syndrome who successfully returned home from a nursing home was invited to contribute her views on services for people with Korsakoff's Syndrome. During the interview, she described the constant challenges that he faces and the physical and mental toll on them both, as can be seen in the quotes below. 'John' is a pseudonym.

- *On a daily basis John has a lot of complex needs, from the standard memory issues, his mobility has exacerbated and he needs a new hip, he is in a lot of pain, he is also recovering from prostate cancer.*
- *On a daily basis you just don't know, it can change every minute. One day he can be in great form, next day if he gets up and there is not enough milk – he could be in a bad mood for a large part of the day. The behaviour and mood I find exceptionally difficult. I am not trained to deal with it.*

She had the following messages for people who are tasked with the responsibility of provision of services for people with Korsakoff's Syndrome:

- *People with Korsakoff's Syndrome are brushed under the carpet.*
- *There should be equal footing to other people with brain injury. There is discrimination towards Korsakoff's Syndrome because of the source/cause – we cannot access services for brain injuries.*
- *We need a long-term strategy for all round rehabilitation - physical rehab and mental health and well-being.*
- *We need proper respite. I need somebody to be calling to John if I went away. It would be nice if John went somewhere. If I am away, it is important for me to know that he is in a safe secure environment*
- *It needs to be considered that Korsakoff's Syndrome is increasing and age profile younger.*
- *There should be a vision for that person. John would love to get back to work. He needs to be valued – he can still make contributions to society.*
- *The awareness message needs to say there can be improvement.*
- *There is the stigma associated and families are embarrassed. They need support, respite, education to assist their family member in the recovery process.*
- *The system works against you – which makes it even harder. Just to give you an example. We have the home care grant suspended at the moment because of his hip. If we don't take it up again, we will lose it.*

c) A case history of a 53-year-old woman was presented at the November 2020 Webinar. She was diagnosed with Korsakoff's Syndrome 11 years previously and is currently detained in a mental health hospital under the Mental Health Act (2001), with admission orders retained following repeated reviews by mental health tribunals. Overall improvements in her demeanour and functioning were noted following withdrawal of medication (i.e. she had been prescribed a large number of psychiatric medications to manage frustration and distress at being "locked up" and having little access to her family or to meaningful occupation). There is still no safe pathway to enable her discharge into the community. She expresses anger at her predicament in weekly letters to management, and a copy of one of these letters is exhibited below, with her consent.



These powerful contributions give some insight into the complexity of care and support required to support someone with Korsakoff's Syndrome and their family. It also captures some of the anguish, distress and isolation experienced as a result of this condition.

6.2 Perspectives from Service Providers

As part of the stakeholder consultation, a survey was completed to assist in gathering a profile of people with Korsakoff's Syndrome in Ireland who accessed services in the past 12 months. Nine professionals participated in the survey representing views from Addiction Psychiatry, Alcohol-related Brain Injury Service, Clinical Neuropsychology, Liaison Psychiatry, Medical Social Work, Neurology, Not for Profit Service Providers, Nursing Homes Ireland, Safetynet Primary Care, Neurology and Population Health. These slides outline the combined responses.

Insight into profile of people with Korsakoff's Syndrome in Ireland

The respondents noted a broad age range of people with Korsakoff's Syndrome who were accessing their services with a 2:1 ratio of male to female. The referrals to the services came from a wide variety of services.

What does an individual with Korsakoff's Syndrome look like?

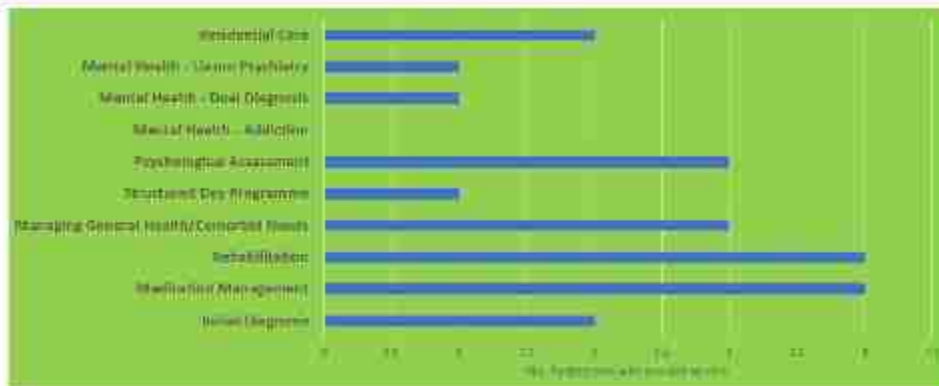
- **Age:** relatively evenly spread between (20-30, 31-40, 41-50, 51-60).
- **Gender:** 2:1 male to female
- **Referred from:**

Acute Hospital, GP, Psychiatry, Geriatricians, Addiction Services, Probation Services, Social Work, Assertive Outreach Workers

Range of Services provided to people with Korsakoff's Syndrome

The predominant service provided by those who participated in the consultation was medication management and rehabilitation, with psychological assessment and management of general health also prominent.

