



A **recovery** approach to mental illness

A guide for students developed by people with a
serious mental illness and their carers



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This guide to the recovery approach, which is based on the experiences of over 1000 people with a serious mental illness and their carers, has been produced as part of a groundbreaking Comic Relief-funded initiative. The **Expert Patient Trainer Project** is a unique training opportunity aimed at bringing the expertise of those who have a direct experience of mental illness to a wide audience of students, health professionals, employers, policy makers, service users and carers.

Building on the successes of Hafal's National Learning Centre, and in particular the contribution made by service users as trainer-consultants, the Expert Patient Trainer Project has worked to develop training for a variety of organisations in the educational, voluntary, private and public sectors. Through this new initiative service users and carers are delivering and developing courses and gaining their own training qualifications in the process. The aim is to empower these service users and carers, to give them a leadership role, and to reduce stigma.

This guide is a key part of our strategy to deliver a service user perspective to health professionals in order to improve practice and introduce a recovery ethos into services. For more information about the project, or if you'd like to hear how our Expert Patient Trainers can help take your training beyond theory, please get in touch (our contact details are on page 10).

► How to use this guide

This guide is designed for formal and informal students in the areas of health and social care, mental health nursing, medicine, psychology and criminology. It complements professional training in nursing/social work and is also of use for people delivering services in any area of the Whole Person Approach – including housing, finance, medical or psychological treatments, education and employment (see page 6). It is also a useful guide for service users on their recovery path (see page 10 for details of Hafal's accredited recovery training for service users).

The guide provides an introduction to Hafal's unique recovery approach which has proved successful for hundreds of service users over the past decade. Although holistic care planning has legal backing in Wales the information contained in this guide is appropriate for application anywhere in the world. It describes best practice as determined by the people who know best what works: patients.

More extensive resources for students are available online:

On Hafal's Mental Health Wales information website – www.mentalhealthwales.net – you will find:-

- the Welsh legal/policy context including information on the Mental Health (Wales) Measure, Mental Health Act and mental health strategy
- information on “Who's Who” in mental health in Wales including key figures in the National Assembly, social services and the NHS
- detailed information and guidance on each area of the Whole Person Approach (see page 6).

Our partners at the Mental Health Foundation and Bipolar UK also provide a wealth of valuable resources for students:-

- For a complete “A-Z” guide to mental health issues and treatment options go to www.mentalhealth.org.uk
- For detailed information on bipolar disorder please go to www.bipolaruk.org.uk

For information about looking after your own mental health as a university student go to: www.mhhe.heacademy.ac.uk/themes/about-themes/student-mental-health/

For research and information from the world's largest user-led organisation, NAMI, go to www.nami.org

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Recovery: an overview

► What does 'recovery' mean?

Recovery means regaining mental health and achieving a better quality of life.

Many people with serious mental illness can make a full recovery; others can make far greater progress than has traditionally been thought possible. Too often mental health services have confined their objectives to looking after people or alleviating some symptoms. Recovery is different. It is focused on enabling people to improve their lives in all areas rather than just maintaining an adequate existence.

Recovery is not just about medication or other therapies which deal directly with symptoms. These can be very important, especially for those who have experienced serious mental illness, but mental health is built on much broader foundations. For any one individual the biggest step to recovery of mental health may be finding a great place to live, getting a job, establishing a good relationship with their family, meeting new friends or identifying a professional who can help them work through their problems. Usually there are a set of different things which are important to an individual's recovery.

