Supported Living for People with Korsakoff Syndrome- Does it work?

Tenant progress 12 months after entry to the scheme

December 2006
Praxis Care Group

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Names have been changed within the report in order to protect the identity of participants.

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Praxis Care Group is a registered charity and a major provider of support services for adults and young people with a learning disability, mental ill health and older people. The Praxis Care Group Research Department is responsible for undertaking internal evaluations of projects and carrying out research related to health and social care issues.

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www.praxiscaregroup.org.uk

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Summary

This report is based on a 1 year study which has investigated the usefulness of a specialised supported living unit, for people who have korsakoff syndrome which has been caused by excessive alcohol use. This paper has documented the progress of 4 tenants over their first 12 months of living in Connaught House. The unit opened in June 2004 and has implemented a ôno alcohol policyô It is the first specialised supported living facility of its kind to be set up in Northern Ireland.

Korsakoff syndrome is a short term memory disorder which is caused by a deficiency of vitamin B1/ thiamine. For the people within this report, the vitamin deficiency has been caused by excessive alcohol use. Historically people with korsakoff syndrome would have been left undiagnosed or misdiagnosed for many years (Alzheimerôs Society 2003). Even for those who were properly diagnosed, lack of specialised accommodation has meant that they have been inappropriately placed in nursing homes or long stay hospitals for significant periods of their life (MacRae & Cox 2003, Scottish Executive 2004). Connaught House wished to bridge the gap between support services which were providing either ôtoo muchôor ôtoo littleôsupport for these individuals.

The research has suggested that a unit such as Connaught House will be suitable for some people with korsakoff syndrome. The severity and extent of the korsakoff symptoms, as well as the additional symptoms of their co-morbid disorders and personality type, will add to the complexity of each individual case, and as a consequence their suitably for a unit such as Connaught House. The greatest improvements were found in those tenants who showed an insight into their condition, the limitations their condition presented, abstained from alcohol, accepted their support needs and were able and willing to apply themselves in all aspects of their support plan. Four tenants had their tenancy ended prematurely for 2 main reasons, (1) unmanageable drinking behaviour and (2) inability to work with the structure and routine of the unit.

The report has highlighted the importance of good management structures including staff training and support, for the successful working of such a unit. The report has also presented a list of challenges and practical recommendations for the unit. Overall, the report has aimed to provide a realistic insight into a supported living unit for people diagnosed with korsakoff syndrome.

Background

This report is based on a 1 year study which has looked at the progress of 4 tenants within the first specialised Korsakoff unit in Northern Ireland. The report describes the progress of the tenants over their first 12 months of living in Connaught House.

What is Korsakoff Syndrome?

In its simplest terms korsakoff syndrome is a memory disorder which is caused by a deficiency of vitamin B1/thiamine, an important brain nutrient. Excessive use of alcohol is usually the cause of this vitamin deficiency for two main reasons:

- Heavy drinkers have poor eating habits and
- Alcohol impedes the absorption of key vitamins (Alzheimerôs Society 2003).

Wernickes- Encephalopathy usually precedes korsakoff syndrome. If Wernickes-Encephalopathy is diagnosed quickly and the person is given a high dose of vitamin B1/thiamine, the brain damage which results in korsakoff syndrome does not progress. In reality there is a difficulty in diagnosing first stage Wernickes-Encephalopathy, as the onset of the symptoms can occur suddenly and can be easily mistaken for straightforward drunkenness (Alcohol Concern 2001).

Symptoms

The classic symptom of korsakoff syndrome is the loss of short term memory. This can make it difficult for people to acquire new information or learn new skills. The long term memory of events before the onset of prolonged alcohol abuse seems to remain intact, as does general intellect and personality. Other symptoms of the condition include loss of spontaneity and initiative, confabulations (presenting inaccurate accounts of their own personal history or recent events), lack of insight into their condition, apathy or talkative and repetitive behaviours. The main physical symptoms of the condition are an unsteady gait when walking, slow walking and difficulty with hand and finger movements (Alzheimerôs Society 2003).

In addition to the direct symptomology of the condition, the years of problem drinking are likely to have negatively affected all elements of the lives of people with korsakoff syndrome. Often any positive social contacts with friends and family are gone. They tend to be unemployed/unemployable which is also likely to have affected their financial situation and ability to pay rent or budget for other daily living costs such as

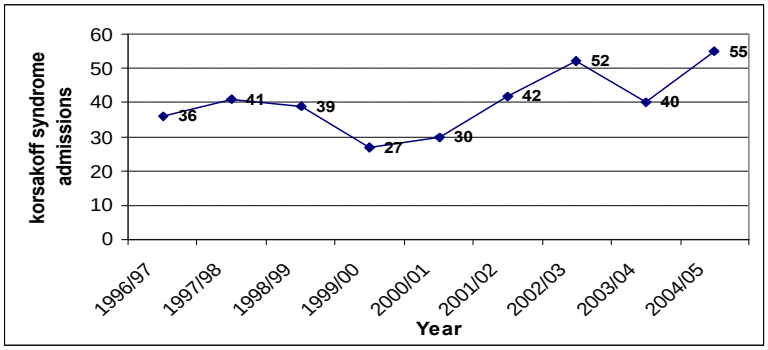
heating, lighting or food. This group will also be likely to have disengaged from mainstream health care services i.e. GP, Dentist. The majority of contact made with health services will have been as a consequence of alcohol related illnesses and will have been accessed via emergency services.

There is also a clear association between mental illness and alcohol related problems (Weaver et al. 2002). Often co-morbid disorders such as depression and traumatic head injuries (from falls or fights) are found in people with korsakoff syndrome. These additional problems add to the complexity of each individual case and how they are managed (Oscar-Berman et al. 1997).

Rates of Korsakoff

Figure 1 shows statistics calculated by the Northern Ireland Hospital Inpatient system. It indicates that over the 10 year period- 1996-2005, hospital admissions for korsakoff syndrome have increased by 35% from 36 admissions in 1996/1997 to 55 admissions in 2004/2005 (drugsalcohol.info 2005).

Figure 1: Korsakoff Syndrome Admissions to Northern Ireland Hospitals from 1996/97 - 2004/05



Source: Hospital Inpatient system cited from www.drugsalcohol.info

The Scottish Executive expert group (2004) which was set up to look at the unmet needs of people with ARBD, suggest that any statistics provided in terms of rates of korsakoff syndrome are likely to be an underestimation of the real situation. They believe that there are many more people who are left undiagnosed due to being hidden in the community or placed in inappropriate health care facilities i.e. nursing homes, psychiatric hospital beds or acute hospital beds. It is likely that this is also true for Northern Ireland.

It is predicted that rates of ARBD such as korsakoff syndrome will increase as cultural trends move towards greater harmful drinking i.e. binge drinking, drinking at a

younger age, more women drinking and increased accessibility and affordability of alcohol (Health Promotion Agency 2005, Mental Health Foundation 2006). It is also predicted that rates of dual diagnosis (korsakoff syndrome with severe mental illness) will increase due to the strong association between alcohol problems and mental health problems (Weaver et al.2002).

Northern Ireland government initiatives to target ôunmet needsôand ôgaps in service provisionôfor people with alcohol related problems have been highlighted in recent legislation such as the Northern Ireland Drugs & Alcohol Strategy and the setting up of regional Drugs & Alcohol Action Teams (DHSSPSNI 2000, DHSSPSNI 2002).

Potential for recovery

Although there are classical symptoms of korsakoff syndrome, the severity of these symptoms will vary from person to person and can range from mild to severe (SAMH 2005). In particular, the degree of recovery will depend on the amount of irreparable damage already done to the brain (Beattie et al. 2000). Evidence has shown that further brain damage can be halted if the person completely abstains from alcohol use (Godfrey et al. 1985). It is also recognised that the progress of korsakoff syndrome can be minimised if the person reduces their alcohol intake and adopts a healthy diet with vitamin B1 supplements (Alzheimerôs Society 2003).

Implementation of appropriate intervention

Experts in the field report that whilst medical intervention cannot repair brain cells which have been destroyed, the brain can learn to develop new ways of processing information and can recover some cognitive functioning (Wilson 2002, Oscar-Berman et al. 1997). The potential recovery for those with korsakoff syndrome improves with the speed of diagnosis and subsequent implementation of appropriate intervention (Smith & Hillman 1999). Unfortunately, early diagnosis and appropriate early interventions are the exception rather than the norm.

Historically inappropriate placements/support

There seems to be a historical pattern of professional care/support for people with korsakoff syndrome which comes from two polar extremes- ótoo much supportôwhich is the case in institutional settings, such as long stay hospitals or nursing homes or ótoo little supportôwhich is likely for people living on the streets or living alone in the community.

The main body of this report will detail the outcomes of 4 individuals with korsakoff syndrome, who have come from living in inappropriate placements for a significant period of time. In particular, this report will ask whether supported living accommodation makes a positive contribution to enhancing the óquality of lifeô and the ólife chancesôof these individuals.

The Connaught House Evaluation

Due to the lack of specialist Alcohol Related Brain Damage Services in Great Britain and Northern Ireland, it is common for individuals who have been diagnosed with korsakoff syndrome to be placed in nursing homes or psychiatric hospitals. A limited amount of research has been carried out on the outcomes for people with korsakoff syndrome, who have been placed in supported living accommodation. However, a relatively recent literature review by MacRae & Cox (2003) has indicated that small group living in domestic style accommodation can be a suitable alternative accommodation. In addition, Price et al. (1988) has suggested that the degree of social deterioration is reduced for those who are supported to live more independently.

"Those accommodated in long stay non-specialist accommodation (i.e. general nursing homes, dementia hospital wards) had greater degrees of social deterioration than those who received encouragement to live independently within supported accommodation" (Price et. al. 1988)

This study aims to add to the existing knowledge base, concerning the support and management of people with korsakoff syndrome. In particular, this report has aimed to better understand the benefits of a small, intensively supported living unit for people with korsakoff syndrome. The progress of 4 individuals living in Connaught House for 12 months has been monitored. Their progress was assessed based on 6 outcome areas -

(1) Health (physical & mental)
(2) Daily Living Skills
(3) Meaningful Activities
(4) Family Involvement
(5) Abstinence (no alcohol policy is used)
(6) Everyday Memory Functioning.