Services Currently Provided



Services referred to

The range of services that people with Korsakoff's Syndrome were referred to indicate the breadth of supports and services that people with Korsakoff's require across disability, mental health and primary care.

What services are they referred to during/following treatment?

- **Residential care:** Nursing homes, homeless services, long-term mental health facilities;
- **Medical:** G.P., Geriatrician, Acute Hospital, Rehabilitation;
- **Social Care:** Social Workers, Inclusion Workers, Family Support Services, Day Services;
- **Community Support Services,** Community MDT;
- **Addiction Services.**

These responses indicate the wide range of services and providers who are currently involved in delivery of treatment for people with Korsakoff's syndrome, and the need for a coordinated response and clarity for clinical leadership.

7. Themes Emerging

When considering the views gathered during the consultation process, the relevant policies, strategies and publications and taking consideration of the service models in other countries, a range of issues present when seeking to deliberate how to progress services for people with Korsakoff's Syndrome in Ireland. These issues are gathered into the following three themes and are subsequently expanded on:

- Development of Services to include the need for Data/Research
- Lack of Clarity and Awareness
- Views from Service users and their Families.

7.1 Development of Services to include need for Data/Research

7.1.1 Governance and leadership for health provision.

Currently in Ireland there is no clear treatment pathway for people with Korsakoff's Syndrome, and as a result there are no funding streams to support their treatment. As a result, the services that are available are significantly under-resourced. It is not clear which clinical programme has responsibility for services for people with Korsakoff's Syndrome, and this partly explains the dearth and limited range of services people with Korsakoff's Syndrome can access. In other countries the responsibility for Korsakoff's Syndrome services is led from Mental Health services with partnerships and collaborations established so the full breadth of needs is met.

7.1.2 Diagnosis and treatment

The current services for people with Korsakoff's Syndrome are ad-hoc and the availability of specialist assessment is very limited, with no designated treatment centre for people with Korsakoff's Syndrome.

On receipt of a diagnosis, the support services for treatment appear to be scant, with very limited cognitive rehabilitation and community supports available; comorbid health challenges are often neglected. The services that are available are not interconnected.

In comparison, The Dutch Model of Care for people with Korsakoff's Syndrome is based on specialist services available to support and inform the wider regional services – described as a hub and spoke model. As well as establishing a pathway, this also provides the network for service delivery, development and connection.

7.1.3 Residential care

Despite the absence of data, it is thought that a large proportion of people with Korsakoff's Syndrome in Ireland are living in residential care settings, specifically nursing home settings, hostels and homeless settings, which are not designed or suitable for this population. Structured rehabilitation is rarely available, and regulation in residential settings can draw unwanted attention as it is extremely difficult to meet required standards when providing care to people with Korsakoff's Syndrome.

Nursing homes who provide care for people with Korsakoff's Syndrome rely on and value community psychiatric services for medication management, however this is not widely or readily available, nor the most appropriate intervention for this group.

7.1.4 Exclusion criteria

People with alcohol-related Korsakoff's Syndrome can be excluded from relevant services, including a key player providing support to those with acquired brain injuries in the community in Ireland. However, this exclusion is not consistent, with other similar services accepting such referrals. Concerns regarding the likelihood of relapse with regard to alcohol use is the primary reason for exclusion given, despite the majority of clinicians working this field reporting, anecdotally, that relapse does not present a significant challenge for those with Korsakoff's Syndrome. Of note, it was reported that it was only when the needs of people with Korsakoff's become severe and chronic that services rallied.

7.1.5 Data

Critical for the development of any service is the need for accurate data on the prevalence, incidence rate as well as location and the treatment pathways. Currently in Ireland there is no basic data collected on this cohort of people, and where data is collected, due to lack of awareness of the condition, it is likely that the current data collected is not consistently recorded.

7.2 Lack of Clarity and Awareness

One contributor reported the significance of alcohol relapse as an issue for people with Korsakoff's Syndrome, in his professional experience. This perspective influences how people with Korsakoff's Syndrome can be excluded from services that they may otherwise benefit from.