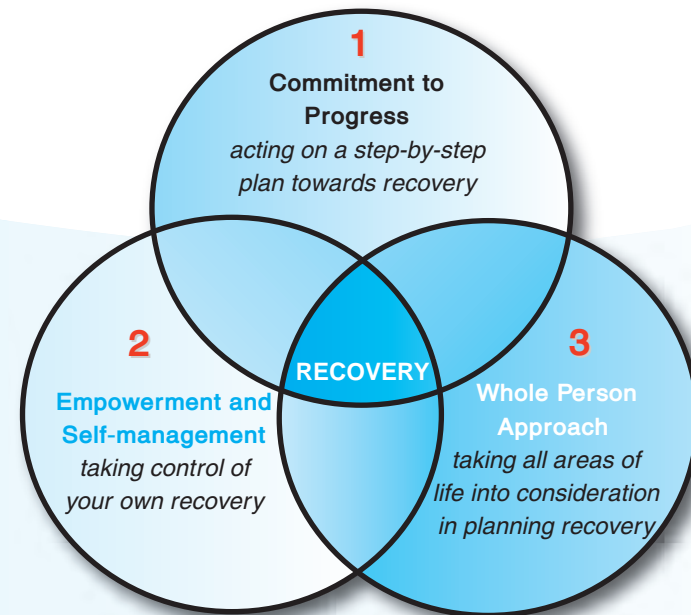
Many people achieve good mental health without formal plans but rather by looking after themselves and meeting their own broad needs. But when people experience serious mental illness it can be helpful to be much more methodical in looking at how to improve their lives. This plan offers that methodical approach to recovery.

► Who is recovery for?

Recovery is for everybody. Everyone can make significant steps to regain or enhance mental health and achieve a better way of living. It is the right of those who experience mental illness – and a duty which they owe to themselves – to make improvements in all areas of their lives which together contribute to mental health. People with serious mental illness will usually need support in order to make progress towards recovery. Some people have a higher level of need and require a lot of support – for example, people who have lived in hospital for some time – but this does not exclude them from achieving recovery.

► What makes recovery happen?

There are three components essential to recovery. These are:



Recovery **depends on** these three components being in place: this poses a real challenge but the good news is that all three components are realistic and achievable. Next we talk about each component in more detail.

1 Commitment to progress

A **Commitment to Progress** is the first component essential to recovery. Recovery depends on actively taking steps to improve life. It is vital to agree and act upon a step-by-step, goal-focused plan.

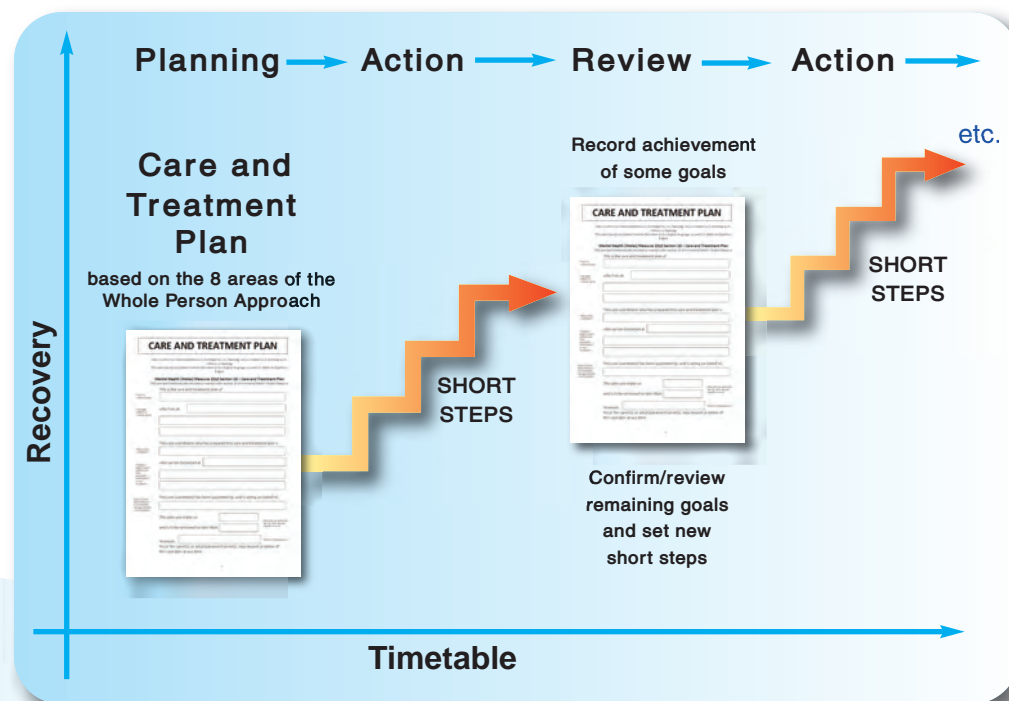
Too often planning concentrates on assessment: in other words it says a lot about where the individual is at a particular point but not about where they want to go. Alternatively plans may include long-term goals but not the simple, short-term steps that need to be taken to achieve them. A good plan needs to hold its focus on long-term goals but include the intermediary, less intimidating steps which allow a person to take action.