The report has been presented in a case study design approach, in order to retain the individuality and complexity of each tenant's situation.

Introducing Connaught House

Connaught House is a 5 bed supported living accommodation unit based in Newry, Northern Ireland. The scheme is provided by Praxis Care Group which is a voluntary organisation. Praxis Care Group is a major provider of support services within the fields of mental health, learning disability and older age. The range of services provided by the organisation includes supported housing, home response, day care, befriending, counselling support and carer advocacy. There are services tailored for children, young people and adults. The organisation has schemes in Northern Ireland, the Republic of Ireland, England and the Isle of Man (for further information see www.praxiscaregroup.org.uk.

Connaught House opened in June 2004. Referrals for both male and female clients were taken and the first tenant arrived in July 2004. The building is rented from Choice Housing Association (www.choiceha.org) and the support and care is provided by Praxis Care Group. The majority of funding comes from the Supporting People Department within the Northern Ireland Housing Executive (www.nihe.gov.uk/sp). The Health and Social Service Trust that the tenant is registered with also provides funding.

Aim of the Unit

The major reason for establishing a specialist korsakoff unit in Newry was to provide an alternative accommodation option for people with korsakoff syndrome in the area.

"As the incidence of clients with ARBD is on the increase, rehabilitation units need to be developed in all areas of the country. Supported living units are a realistic alternative to Residential and Nursing care, both in terms of providing for the needs of the individual and in terms of cost effectiveness for the health boards and social services". (carenzacare.co.uk)

During the service planning stages, Praxis Care Group personnel consulted with other korsakoff syndrome service providers and undertook a rigorous review of literature within the field of ARBD service provision and management. A small needs analysis survey was also carried out with health professionals in the local area. It reinforced the need for a specialised supported living accommodation unit which

focused on increasing the life chances for people with this particular type of alcohol related brain damage. This preliminary research resulted in the development of the present support model (page 12). The overall aim of the unit is to optimise the possibility of people regaining parts of their life which were negatively affected by their alcoholism and resulting korsakoff syndrome i.e. relearning skills, regaining interests, rekindling relationships, optimising memory ability and promoting alcohol abstinence.

The Building

Connaught House is a grand heritage building which is based on three levels. There is a farm house style kitchen which helps to give the house a domestic and home likeôfeel. There is also a TV room, smoking room, WC, laundry room and 2 bedrooms on the ground floor. The second floor has 1 bedroom, a shower room/WC, a bathroom and a games room. The third floor has two bedrooms and an office /sleepover room for staff with an ensuite shower/ WC. Each tenant has their own bedroom which they are encouraged to make their own by adding family pictures, having their own bedspreads, TV, CD player etc. The building design is not ideal for this client group, the unsteady gait which accompanies the korsakoff condition makes using stairs difficult. PCG management is fully aware of the limitations of the building and has made efforts to add assistive technologies into the home where it can i.e. electronic alarms on doors, call bells in rooms and automatic taps.

There is a large garden surrounding the house which has a hen coup. The eggs that are collected are often used for breakfast. Honey the dog can be found walking around the garden or lying in her bed at the side of the kitchen. There is a small patio area off the kitchen which is used during the summer by the residents and staff. These elements of the house help provide a relaxed and homely environment.

Connaught House is close to the edge of a town, which has all the usual amenities. It is in close proximity to three mental health day centres. Two of the day centres place emphasis on building social skills and interests. The other day centre follows a more structured program where people are contracted to work in a kitchen, helping to cook or to clean dishes. The unit is also close to an Alcoholics Anonymous support group and a leisure centre.

Pictures of Connaught House

Hens

Hen Coup

Front of Building

Laundry Room

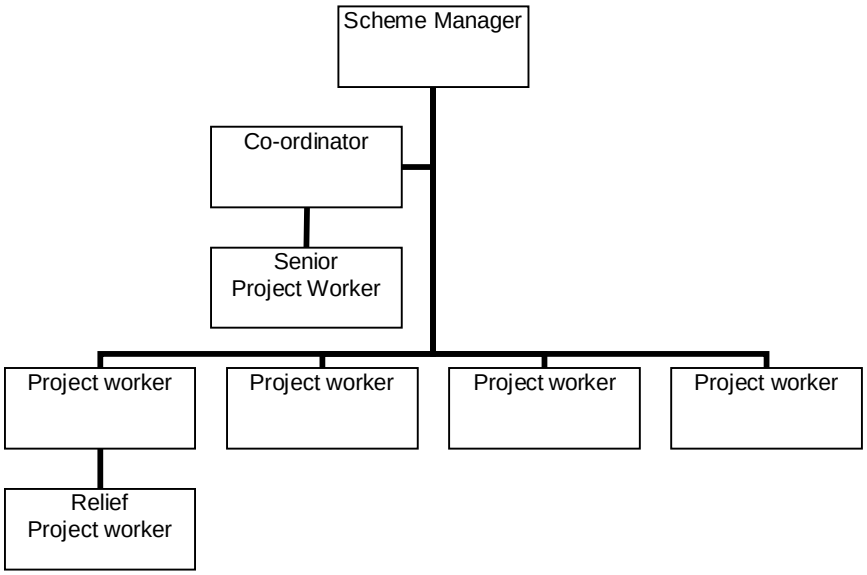
Games Room

TV Room

Honey the Dog

Kitchen

The Staffing Structure



Connaught House is staffed by 8 workers, 3 of which are professionally trained nurses. There is also regular contact with multi-disciplinary teams outside of the unit i.e. the Community Mental Health Team (CMHT), Occupational Therapists (OTs), Social Workers (SWs), Community Psychiatric Nurses (CPNs), GPs, and Consultant Psychiatrists.

Staff Training

Each new staff member must carry out a 5 day mandatory induction which includes health and safety, administration and personnel policy and procedures. Also, new staff members receive skill based training in moving and handling techniques and intervention techniques i.e. calming and diffusing and breakaway. Staff members have also received specific awareness raising training in korsakoff syndrome and alcohol abuse. In addition, staff are trained in other areas depending on the needs of the individual tenants i.e. diabetes training and epilepsy training. Praxis Care Group provides a comprehensive internal training programme for staff. Also, additional external training is made available to staff if it is deemed to increase the quality of support for the client group.

Selection Process/ Referrals

Referrals to the scheme can only be made via the Community Mental Health Team (CMHT). At present referrals can be made from any Trust area. After a client shows an interest in coming to the scheme an informal assessment is carried out. This assessment examines their mobility, willingness to move accommodation, willingness to relocate to a new area, risk of harm to self or others and determines that there are no obvious signs of drinking. If the person is successful in the informal assessment, a

formal selection panel is set up which includes Mental Health Professionals, Occupational Therapist as well as the Assistant Director, Manager and Co-ordinator of Connaught House.

Eligibility Criteria for Connaught House

- Diagnosed with korsakoff syndrome[1]
- Completed a full alcohol detoxification or natural detoxification[2]
- Shows a desire to stay off alcohol
- Accepts the Praxis Care Group tenancy agreement
- Presents with low risk of harm to self and others
- Referred via a Mental Health Professional (Social Worker, CPN, Consultant Psychiatrist)

John is a 52 year old man. He had been living in a number of elderly nursing homes and long stay psychiatric hospitals before being referred to Connaught House. None of these previous placements had been able to cope with his complex needs and his family felt unable to cope with his needs in the community. John would regularly abscond from the nursing home placements and create great risk to his own safety. Without any other suitable housing being available, John was placed in a secure ward in a long stay psychiatric hospital. At this time he was also diagnosed with korsakoff syndrome. John continued to attempt to abscond while in the secure ward. He stayed there for 1 ½ years before being successfully referred to Connaught House.

[1] Or a similar alcohol related brain damage condition- memory impairment being a significant symptom
[2] Natural detoxification- i.e. individuals are in a situation where they have no access to alcohol, for example if they have been in long stay hospital.

Referral Agent Views' of the Unit

On entry to the scheme, each tenant's referral agent (the professional who referred the tenant to the scheme) was asked to fill out a questionnaire giving their views on different aspects of the service. 3 of the referral agents were the client's social worker and 1 was their CPN (community psychiatric nurse). The length of professional contact ranged from 7 months to 4 years, with an average of 2 years of contact.

Figure 2 below indicates that the main reason why health professionals referred clients to Connaught House was the specialist nature of the unit.

Figure 2: Table showing reasons given by referral agents for referring individuals to Connaught House

Reason for Referral	%	n =
Specialist nature of Connaught House	100	4
Previous accommodation unsuitable	25	1
Request from family/friends	25	1
Deterioration in health in previous accommodation	25	1

As Figure 3 shows, all 4 referral agents stated that they expected to see an improvement in the 'mental well being' of their client. 3 out of the 4 referral agents expected to see improvements in the 'physical well being' and the 'quality of life' of their client. 2 of the 4 referral agents stated that they expected to see an improvement in their 'ability to remain abstinent' and their 'cognitive functioning'

Figure 3: Table showing referral agent expectations for Connaught House tenants

Expectations of Connaught House	%	n=
Improvement in mental wellbeing	100	4
Improvement in physical wellbeing	75	3
Improvement in quality of life	75	3
Better chance of abstinence	50	2
Improvement in cognitive functioning	50	2
Improvement in living conditions	25	1

The Connaught House 'Support Model'

The following support model was shaped on the basis of a report produced by MacRae & Cox (2003, p.15), which reviewed the existing and recommended models of care for people with alcohol related brain damage. Evidence-based practice from other supported living units within Praxis Care Group was also used. The support model covers 6 key areas which were deemed to be important areas of development for individuals with korsakoff syndrome.

1. Improvements in Health

- Physical health
- Mental health (Depressive feelings/ behaviours)

2. Improvements in Daily Living Skills

- Personal care tasks i.e. showering, laundry, attending appointments
- Household chores i.e. cooking, ironing, hoovering, looking after the animals

3. Increase in Meaningful Activities

- Day centre placements
- Going out for meals, concerts
- Building social skills

4. Family Involvement

- Increasing social contact
- Involvement in the planning of support etc.