In the absence of specialist services or advice, some of those consulted were unclear as to which issue should receive more attention: brain damage or alcohol use. Others noted the need for alcohol treatment programmes to be made aware of the benefit of cognitive rehabilitation.

Some of the contributors noted the intolerance within generalists' services to active alcohol users. This sector would benefit from greater awareness and understanding of the needs of those with Korsakoff's Syndrome, as these users tend not to continue to abuse alcohol. As Thiamine deficiency (Vitamin B1) is seen in both alcohol and non-alcohol related liver disease, generalist services should also be made aware of the need to introduce thiamine replacement to help prevent the development of the Wernicke's Encephalopathy that is a precursor to Korsakoff's Syndrome.

It was also noted that the lack of awareness of needs and treatment options for people with Korsakoff's Syndrome amongst health and social care professionals in the homeless sector and acute sector also puts this cohort at a disadvantage.

7.3 Service Users and Families

When seeking to consider the issues that present for people with Korsakoff's Syndrome, the input from service users and families has been extremely insightful.

The degree of isolation and (re)traumatisation and discrimination is sorely evident, in addition to the discrimination, stigma and shame that people experience. To compound this, it was reported that families experience loss, grief and helplessness as they seek to support their family member and feel guilty as if they were in some way responsible for the situation that has evolved.

8. Where to Next?

The needs of people with Korsakoff's Syndrome and their families are complex and challenging. In addition, their support and treatment needs will vary depending on the stage of the disease. To date, there has been no national focus on the needs of this group, and consequently the services are severely lacking. When seeking to determine how to shape and plan services for people with Korsakoff's Syndrome, the key areas to be considered are how to plan for the future, what can happen to help service provision in the short-term and what opportunities are there to gather data. These are explored below with some suggestions for actions.

8.1 Leadership - The Role of Clinical Programmes

a) Although several clinical programmes have a role in supporting people with Korsakoff's Syndrome, leadership and strategy for the treatment pathway needs to be assigned to one of the programmes. It would be beneficial if the relevant clinical directors and clinical leads debate, consider and agree which programme should take the lead, and how to ensure cross collaboration and coordination of expertise.

8.2 What specialist service model would work in an Irish setting?

a) Is it possible to replicate the hub and spoke model that exists in the Netherlands, with academic links to service development? How would this map or mirror a plan for development of other rare conditions that require specialisation? Are there academic links that could be explored to support the research needed?

b) Would it be possible to introduce a staged approach to include an initial stabilisation programme, and subsequently develop a dedicated rehabilitation unit that would link with and support specialist long-term residential facilities?

8.3 Cross collaboration

a) As people with Korsakoff's Syndrome avail of services funded from Social Inclusion, Disability, Mental Health and Primary Care, what system can be put in place to avoid "*the silo service experience*" and lack of connectedness that people with Korsakoff's Syndrome and their family experience?

b) Would a case management approach help?

8.4 Residential Services

- a) What mechanism can be put in place to adequately resource residential services, so they can provide appropriate care and rehabilitation?
- b) Are all the relevant community-based outreach services available to people living in residential care settings?
- c) Is it possible to provide a national support network to residential services who are currently providing care to people with Korsakoff's Syndrome?

8.5 Increasing access to services

- a) What is the best way to ensure that people diagnosed with Korsakoff's Syndrome can access the cognitive rehabilitation interventions they need to help them live a meaningful life?
- b) Can criteria for access to current brain injury services be reviewed to assist access, which would require additional resourcing to expand their services to cater for this group?

8.6 Building awareness

- a) What initiatives would help address the stigma and isolation that people with Korsakoff's Syndrome and their families face?
- b) What mechanisms can be put in place to increase the general public's understanding of the impact of alcohol on brain health? Is it possible to build this into existing public health awareness campaigns?
- c) What organisations would be able to assist in developing targeted awareness and education programmes in services currently working with people with Korsakoff's Syndrome?
- d) Is there a mechanism to standardise the language and terminology?
- e) Would it be feasible to establish an information hub/portal to improve access to existing information and resources?

8.7 Prevalence and Pathways

- a) Would a survey within nursing home settings/residential care settings be useful to help determine how many people with Korsakoff's Syndrome are living in residential care? What else could such a survey tell us?
 - b) In order to understand the referral and discharge pattern of people with Korsakoff's Syndrome who access acute settings, would an audit in a number of acute settings help to demonstrate the current pathways, recovery and relapse rates?
 - c) Are there opportunities to examine the number of people prescribed thiamine, as a potential proxy method of gathering numbers of people being treated for ARBI, and potentially also Korsakoff's Syndrome, in Ireland?
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8.8 The financial impact of current service provision

- a) To understand the economic impact on the health service, would it be possible to cost the long term stays of people with Korsakoff's Syndrome in acute settings whilst waiting for placement?
- b) How helpful would it be to determine the cost benefit of rehabilitation in the community yielding independence and contribution to society compared with the long-term funding of placement in residential care with no appropriate rehabilitation?