5. Maintaining Abstinence

- Providing an alcohol free environment with a ónо alcohol policyô
- Supporting abstinence i.e. AA, encouragement

6. Improvements in Everyday Memory Functioning

- Memory for names, places, events from the recent past or events planned for in the near future.

Implementing the Support Model

A support model will work most successfully if implemented within a structured framework of trained staff, with a low staff turnover, good management, clear support plans and interagency communication and collaboration (Schofield et al. 1995). Mansell (2005) has highlighted the importance of good management and staff who provide facilitative and enabling support for individuals. This is particularly important for those individuals with the most severe or complex disabilities. Due to the intensity of work carried out by staff, regular breaks and opportunities to discuss issues individually and as a staff group are vital. Mansellôs paper focused on the movement of people with learning disabilities from institutional care to supported living. However, the principles of support provision can be applied across social care fields.

> ñBetter large institutions can produce outcomes as good as weaker small settings and better small institutions can achieve outcomes as good as weaker supported livingò(Mansell 2005)

Key features for the successful implementation of a support model

As Connaught House has developed experience and knowledge of the support needs of these specific clients, key features for the successful implementation of the support model have been identified- (1) intensive support (2) consistent staffing (3) consistent approach by staff to tenants (4) individualised support plans and (5) multi-disciplinary communication.

(1) Intensive support through high staff to client ratio

The main ethos of the unit is that each individual is encouraged and supported to become actively involved in all aspects of daily life. This requires a consistently high level of support and encouragement by staff members. Staff members supervise and direct tenants in carrying out tasks and only assist the tenant when they feel it is necessary. The amount of time given to tenants for re-learning skills and motivating tenants to regain interests would not be possible in an environment with a lower staff to client ratio, such as a nursing home or long stay hospital. In fact, many daily living skills are ólountedôonot only due to the symptoms of korsakoff syndrome but also due to being in care environments where they have little or no input into daily life activities such as cooking, cleaning etc.

John found it difficult to settle into Connaught House. Particularly in the early part of his tenancy, he would go to bed during the day with his pyjamas on over his day clothes. The staff supervise John closely to discourage this behaviour by providing diversionary activities.

(2) Consistency in staff

Only two members of staff have left Connaught House in the 2 years that the project has been in operation (1 full time and 1 part-time support worker). Consistency in staffing is particularly important for people with korsakoff syndrome, as learning names and faces is a much slower process than normal, due to the reduced ability to learn new information. Consistency in staffing also affords tenants the time and opportunity to build trusting relationships with staff.

(3) Consistency in staff approach to tenants

A standard approach to dealing with tenants is vital. Staff members have reported that tenants settle into the routine and rules of the house more easily when the staff relay consistent messages to tenants and provide an environment with a set structure and routine (SAMH 2006). However, the unit ensures that structure and routine is not at the expense of choice and variety. Tenants are encouraged to have full input into their support planning, to rekindle old interests and build new ones. House meetings are also called regularly for both staff and tenants to communicate their opinions on group issues i.e. housework rota, menu for the week and planning group outings.

(4) Individual Support Plan

Although each tenant will be primarily diagnosed with korsakoff syndrome, each will also have a range of other mental, physical, personal, and social difficulties which serve to increase the complexity and diversity of their support needs. For this reason it is important that each tenant has an individually tailored support plan. This plan should provide a clear holistic outline of their present support needs. The overarching aim of the plan is to maximise their independence and quality of life (Jacques & Stevenson 2000). The tenant, health professionals and family are all encouraged to

become involved in creating and adapting support plans. In some cases tenants are unwilling or unable to feed into this process, however, support plans continue to be reviewed by the scheme on a regular basis, usually every 3-4 weeks or earlier if required. Previous research carried out in Scotland and the Republic of Ireland has reported that a weakness of some services for people with korsakoff syndrome is the limited use of support plans and review systems (Jacques & Anderson 2002; Kiernan 2004). Each tenant in Connaught House has a staff key worker. The key worker is scheduled to spend dedicated 1 to 1 time carrying out the aims outlined in the tenantôs support plan.

(5) Good multi-disciplinary communication

Good multi-disciplinary communication is essential in order to provide an effective and integrated approach to supporting individuals with korsakoff syndrome. Staff and tenants have regular contact with a range of professionals including Social Workers and CPNs from the Community Mental Health Teams, Consultant Psychiatrists, GPs and Key Workers from day centres.

Philip at 38 years of age is the youngest of the tenants in Connaught House (mean age of group, 51 years). Philip was a street drinker and a heavy gambler. He has also been diagnosed with bi-polar affective disorder. He has 2 children from a previous marriage. However, during his time of drinking and unsettled lifestyle limited contact was made with his children or other family members. Before being admitted to long stay hospital, Philip had a long history as a 'revolving door' patient. Due to the nature of life on the streets, injury from falls due to intoxication and fights were not uncommon. Philip was well known to the local A&E Department and the local Police station. Philip shows good insight into his condition, the fact that alcohol has damaged his brain and that further drinking would increase the damage.

"If I drink, I would be dead in a day. One bad fall and that's it. I used to be able to drink 6-7 bottles of vodka a day and Carlsberg Specials and be up early in the morning, getting up for more drink."

Demographics of the 4 Connaught House Tenants'

The 4 tenants who form part of this report have a mean age of 51 years (age range: 38-57 yrs old)[3]. 3 of the tenants came to Connaught House from a long stay psychiatric hospital. The length of time they had been living in long stay hospital ranged from 1 ½ years to 14 years. 1 tenant came from a 4 year tenancy in a flat cluster supported living unit for people with mental health difficulties.

3 of the tenants have co-morbid disorders. 2 tenants have frontal lobe brain injury due to falling while intoxicated and 1 tenant has bi-polar affective disorder.

Figure 4: Demographics of the 4 tenants

Case Study 1: Philip	**Case Study 2: Mark**
Age on entry to scheme: 38 **Length diagnosed:** 5 years **Previous Accommodation:** Long Stay Psychiatric Hospital, for 5 years **Co-morbidity:** Bi-polar affective disorder **Alcohol relapses*-** 1 occurrence of relapse	**Age on entry to scheme:** 57 **Length diagnosed:** 6 years **Previous Accommodation:** Mental Health Flat Cluster, for 4 years **Co-morbidity:** Brain Injury due to a fall **Alcohol relapses*:** No relapse
Case Study 3: Cormac	**Case Study 4: John**
Age on entry to scheme : 57 **Length diagnosed:** 23 years **Previous Accommodation:** Long Stay Psychiatric Hospital, for 14 years **Co-morbidity:** Brain Injury due to a fall, Epilepsy **Alcohol relapses*:** No relapse	**Age on entry to scheme:** 52 **Length diagnosed:** 1½ years **Previous Accommodation:** Long Stay Psychiatric Hospital, for 1½ years **Co-morbidity:** None **Alcohol relapses*:** No relapse

** Since entering Connaught House*

[3] Tenant ages mentioned in the report relate to their age on entry to the scheme

Tenant Outcomes based on the Support Model

The following section of the report will describe the outcomes for the tenants based on the 6 key areas of the support model. These areas are (1) Improvements in Health, (2) Improvements in Daily Living Skills, (3) Increase in Meaningful Activities, (4) Family Involvement, (5) Maintaining Abstinence and (6) Improvements in Everyday Memory Functioning. This section of the report will provide a comprehensive description of how the model has been implemented within Connaught House. This section will also describe the outcomes for each individual, using data collected across 3 time points, baseline (on entry to the scheme), 6 months and 12 months follow-up.

Mark, at 57 yrs of age, is one of the older tenants in the house. Mark has particularly poor mobility. He has walked with the aid of a crutch since entering Connaught House. In addition to korsakoff syndrome, he also has frontal lobe damage from a fall while intoxicated.

Mark came to Connaught House from a flat cluster type of group living accommodation for people with mental health difficulties who required low to medium support. It became increasingly clear that this type of accommodation service was inappropriate for his needs and that he required a greater level of support. Mark was often returning to the flat intoxicated. This would result in him being highly confused for days afterwards and was potentially causing further brain damage. He was also showing an overall deterioration in his living conditions, general health and hygiene.

Moving to Connaught House has resulted in a significant improvement in Mark's personal hygiene and diet due to increased staff support. He is also attending to his dental problems. There have been no occurrences of drinking since moving to this higher support accommodation. The amount of input into his own personal hygiene and household tasks had always been limited. However, these activities are becoming increasingly difficult for Mark, due to his mobility problems.

(1) Improvements in Health

The unit aims to promote good mental and physical health in tenants through a healthy diet, improved living conditions and engagement with healthcare services, such as the Dentist and GP. A more stable lifestyle has meant that the demand on health care services and emergency services, such as, Accident & Emergency, Long Stay Hospital Care and the Police has been reduced. This is a positive change, as in the Reducing Alcohol Related Harm Report, it has been estimated that £34.3 million is incurred in costs from alcohol related illness that directly impact on government spending (DHSSPSNI 2000).

Overall, the unit has found improvements in the general health of the tenants. Connaught House encourages a healthy diet, healthy sleeping pattern, supports tenants to address health needs and assists them with the administration of medications. The additional physical health problems, mental health problems, and behavioural/ emotional difficulties of some of the tenants have impacted on the degree of improvements shown in their daily living skills, social skills and community involvement.

Alcohol and Depression

The association between alcoholism and depression is now a well established fact (Mental Health Foundation 2006, Gilman & Abraham 2001, Nunes et al. 2006). Depression can affect a person emotionally, mentally and physically (www.aware.ie). It is also suggested that depression and quality of life are negatively correlated (Logsdon 1999).

Depression rating scores

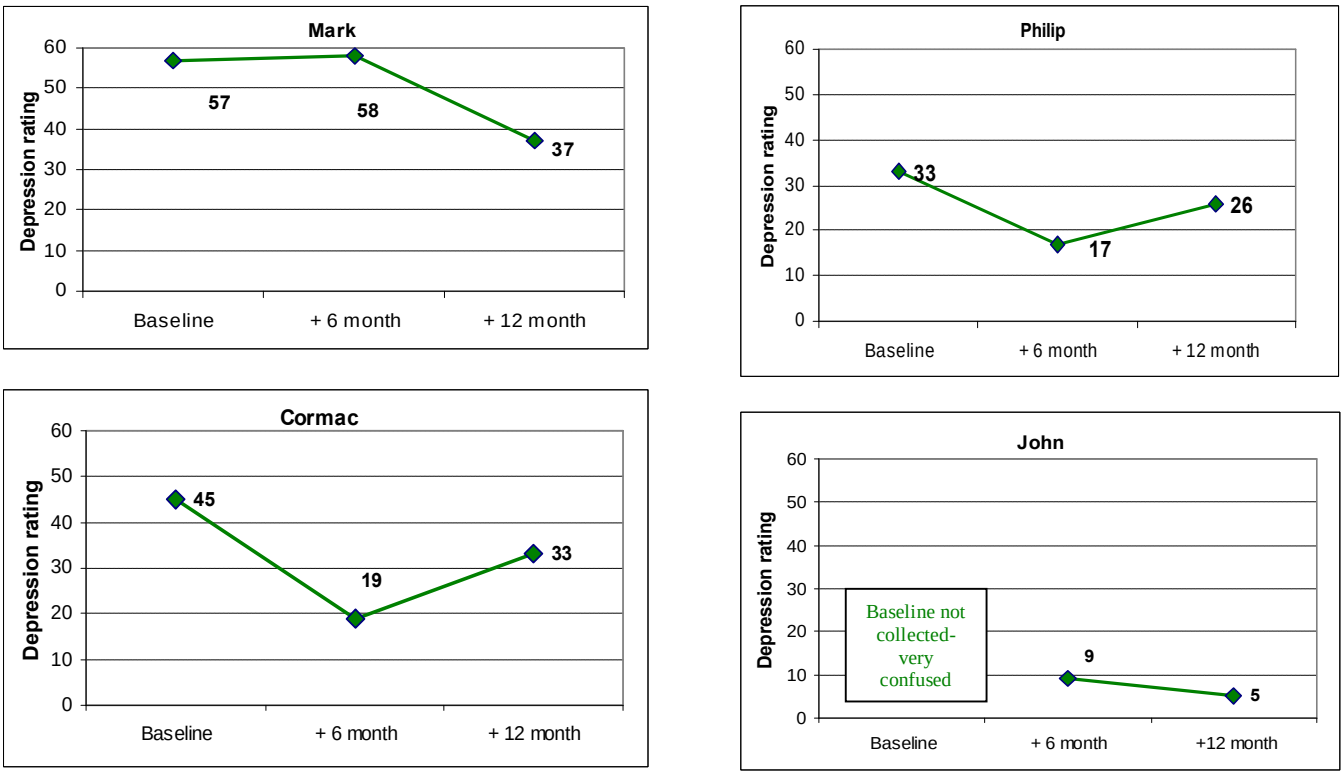
Each tenant was asked to self score themselves on the CES-D depression scale[4], at 3 time points. The CES-D scale is an indicator of depression rather than a diagnostic tool. It asks people to rate themselves on depressive feelings or behaviours over the previous week. Due to the memory problems of the tenants, the scores were taken as ómoment in timeôratings. A score of 16 or more on the scale indicates that the person suffers from depression. If the score falls between 16 and 21, this is

[4] The Centre for Epidemiological Studies Depression Scale

classified as mild/moderate depression. A score of 22+ indicates that the person may be suffering from severe depression (Radloff 1977).

Figure 5: CES-D depression scale scores- self score

<16	**No Depression**
16-21	**Mild/Moderate Depression**
≥ 22	**Severe Depression**



As Figure 5 shows, three of the tenants, Philip, Mark and Cormac have self rated themselves with severe depression at each of the 3 time points. This would fit with the fact that Philip has been diagnosed with bi-polar depression and both Mark and Cormac have had traumatic head injuries which is strongly linked with depression. Van Reekum et al. (2000) reviewed available literature in this field. He suggested that 44% of people with traumatic brain injury also have depression.

A baseline rating was not taken for John as he was in a very confused state when he first entered the scheme. At 6 and 12 months data collection, Johnûs scores indicated no depression at either time points. The scores for each of the 4 tenants show an overall fall in their depression score, between baseline and 12 months, which indicates an improvement in depressive feelings/ behaviours. This is a positive outcome as depression or low mood can impact on individuals engagement in daily

living skills, social interaction etc. The dip in depression rating at 6 months and then the increase at 12 months for Philip and Cormac may have been affected by different factors. Philip voiced concern during his 12 month interview that he may be doing ótoo wellô and therefore may be asked to leave the unit.

ñ*I'm not ready to leave yet. I had been saying that I want to get a flat. (But Connaught House) is going to be my home, until I am ready to leave" (Philip 12 months.)*

Cormac was showing a deterioration in his general mental health between 6 months and 12 months. This may explain the dip and rise in his depression rating during this same period.

Cormac had been a successful business man before his alcohol problems and resulting korsakoff syndrome. He had been in long stay psychiatric hospital for 14 years prior to coming to Connaught House. Like Mark, he also has frontal lobe damage due to a fall while intoxicated. The staff were informed, on his entry, that at one stage in hospital he was unable to feed or wash himself. When Cormac first arrived at the scheme he was presenting with some highly institutionalised behaviours. He would start to undress when the staff entered the bathroom. He believed that his freedom was limited to the grounds of the house. These behaviours are not surprising, as during his 14 years in hospital nursing staff would have carried out the majority of his personal hygiene and daily living duties for him i.e. laundry, cooking and cleaning. There was a reduction in these behaviours by 6 month follow-up. Cormac was capable of reacquainting himself with carrying out personal hygiene tasks and helping with household chores. However, he often refuses to do so and does not see any benefits of doing this himself.

"They (staff) don't think it is their place to do anything they think looks like a chore. I say 'who is getting paid for doing what?' I was a carpenter and then a publican and then a hotelier. I never did what you would call menial tasks."

(2) Daily Living Skills

The unit aims to support the tenants to re-learn daily living skills lost through korsakoff syndrome and through lack of use; skills such as showering, washing, laundry, ironing, cooking, buying personal goods and also household chores such as hoovering, washing dishes, wiping down tables, putting out rubbish and grocery shopping. The type of tasks and amount of staff support given to tenants has depended on their physical health, level of challenging behaviour, willingness and/or motivation to work with their support plan and the extent of their memory impairment. Re-learning skills has also been a confidence boosting exercise for some of the tenants.

Philip has an obvious unsteady gait and a numbness in his hands which makes fine motor tasks difficult i.e. peeling potatoes, using a tin opener. However, he is very capable of taking on other household chores such as feeding the hens, wiping tables, putting out the bins and emptying the dishwasher.

"I think I have been given nearly every job in here. I think I am still the fittest. I have surprised myself."

Over the 12 month period Mark's mobility problems and challenging behaviour has affected the amount of personal care tasks and the type of household chores he has been able to do. However, the staff try to promote his independence where possible. A bath chair has been provided to allow Mark to shower himself and an electric shaver was bought so that he could shave himself more easily. He is asked to make his own bed and to attempt to participate, in some way, towards household chores i.e. emptying

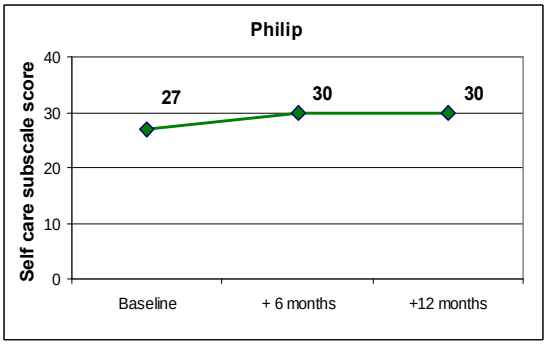
Life Skills Profile (LSP) Sub Scale: Self care

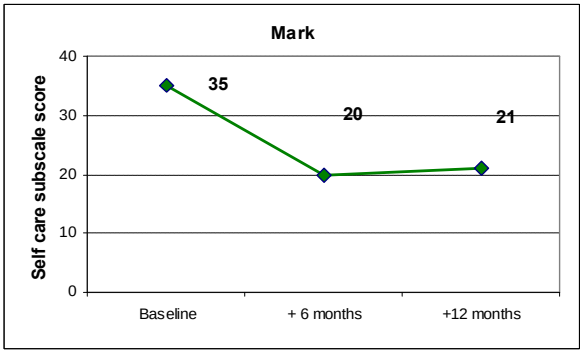
Each of the tenantsôsupport key workers were asked to rate the tenant on their self care ability at 3 time points (baseline, 6 months and 12 months). The self care scores shown below (Figure 6, page 22) are one of 5 subscales of the LSP questionnaire. Scores on this subscale range from 10-40, a higher score indicates greater

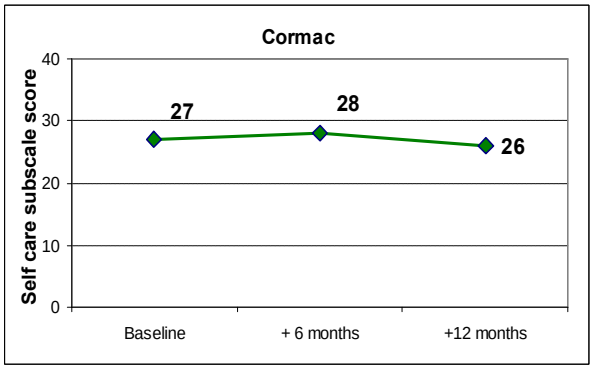
observable self care abilities.[5] As the graphs below show there has been varying self care scores given for the 4 tenants.