9. Conclusion

Individuals with Korsakoff's Syndrome live "wasted lives" and they know it. Despite the profound short-term memory loss, they are sufficiently cognitively intact to see every day as a disconnect from family, friends and society. Alcohol, if it was the cause, is no longer relevant. Their vitamin deficient circumscribed brain injury resulted from an acute event, namely Wernicke's encephalopathy. The injury is fixed and non-progressive and without rehabilitation so is their life. They are most likely to be resident in nursing homes or mental health facilities indefinitely. They find no common purpose with their peers, and because those professionals that provide care to them are not equipped with the specialist skill-set required to assist them, distress and the associated behavioural challenges are typically met with medication.

It is imperative that a bespoke person-centred, national service for Korsakoff's Syndrome be developed to maximise potential, minimise suffering and ensure community reintegration.

In this report we have considered a number of issues in relation to Korsakoff's Syndrome in Ireland. We recognise that we are posing more questions than we are providing answers. However, we hope this report will be a starting point for detailed consideration of the issues raised and look forward to engaging with all relevant stakeholders.

Appendix One

November 2020 Webinar Programme

The purpose of the webinar was to outline, via case studies, current pathways for people living with Korsakoff's Syndrome living in Ireland, gather insights from Prof. Roy Kessels on the Dutch Model of Care for people with Korsakoff's Syndrome and seek to grow the momentum amongst Irish healthcare professionals in developing services for people with living with Korsakoff's Syndrome in Ireland.

The webinar was chaired by Dr Clíona Ní Cheallaigh, Clinical Lead at the Inclusion Health Service at St. James's Hospital in Dublin, Associate Professor at the Department of Clinical Medicine at Trinity College Dublin, and a faculty member of the Global Brain Health Institute.

Arising from the discussion at the end of the webinar, the Interest Group on Korsakoff's Syndrome committed to arranging structured consultations with key stakeholders to seek to begin to address the gaps in service provision for people living with Korsakoff's Syndrome in Ireland.

Appendix Two

Structured Consultation

- A survey was circulated to targeted individuals (via Survey Monkey), to ascertain their views on gaps, challenges and opportunities for people with Korsakoff's Syndrome in Ireland, and where relevant, what services they provided to people with Korsakoff's Syndrome.
- The responses from this survey provided discussion material for the subsequent virtual consultation.
- Individual consultations to seek the views of those who were unable to participate in the virtual consultations.

Range of individuals and professionals who contributed to the consultation:

- Nursing Home – Director of Nursing
- GP Safety Net
- Alcohol Forum – Specialist Care Coordinator in Alcohol Related Brain Injury
- Headway Cork, Day Service Manager
- ABI Ireland – Principal Clinical Neuropsychologist
- National Rehabilitation Hospital - Principal Clinical Neuropsychologist
- National Rehabilitation Hospital - Senior Social Worker
- Consultant Addiction Psychiatrist

Individual consultations

- Family member
 - National Clinical Advisor and Group Lead for Mental Health
 - Consultant Liaison Psychiatrist
 - Consultant Neurologist
 - Leonard Cheshire, Northern Ireland
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Related Reports

Wasted Lives: Time for a better future for younger people in nursing home.
An investigation by the Ombudsman Ireland 2021.

Alcohol-related brain damage in Northern Ireland Treatment, not just care.
Northern Ireland Psychiatry College Report 2018

Evidence Based Profile of Alcohol Brain Damage in Wales.
March 2015. Public Health Wales, Chris Emerson and Josie Smith

Preventing Harm, Empowering Recovery a Strategic Framework to Tackle the Harm from Substance Use (2021-31)
Dept of Health Northern Ireland.

Alcohol Change UK Rapid Evidence Review July 2019.
Dual diagnosis, double stigma: a rapid review of experiences of living with alcohol-related brain damage (ARBD). Dr Lisa Schölin, Dr Sarah Rhynas, Professor Aisha Holloway, Dr Ruth Jepson, The University of Edinburgh.

Care and treatment for people with alcohol related brain damage in Scotland.The Mental Welfare Commission Scotland, Sept 2021. A report based on visits to people and services across Scotland.

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