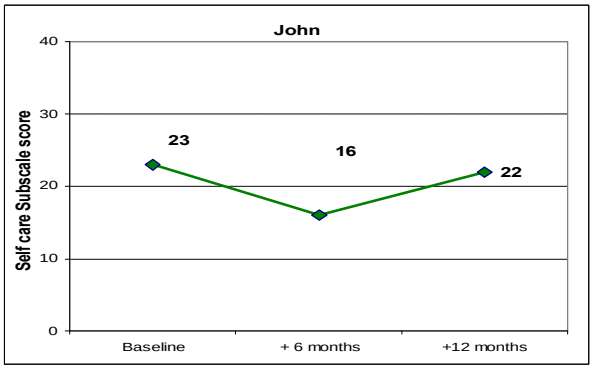
Figure 6: Life Skills Profile (LSP) Sub Scale: Self care

Minimum score possible	**10**
Maximum score possible	**40**









Each of the tenants were rated with quite good self care ratings at baseline. Philipôs self care rating had risen slightly over the first 12 months. Markôs self care ratings dropped from 35 at baseline to 21 at 12 months. This drop may be largely due to his reduced mental and physical health. Cormacôs self care rating has stayed largely the same over the course of the 12 months. John had an infection between baseline and 6 months which negatively affected his physical and mental health and behaviour. This may have caused the drop in the self care rating during this period.

[5] See page 50 of the methodology section for a full description of the LSP scale. Appendix 2, page 53, provides all LSP subscales and total scores, for each of the 4 tenants, across the 3 time points (baseline, 6 months and 12 months).

(3) Increase in Meaningful Activities

The staff support tenants to get involved in ómeaningfulôactivities i.e. activities that hold an interest to the individual tenant. Interests are discovered by talking to tenants themselves, through informal conversations or through memory work sessions. Family members also act as a useful source of information for building a picture of tenantsôinterests, pre-korsakoff syndrome. As people with korsakoff syndrome can have limited motivation and initiative, the staff members play an important role in supporting and encouraging tenants to rekindle old interests and to find new ones. Encouraging meaningful activities acts as a positive way of reintroducing choice and control back into their lives (Consultation and Involvement Trust Scotland 2003).

John worked as a fabric cutter in a factory before developing korsakoff syndrome. John loves Manchester United and listening to Status Quo. Since coming to Connaught House, Joe has been spending time on the computer typing for fun. This is a new skill and experience for John. The staff engage John in conversations about his interests and encourage him to spend time on them.

The staff organise outings for the group for dinner, bowling etc. The Connaught House key workers will also often accompany individual tenants, when carrying out personal tasks or when going on social outings i.e. the shops to buy clothes or presents, to go out for a drive, to go to a doctorsôappointment.

All the tenants enjoy listening to popular music, from their pre-korsakoff years. Years for which their memory is very clear. Tenants listen to the radio or CDs in the smoke room. Mark spends most of his time in the smoke room listening to music and likes to sing Joe Dolan songs to staff and visitors.

Philip, Mark and John also enjoy personal time in their room listening to their favourite bands. The tenants would not have had this type of privacy while living in ward beds.

In long stay hospital: *"I never left the smoke room, the only time was to shower or go to the toilet" (Philip)*

In Connaught House: *"If I want to get away on my own, I go upstairs and listen to my music" (Philip)*

Connaught House staff have accompanied tenants to concerts of bands/musicians they would have listened to before the onset of korsakoff syndrome. During the reporting period, staff also accompanied tenants for meals in town. These activities would have been a rare occurrence in their previous accommodation, where staffing levels would have made regular outings impossible.

Day Centre Placements

A consultation was carried in Scotland with people affected by alcohol related brain damage and their carers. It stated that there was not enough appropriate day time activities available for such individuals (Consultation and Involvement Trust Scotland 2003). A similar view has been voiced by Connaught House staff. There are no specialised day centre placements for people with korsakoff syndrome in Northern Ireland. Philip, Mark and Cormac have attended a mental health day centre placement during their first 12 months of living in Connaught House. John has voiced an interest in day centre placement and the staff are currently supporting him to find a local placement.

Tenant Views of Day Centres

- *“Meet people, smoke, play pool” (Philip)*
- *"It's different, it’s no big deal." You sit around the table, play pool and talk" (Cormac)*
- *“They are psychiatric places, they are for psychiatric people” (Mark)*

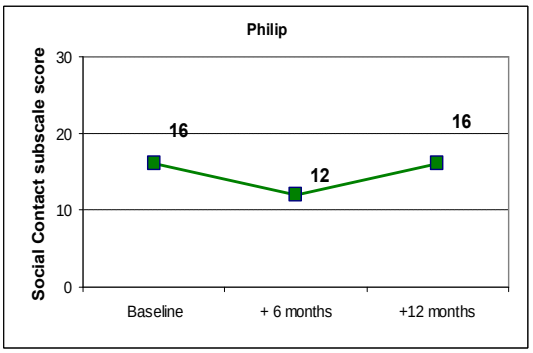
Staff members encourage tenants to go to the local mental health day care centres. As it is an opportunity for the tenants to interact with people who are not Connaught House staff or tenants and it also gives them a chance to develop social skills and build confidence. Philip is attending day centres regularly and takes part in pool tournaments with other day centre service users. This is a skill he would have picked up during his drinking years and one which he remains good at and enjoys using. Cormac attends the centre and enjoys getting attention from the staff there. Markôs inappropriate conversation and aggressive tone make it difficult for day centre staff and other service users. Markôs increasing mobility problems were difficult to manage with the resources of the day centre. For both of these reasons, day centre attendance stopped for Mark. Connaught House staff attempted to provide alternative day activities, by adapting his support plan, to incorporate more one to one activities with his support key worker.

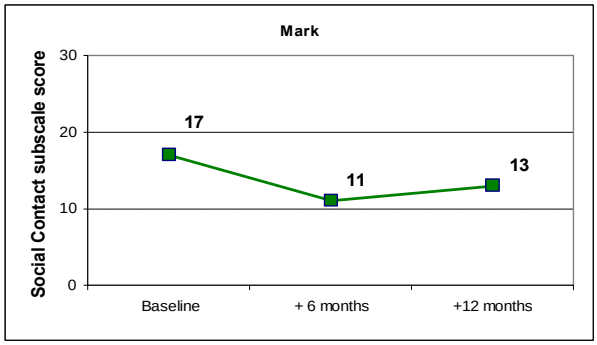
LSP Subscale: Social Contact

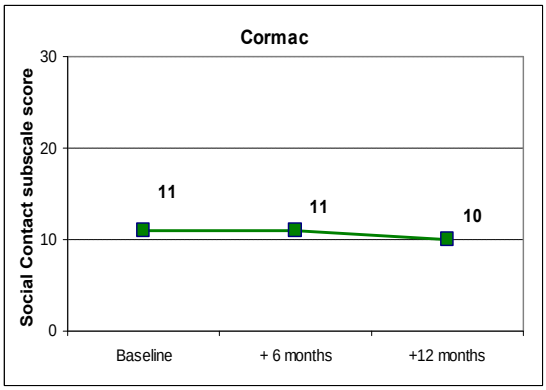
Like the self care scores, each of the tenantsû support key workers were asked to rate the tenant on their social contact, at 3 time points (baseline, 6 months and 12 months). Social contact is one of 5 subscales on the LSP questionnaire. Scores on this subscale range from 6-24, with a higher score indicating greater observable social contact.[6]

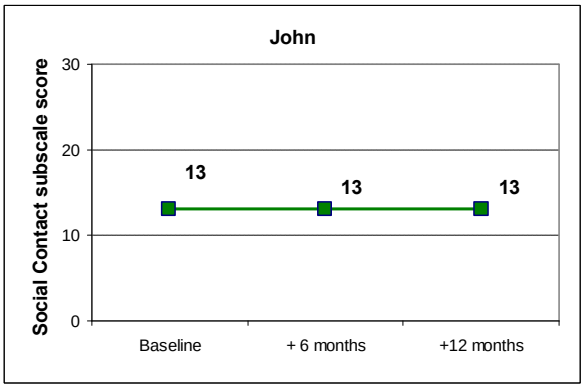
Figure 7: LSP Subscale: Social Contact

Minimum score possible	**6**
Maxiumum score possible	**24**









As the social contact graphs show (Figure 7) scores for Philip, Cormac and John have remained relatively stable over the 12 month period. Mark has shown the biggest change in social contact scoring. Mark was attending a day centre, however, attendance was stopped because of the inappropriate conversation and aggressive language towards day centre staff and service users. These behaviours are typical of people who have frontal lobe damage. Challenging behaviour such as verbal

[6] See page 50 of the methodology section for a full description of the LSP scale. Appendix 2, page 53 provides all LSP subscales and total scores for each of the 4 tenants, across the 3 time points (baseline, 6 months and 12 months).

aggression and mood swings, as well as, social difficulties such as inappropriate language, behaviours, and conversation make developing social circles and friendships difficult (Barrett 2006).

(4) Family Involvement

Encouraging positive family involvement is also one of the aims of the Connaught House support model. Previous literature in the management of and service provision for people with korsakoff syndrome has highlighted the benefits to be gained from positive family/social networks. Maintaining supportive and consistent social networks are ócrucialô for those individuals who are able and willing to make the transition towards óindependentôliving (Jacques & Anderson 2002; Scottish Executive 2004).

The staff support tenants to maintain contact with family members and to rekindle relationships lost through the damaging effects of alcoholism. Any form of contact from family is welcome i.e. family visits, letters or telephone contact. Both Philip and John are showing good progress in rebuilding relationships with family. For Cormac, contact with his family has caused increasing stress and anxiety for both parties. Mark has no family contact; however social contact is made by his ex-girlfriend, who continues to telephone. He also has regular visits from a home response worker, who he has known since he lived in the mental health supported living facility.

Philip had lost contact with his children for many years through alcoholism and through being placed in a long stay hospital, many miles from where they lived. Since moving closer to his family, Philip has gradually built up regular contact with his children, who visit him once a week.

ñI have contact with my kids because Iôm living properly. They visit once a weekò

"I just want to stay off the drink and see my children"

Cormac has found dealing with the limitations of his condition and his current living situation, increasingly difficult.

"I was never an alcoholic. I used to drink to pass myself with locals that would come into the (pub), I had a bad accident. That's a long time ago. I feel fit as a fiddle now"

Cormac enjoys visits from his family, but he has placed a lot of pressure on them, to bring him home to live with them. His family believe that Connaught House is the most suitable place for him. Cormac vents his anger at his family by asking them to leave when they visit and will ring them multiple times per day with the same conversation. Cormac also makes regular phone calls to 999, to tell them he is being held in Connaught House, against his will. This problem is exacerbated by his difficulty in remembering visits or conversations with people and also his lack of insight or acceptance of his condition.

Family Member Views

A family member[7] of each of the 4 tenants was asked to comment on their relationship with their family member, since they moved to Connaught House. They were also asked to give their views on different aspects of the unit. 2 of the 4 family members reported that they were making a lot more contact with their family member, since they had moved into Connaught House. The remaining 2 family members stated that their level of contact had not changed. However, irrespective of whether contact had changed or not, all 4 family members agreed that their relationship had improved since their family member moved into the unit. 2 family members reported that it had got ña lot betterô and 2 reported that it had become ñsomewhat betterô

All 4 family members agreed that Connaught House was the most suitable place for their family member to live. Positive aspects of the unit mentioned by family were-

[7] Mark has no family contact. His home response worker filled out the family member questionnaire. He has known her for approximately, 4 years.

good staff support, the unit being unlike a hospital environment and that the tenants had their own bedrooms. They also stated that their family member was showing improvements in key areas of their daily functioning. As Figure 8 shows, no family member perceived that their loved one had become worse, in any of the key outcome areas. The areas are (1) Staying off Alcohol, (2) Housing Conditions, (3) Daily Living Skills, (4) Quality of Life, (5) Brain Functioning, 6) Mental Well Being and (7) Physical Well Being. All respondents believed that the ability of their family member to stay off alcohol had become ôa lot betterô since moving to Connaught House. They also reported that their family memberôs housing conditions, daily living skills and quality of life had got either ôa lotôor ôsomewhat betterôsince moving to Connaught House. 3 of the 4 family members also believed that their family memberôs brain functioning and mental well being had got ôsomewhat betterôsince moving to Connaught House. One family member perceived there to be no difference in brain functioning, mental well being or physical well being since moving to Connaught House.

Figure 8

Family member perspective: Perceived changes in tenants since entering Connaught House:

	A lot better	Somewhat better	No difference	Somewhat worse	A lot worse
1. Staying off Alcohol	100% (n=4)				
2. Housing conditions	50% (n=2)	50% (n=2)			
3. Daily Living skills*	25% (n=1)	75% (n=2)			
4. Quality of life*	25% (n=1)	75% (n=2)			
5. Brain functioning		75% (n=3)	25% (n=1)		
6. Mental well being		75% (n=3)	25% (n=1)		
7. Physical well being	25% (n=1)	25% (n=1)	50% (n=2)		

** No answer (n=1)*

Overall, 3 of the 4 family members were ôvery satisfiedôwith Connaught House and 1 family member reported that they were ôquite satisfiedô

(5) Maintaining Abstinence

Supporting tenants to abstain from alcohol is a major aim of Connaught House and as such the organisation has implemented a ôno alcohol policyô However, relapse remains a realistic possibility for tenants as (a) Cravings for alcohol may persist and

(b) Proper insight into the severity of their condition may be lacking. The unit does not view one breach of the alcohol policy as an immediate eviction. Due to the nature of the condition, alcohol relapse is not surprising. However, the unit promotes itself as providing an alcohol free environment for other tenants. Therefore, a tenant who continually breaches the no alcohol policy and presents with unmanageable drinking behaviour, will have their tenancy ended.

Philip regularly seeks support from staff when he has cravings for alcohol. The onset of these cravings is often linked to him feeling in a low mood/ depressed. Mark has contradicted himself during interview conversations, in terms of both his insight into his condition and his concern for the damaging effects of further drinking. He will show recall of his drinking problems and awareness of his memory problems. However, he will also state that he wants to go and drink and that he doesn't identify with the other tenants or report that he requires the support of Connaught House.

"I swear I will never touch it again (alcohol)"
"I want to get out of here and go and get a wee drink"
"Those clowns were born in that condition. I was injured."
(Mark- all comments were made during the 12mth interview)

As the tenants strengthen mentally, physically and cognitively, their independence and community involvement also increases. In reality, this also means greater exposure to pubs and the many other outlets where alcohol is easily accessible.

Alcohol relapse rates during the first 12 months

To date there has been a very successful record of abstinence for Philip, Mark, Cormac and John. Over the 12 month period of data collection there was 1 incident of Philip taking alcohol. On two other occasions Philip bought alcohol and brought it back to the unit. However, he told staff he had done so and allowed them to take the alcohol, before drinking it. This is a good example of how a

During the 12 month period, there was 1 incidence of alcohol relapse for Philip.
>>>>>>>>
None of the other 3 tenants had occurrences of relapse. Poor mobility, greater staff supervision and absence of cravings for alcohol factored in this.
>>>>>>>>
Relapse was a major factor in other tenancies ending prematurely (see page 36)

supported living accommodation with good staff-tenant relationships can help to reduce the incidence of alcohol relapse and essentially prevent further brain damage. A recent document from the Department of Health has identified the usefulness of simple motivational interventions by mental health staff, as part of a support plan, rather than a need for staff with specialist addiction skills (DoH 2006).

There has been no incidence of alcohol relapse for Mark, Cormac or John. However none of these tenants go out of Connaught House unaccompanied, due to their poor mobility and memory problems. Therefore, there is little opportunity for them to go into an off licence or pub. In addition to this, both Cormac and John have little insight into their condition, do not report to have cravings or have memory of their alcoholism. Mark has very poor mobility and uses crutches to walk. He is different from the other tenants in that he shows intermittent insight into his condition. However, he can also present with little concern towards the effect of further drinking or of the limitations his condition holds.

(6) Every Day Memory Functioning

Memory exercises

Having a routine in the house has assisted the tenantsôshort term memory capacity. For example, associating a meal with a day i.e. fish and chips and Friday or knowing that they have visitors on a particular day i.e. family visit on a Sunday. The staff provide consistent reassurance and continue to provide answers to repetitive questions. The staff encourage the tenants to answer their own questions, by giving the questions back to them or giving prompts to aid them in answering their own questions.

Memory Worksheets

The staff act as a memory aid for the tenants. The scheme uses structured memory sheets and reminiscing exercises, in the form of quizzes and games, to help tenants to exercise their brains, build confidence and to reduce the anxiety and frustration created by memory problems.

The memory worksheets are administered at 3 month intervals. At each 3 month interval, the worksheets are taken at the beginning and end of the same week.

Depending on memory functioning, tenants are questioned on things that have happened or things that they have done either a number of hours before or a number of days/weeks before. Topics used within the worksheets include *family contact, finances/budget, meals and social events.* These are areas in which memory loss has been shown to cause most distress to the tenants in Connaught House. As with all aspects of the study, participation is voluntary. To date, 2 of the 4 tenants have taken part in the memory worksheets, Philip and John.

On entry to the house, John was extremely confused and anxious. He would ask both staff and other tenants *"How am I getting home"* and *"Where am I?"* repeatedly throughout the day. 'Home' being the house that he lived in with his wife and children, in the years before his memory problems began. John's family no longer live there. John remained in this 'groundhog day' for a number of months, believing that he had just arrived to Connaught House that day and that he was meeting staff for the first time. Staff provided continual reassurance and repetitive explanations of where he was and why.

John continues to get 'confused' and 'down' with his memory problems. When John first entered the house he spent a lot of time stating "*I can't remember, why can't I remember?"* **However, 4-5 months after entering the scheme, John was able to answer his own questions when encouraged and prompted to by staff.**

John: "Where am I?"

Staff: "Where do you think you are, John?"

John: "Is it N****"

Staff: "Yes that's right, you are living in N****"

The aim of the structured memory worksheet is two-fold-

(1) To provide an opportunity for the tenant and project co-ordinator to go over any issues which create anxiety for a tenant, because they cannot remember. Initially this could involve reminders of why they were in Connaught House

and then progress to more detailed discussions of planned or previous family visits or appointments.

(2) To have a basis upon which to measure improvements in memory for recent events. This is done by measuring changes in the number of ópromptsô required for a tenant to answer a question on something they had done recently i.e. contact with family and friends, financial issues, social events, and meals taken. That aspect of the evaluation is beyond the scope if this report.

Reminiscing exercises e.g. quizzes, games

Some tenants do not wish to take part in óone to oneô memory work. Therefore, staff incorporate informal memory exercises into daily activities in the form of quizzes i.e. music, trivia and general knowledge from the 60, 70, 80ôs. Years before the onset of their korsakoff syndrome and therefore years for which their memory is good. It also acts as a good social activity for the house and also helps tenants to rebuild confidence in their memory ability.

Key outcomes for tenants over 12 months

Case study 1- Philip

Philip is showing good insight into his condition, good mobility and acceptance of his support and living situation. He has shown improvements in all outcome areas. Staff are carrying out memory exercises with Philip. He is showing improved confidence in his memory abilities.

Case Study 2- Mark

Improvements were shown in Markôs physical health, living conditions and amount of social interactions. Mobility problems and challenging behaviour have been factors in the limited amount of daily living skills and day time activities he has been involved in.

Case Study 3- Cormac

Initial improvements were shown between baseline and 6 months in Cormacôs daily living skills, social interaction and depression. Fluctuating mental health and increasing refusal to accept support needs and living situation, between 6 month and 12 month follow up, has influenced the fall in all outcomes.

Case Study 4- John

John was slow to settle into the scheme. However, as he has got used to his surroundings, John has shown good progress in his memory, mental health and social skills. John continues to need a lot of encouragement to attempts to carry out some daily living skills. The staff are using regular memory exercises with John. John is showing progress.

Referrals & Unsuccessful Tenancies

Providing supported living for people with korsakoff syndrome was a new venture for Praxis Care Group and it was also the first specialised korsakoff unit to be set up in Ireland. It has taken the first year of the unitôs existence for statutory professionals, who have potential referrals, to become aware of the service and to visit the unit. It has also taken the first year, to formulate the specific type of client group that this particular support model, will work most successfully for.

Demographics of those individuals whose tenancy ended early

Four males had their tenancy terminated during the first year of data collection. 3 of the 4 tenancies ended during the 6 week probationary period, on average ending after a 1 month period. The other tenancy ended after 1 year. All 4 tenants were evicted, mainly due to ongoing breaches of the óno alcohol policyô These tenants were on average 49 years old. Before entering Connaught House, 1 tenant had been living independently, however, he came to Connaught House directly from a 7 week period of hospitalisation and the other 2 tenants had came from a long stay psychiatric hospital.

The fourth tenancy was different in that it lasted for just over a year before ending and this tenant was much older, at 70 yrs old. Within a 5 month period, there were 15 incidents of drinking, absconding, verbal aggression and falls with this tenant. On exit from the unit he had returned to long stay hospital.

Common traits between tenants whose tenancy ended prematurely

A number of common traits emerged from the 4 tenants whose tenancy ended prematurely. The staff recorded numerous incidents of tenants coming back to the unit drunk and carrying alcohol into the unit. The staff were also reporting incidents of unexplained absences while drinking. In some cases, unexplained absences lasting overnight or over a number of days. These behaviours were felt to be compromising the no alcohol environment and model of support which the other tenants signed up to and which was working effectively.

Characteristics of the 4 tenancies which ended prematurely

- Unmanageable drinking behaviour
- Unable to work within the structure and routine of the unit

Multi-disciplinary decision to end tenancies

The staff reported that these tenants had unmanageable drinking behaviours and were unable to comply with the structure and routine of the house. As a consequence of this, emergency reviews[8] were held to discuss the issues and in all cases it was deemed necessary to organise alternative accommodation. Since leaving Connaught House, 3 tenants have returned to long stay hospital. One of these tenants left hospital voluntarily and is now deceased due to alcohol related illnesses.

Funding for short tenancies

It has been difficult for Connaught House to secure monies for those tenants who have only stayed for a short period of time. There is a time delay between tenants coming into the scheme and monies from housing benefit or supporting people coming through. The scheme has found that people often enter and leave the scheme without any money being given for their short tenancy. Management have set a new system in place to ensure that all funding streams are clearly set up before admission of a new tenant

[8] An Emergency review would include the Connaught House Manager, Co-ordinator and Multi-disciplinary team members (CMHT)

Challenges & Recommendations

Based on the information gathered and analysed on the progress of 4 tenants over their first 12 months of living in Connaught House, a number of challenges have been raised and possible recommendations made for the future development of Connaught House and other similar services.

Challenge 1: Unwillingness to accept support needs or actively participate in the house

The tenants who were showing an unwillingness to accept their living arrangements, their support needs or to work with their support plan have been showing the least improvements in all areas of the support model. Some tenants have a strong desire to live in their own home. Their preoccupation with having their life back to the way it was pre- korsakoff syndrome prevents them from benefiting from the different elements of Connaught House. Interestingly, although Mark and Cormac have not had any alcohol relapses during the first 12 month reporting period, both have presented with challenging behaviour, often triggered by their non-acceptance of their support needs and present living arrangements. This has created stress for themselves and for the other tenants and staff members due to their disruptive behaviour.

Recommendations

The scheme would benefit from carrying out a robust selection process, using effective selection criteria and assessment. This would help to ensure that the most suitable tenants are accepted to the scheme. It is important that tenants are made fully aware of the conditions of their tenancy, including the fact that their placement may be long term. However, processing information and retaining information is difficult for people with korsakoff syndrome. Therefore, regular repetition and reassurance is required by staff. It is important that staff are trained and supported to communicate with tenants effectively. Some tenants have a negative reaction to being told of their limited ability and long term support needs. Staff may reduce negative reactions by tailoring the delivery of such information in a sensitive way. Only by getting to know the individual and reviewing their reactions will this type of tailoring be possible.

Challenge 2: Managing challenging behaviour

Over the first 12 months, the challenging behaviours managed by the staff at Connaught House included verbal aggression, threatening behaviour, physical aggression, refusal to eat, refusal to wash and non compliance with medication. The organisation monitors behaviours in the daily notes of clients and through formal incident reporting. Challenging behaviours have been presented most by those tenants who have frontal lobe damage and who are unwilling to accept their support needs, living arrangements or tenancy agreement. Limited insight and personality type have also been factors in the unwillingness to take support.

The other main challenging behaviours shown within the unit are absconding and alcohol abuse. For those incidents of absconding behaviour, alcohol use has usually been a precipitating factor. To date this has led to tenancies ending prematurely, as the behaviour has been occurring on a continual basis from entry to the scheme.

Recommendations

All new staff should receive role play and skill based training in confrontation skills and breakaway techniques. Personal qualities such as patience, tolerance and empathy are particularly important when working with people with korsakoff syndrome. Management should be aware of the need for these qualities when recruiting staff. It is important that staff continue to work as a team to limit challenging behaviour, by identifying triggers and developing practical support plans, management strategies and risk assessments. The scheme may also find it useful to investigate further assistive technologies which could enhance the support regime in the house i.e. electronic alarms to indicate when someone is leaving the house at night.

Challenge 3: Managing alcohol relapses

The unit will not evict a person for one incident of alcohol relapse. However, staff will have concerns about the suitability of a tenant if they continue to come back to the unit drunk, if they carry alcohol into the unit or present with unexplained absence or absconding behaviour. If there are incidents of alcohol intake, staff have been advised by the local regional hospital for alcohol treatment[9] to increase the amount of

[9] Shaftsbury Hospital in central Belfast is the only regional hospital which deals specifically with alcoholism.

vitamin B1/ thiamine supplements and vitamin B1/ thiamine rich foods given to the tenant and to attempt to reduce their sugar intake i.e. limit coke intake. This can be difficult as some tenants have an addiction to caffeinated/ sugary drinks.

Recommendations

It is good practice for staff to monitor tenants for signs of possible relapse. It is also important for staff to support tenants through their cravings (DoH 2006). One to one work between a staff member and tenant will be very valuable. It is important that management is aware of the intensity of the work being carried out by staff and therefore organise regular breaks and support systems for them. It is also important for the unit staff to liaise closely with statutory key workers, CPNs and family during this time. Staff should continue to follow clear review procedures when relapse becomes unacceptable.

Challenge 4: Managing other addictions

The staff at Connaught House provide support in cases where other addictions remain a problem e.g. gambling, high consumption of coke/diet coke and heavy smoking.

Recommendations

It is important that Connaught House staff seek the expertise of other health professionals in the field of addiction when required. It is also important that staff have a good understanding of the management of addiction and have access to regular updates in this field. However, maintaining good relationships, in which tenants feel they can trust and confide in staff for support, is equally important.

Challenge 5: Co-morbid physical health/ mental health problems

Alcohol related problems such as korsakoff syndrome are often concurrent with other mental health or physical health problems (IAS 2006). Each tenant has a complex range of needs which extend beyond those directly related to their korsakoff syndrome. For example, depression with korsakoff syndrome can lead to greater problems with developing social skills or building motivation. Other conditions such as diabetes or epilepsy mean that the tenant may need close supervision of their diet and medication compliance. The range of needs each tenant has can have an impact on the progress they make in terms of developing daily living skills, social activities

and accessing and maintaining day centre placements. These issues may become a factor in the longer term suitability of the scheme for some of the tenants.

Recommendations

Connaught House has structured systems in place i.e. support plans and review meetings which involve the input of multiple professionalsôi.e. Social Workers, CPNs, and Consultant Psychiatrists. It is important that these systems and good working relationships are maintained, in order ensure that the best support package for each individual tenant is provided. It is also important that clear discharge plans are made for those tenants for whom the service is no longer suitable.

Challenge 6: Lack of appropriate day care facilities in the area

There are no local day care services which are fully suitable for the needs of people with korsakoff syndrome. At present, Mental Health and Dementia day care services are the only alternative options. It is of benefit for tenants to get involved in the community and to interact with people outside of their living environment. However, social interaction with other non- korsakoff service users is affected by the memory difficulties of people with korsakoff syndrome i.e. taking time to remember names and the repetitive nature of conversations (Alcohol Concern 2001). Connaught House staff found that initially these services had little prior knowledge of korsakoff syndrome. The staff also reported initial difficulties in securing local day centre placements for individuals who were not registered within the local trust.

Recommendations

There is a need for more specialised day centre services in the local area which are tailored to the needs of people with korsakoff syndrome. In the interim, it is important that the existing day care services being accessed by people with korsakoff syndrome are informed about the condition and provided with guidance on appropriate and meaningful daytime activities. It may be useful for Connaught House staff to provide an information morning or circulate leaflets about korsakoff syndrome to day centre staff. The introduction of a day co-ordinator, who would be contracted to visit the scheme and bring tenants out for meaningful social activities during the day, may also be an option. However, this would involve increasing expenses for the scheme.

Challenge 7: Limited disabled facilities

Good building design/ facilities, along with a good support model, good staff, and good multi disciplinary communication are viewed as the bedrock of a successful long stay korsakoff syndrome unit (MacRae & Cox 2003) Unfortunately, Connaught House is on 3 levels and the only bathroom is on the 2nd floor. This has created problems for accepting individuals who require the use of a wheelchair or have very poor mobility. The lack of ground floor washing facilities has also been a problem for current tenants. The building is 'listed' and therefore very few physical changes can be made to it and any changes that are proposed require lengthy negotiations.

Recommendations

The organisation is aware of the limitations of the current building. Management has recently secured funding and planning permission to add 2 further second floor flats, with ensuites. An additional ground floor flat with a communal shower room is also planned. Further investigation into the potential use of assistive technologies, may also improve the limitations of the building design, particularly in relation to its disability friendly features.

Challenge 8: Suitable 'move on' accommodation

It is a long term goal of the unit that some of the tenants will be able to move towards more independent living. There are some good examples of people with ARBD living very successfully in the community and holding their own tenancies (MacRae & Cox 2003). The success of these transitions will depend upon support being removed slowly and with sensitivity to the person's abilities. It is also important that support networks are available in the community (Scottish Executive 2004, Consultation & Involvement Trust Scotland 2003).

Recommendation

It is important for Praxis Care Group to hold discussions with members of the multi-disciplinary team, the tenants and their families, concerning the options for those individuals who are potentially suitable for living more independently. A floating support[10] type service would be a suitable transitional support option, for any of the

[10] Within the Floating Support service staff provide a range of practical support regarding home management and daily living tasks as well as emotional and social support through befriending, companionship and encouraging people to participate in educational, vocational and recreational activities.

tenants who are able to move on. If ómoving onôis decided as the best option for the individual, careful discharge planning is imperative.

Challenge 9: Unmet Need for those tenants actively drinking

4 tenants were unable to remain in the unit due to an ongoing breach of the no alcohol policy. Management did not wish to compromise the ethos of the unit and the alcohol free environment, which was a condition set and accepted by the other tenants, within the house.

Recommendation

Connaught House was inappropriate for the needs of those individuals who were unable to abstain from drinking alcohol or to accept the structure and routine set by the house. However, this research has highlighted a need for an alternative service which supports individuals to drink ósafelyô within the community.

Conclusion

This report has provided an insight into the outcomes of 4 tenants, over their first 12 months of living in Connaught House, a specialised korsakoff unit in Northern Ireland.

At this point within the report, it is important to answer the question posed at the beginning of the report-

"Does supported living for people with korsakoff syndrome work?"

This report has highlighted that supported living can work, for some people with korsakoff syndrome. Unfortunately, Connaught House has not been suitable for all of the individuals referred. It has taken time and careful monitoring of individuals coming through the scheme, to learn the type of people the unit is most suitable for. It is clear that people with korsakoff syndrome are not a homogenous group. The severity and extent of the korsakoff symptoms, as well as the additional symptoms of their co-morbid disorders and personality type have added to the complexity of each individual case, and as a consequence their suitability for being managed within the support model set by Connaught House. Within Connaught House, the greatest improvements were seen in those tenants who showed insight into their condition, the limitations their condition presented, abstained from alcohol and accepted they had certain support needs. Those tenants who have engaged with the Connaught House support model have shown that people with korsakoff syndrome are not completely and irreversibly disabled by their condition. This report provides evidence for the argument that people with korsakoff syndrome can re-learn skills, can carry out daily activities, can enjoy meaningful activities, can rekindle relationships, can maintain abstinence and can improve their everyday memory functioning. Interestingly, the depression scores for each of the 4 tenants have also shown an overall fall between baseline and 12 months. This is a positive outcome, as depression or low mood can impact on individual engagement in daily living skills and social interaction.

Family involvement has also been a positive change for some of the tenants and their families. Maintaining positive social networks is important for enhancing the quality of life of the tenants and may also be a factor in reducing their depressive feelings. Positive relationships will be increasingly important for those tenants who

are able and willing to move on to more independent living. This outcome also highlights how the positive outcomes for the Connaught House tenants has extended beyond themselves to their family, who now have an improved and more fulfilling relationship with their family member.

This report suggests that a small, intensively supported unit with good systems, structures and management in place, which follows a support model that is focused on improving life skills and life chances, can work for certain people with korsakoff syndrome. By nature of its size and the intensity of support provided, the service is expensive to run. However, there can be no monetary value placed on supporting people to take back a quality of life which they otherwise would not have.

Those tenants for whom the service was not suitable has highlighted the need for a community based service, for korsakoff syndrome individuals, who wish to remain active drinkers and who have difficulty living within a structured and routinised environment.

The staff have played a vital role in the success of the scheme and the positive outcomes for tenants, during their first 12 months of living in the unit. All tenants require consistent encouragement and prompting from staff. The ósructureô and órouteneôestablished around the daily activities of the house has been effective for the tenants, who process information at a slower pace, due to their condition. Due to the intensity of the work, it is important that management have systems in place, to ensure that staff are provided with regular breaks and management support. It is also important that a wide range of training is provided, to ensure staff are able to manage situations that occur in the scheme.

Overall, it is hoped that this 12 month report has provided a realistic insight into the daily running of a supported living unit, for people with korsakoff syndrome. The report has described the complex mix of needs of the tenants Connaught House supports. It has documented the areas of improvement aimed for and the areas of improvement gained. It has also provided a comprehensive list of the challenges and practical recommendations faced by staff, in providing support to tenants.

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Appendix 1

Methodology

Case study approach

A case study approach was deemed most appropriate to this research, as it is a valuable method in the study of complex social settings. It allows for an in depth focus on the circumstances, dynamics and complexity of a small set of cases, over a period of time (Bowling 1997).

Data collection points

The full Connaught House evaluation is a 3 year longitudinal study, with 5 data collection points. The data collection points are baseline, 6 months, 12 months, 24 months and 36 months. The current report documents the first 12 months of the service.

		BASELINE	6 MTH	12 MTH	24 MTH	36 MTH
Tenant	**Views & Attitudes** **Depression**	Interview CES-D	Interview CES-D	Interview CES-D	Interview CES-D	Interview CES-D
Staff	**Views & Values** **Life functioning**	Interview LSP for tenant	LSP for tenant	LSP for tenant	Questionnaire LSP for tenant	LSP for tenant
Family Members	**Views & Attitudes**			Questionnaire		Questionnaire
Referral Agents	**Views & Satisfaction**	Questionnaire				

Qualitative Methods

Semi-structured interviews were conducted with tenants over the 5 collection points. Due to the possible reduced reliability of self reporting alone, staff reports, written monthly summaries of individual activities and observations were used, to build a picture of tenant activities. This greater range and depth of information helped when interviewing tenants as it allowed for the use of more direct questions which act as a

more effective trigger for memory of events i.e. ñDid you go for a meal yesterday?ò rather than ñDid you go out anywhere yesterday?ò (SAMH 2006)

Referral agents were sent a self completion questionnaire when the tenants first entered the scheme.

Quantitative Methods

To obtain a more objective & comparable measure of tenant skills and personal wellbeing, across time points, the following standardised questionnaires were included in the evaluation. It was important that the standardised questionnaires used were short and used simple language and response scales. The ratings were also understood as ómoment in timeôratings, as for some tenants, asking them to provide ratings over a ó1 week periodôwould be unrealistic due to their memory problems.

THE CENTRE FOR EPIDEMIOLOGICAL STUDIES DEPRESSION SCALE

(CES-D) (Radloff 1977)**:** The CES-D is one of the most common scales used to enable a person to determine his/her depression quotient. The 20 item scale measures the personôs depressive feelings and behaviours. A score of 16 or more on the scale indicates that the person suffers from depression. If the score falls between 16 to 21, this is classified as mild/moderate depression. A score of 22+ indicates that the person may be suffering from severe depression. The measure is not a diagnostic tool rather it is a screening test to identify groups at risk of depression (McDowell & Newell 1996).

LIFE SKILLS PROFILE (LSP) (Parker et al. 1991)**:** This scale was used to gather information on the social and behavioural functioning of individuals living in Connaught House. The LSP is a useful measure as it is based on observable measures of disability. Staff members complete the scale when the service users first enter the scheme (baseline) and again after a period of 6 months, 12 months, 24 months and 36 months. Total scores on the scale can range from 39 to 156, with a higher score indicating that the service user is displaying greater social and behavioural skills.

The LSP is made up of 5 subscales-

- **Self-care**: Appearance, personal grooming, hygiene
- **Non-Turbulence**: Reckless/ offensive behaviour, violence
- **Social Contact**: Interpersonal contact, social activities, friendships, leisure pursuits
- **Communication**: Interpersonal skills, coherence of speech
- **Responsibility**: Medication, treatment compliance

The LSP score is negatively correlated with burden of care /level of support. When the LSP rises, the burden of care/level of support is said to fall (Parker et al. 1991).

Family members were given a questionnaire when their family member had been living in the unit for 12 months. It asked them to comment on their contact with their family member, views on the facility and areas of change seen in their family member since moving into Connaught House.

MEMORY WORK

There is evidence that remedial mental exercises can facilitate recovery from impairment and reduce anxiety and stress due to memory loss (Bird et al. 2004; Groham 2003). The tenants were asked to complete 2 types of memory collection sheets every 3 months, (1) Memory Worksheets and (2) The Digit Span Test.

Memory Worksheets: Memory exercises are administered by the project co-ordinator who focuses on the revision of 4 areas of their day to day functioning for the previous week i.e. *family contact, finances/budget, meals and social events.* These have been developed to capture improvements in tenantsômemory functioning at 3 monthly intervals.

Digit Span Test: This is a standardised measure of working memory capacity and attention, which works by assessing the number of digits a person can hold in memory at one time (CCOP Research, Millar 1956). Both the memory worksheets and the digit span tests are carried out every 3 months.

CONSENT OF PARTICIPANTS

Participation of tenants in the evaluation is voluntary and with informed consent. At each stage of data collection, the purpose of the research and the clientôs role in the study were reiterated. Participants were also informed that they can pass at any stage of the data collection or be removed from the study at any point. The CMHT Social worker for each tenant was also informed of the evaluation and their clients input.

Appendix 2

Life Skills Profile scores by subscale and by total

Total scores on the scale can range from 39 to 156, with a higher score indicating that service users are displaying greater social and behavioural skills.

Philip			
	Baseline	**+ 6 months**	**+12 months**
Self- care	27	30	30
Non turbulence	36	37	40
Social contact	16	12	16
Communication	13	18	20
Responsibility	14	15	16
Total LSP	**106**	**112**	**122**

Mark			
	Baseline	**+ 6 months**	**+12 months**
Self- care	35	20	21
Non turbulence	35	28	29
Social contact	17	11	13
Communication	13	18	15
Responsibility	13	15	14
Total LSP	**113**	**92**	**92**

Cormac			
	Baseline	**+ 6 months**	**+12 months**
Self- care	27	28	26
Non turbulence	38	41	34
Social contact	11	11	10
Communication	20	20	15
Responsibility	16	16	14
Total LSP	**112**	**116**	**99**

John			
	Baseline	**+ 6 months**	**+12 months**
Self- care	23	16	22
Non turbulence	47	36	44
Social contact	13	13	13
Communication	22	20	20
Responsibility	14	9	12
Total LSP	**119**	**94**	**111**