To be effective, a plan must:

1. **Assess current circumstances** – analyse and recognise where the individual is starting from at the planning stage
2. **Identify needs** – practical and personal challenges faced by an individual
3. **Identify long-term goals** – strategic targets which the individual aims to achieve
4. **Identify short-term steps** – simple, manageable actions required to achieve the goals
5. **Identify supporters** – specific people or agencies whose help is needed with the short-term steps
6. **Create a timetable** – target dates to take short-term steps and achieve long-term goals
7. **Timetable regular reviews** – to recognise progress, and confirm or revise short-term steps and long-term goals

Planning for recovery needs to be fully incorporated into conventional or formal planning processes. For example people in Wales should plan their recovery through the **Care and Treatment Plan** which is a standard requirement for people using secondary mental health services (read more on page 7).

The process of recovery based on effective planning can be illustrated as follows:



2 Empowerment and self-management

Empowerment and self-management together form the second essential component for recovery. **Empowerment** means exercising rights and responsibilities in making choices about life. **Self-management** means taking the actions required to lead a life based on those choices.

Most people with a serious mental illness already exercise a significant amount of choice about their lives and take much of the action required to achieve recovery. For example, many people manage the administration of their medication.

The following are different ways in which people can demonstrate empowerment and self-management:

A person is empowered when they:

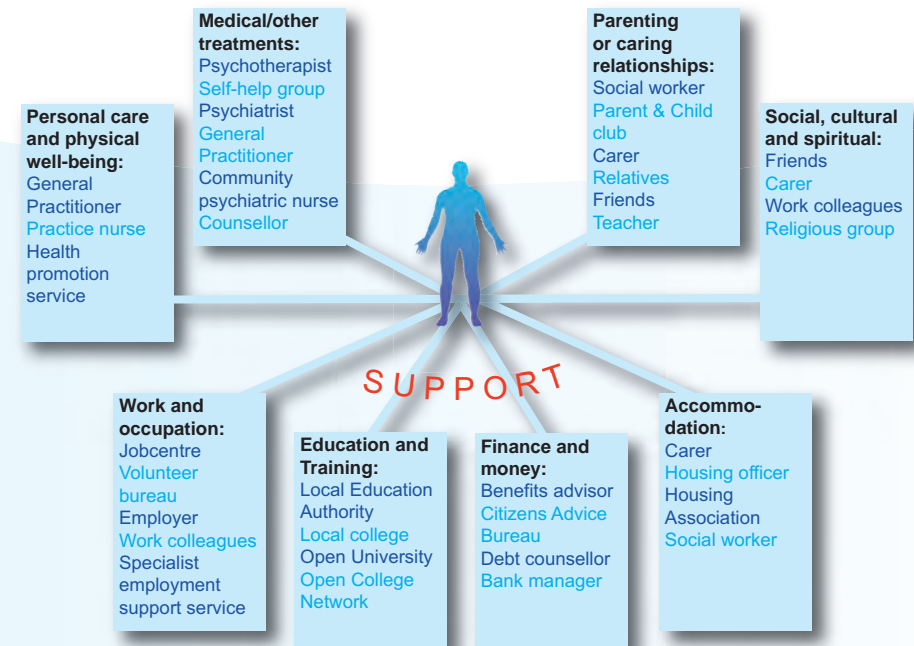
- recognise that they have the same rights and responsibilities as others
- feel a strong sense of autonomy
- are at the centre of decision-making processes concerning their life
- are able to access information necessary to make choices
- are able to choose from a range of options
- see their right to choice respected
- have the first **and** last word in any discussion about them
- feel equal to others and are treated equally by others
- make “advance directives” – telling people how they want to be treated when they are unwell.

A person is self-managing when they:

- make plans in their own language and using their own words
- make phone calls, write letters and fill in forms themselves to address their needs
- sort out their own problems
- negotiate with people to get their needs met
- accept the support of others on their own terms and without resigning responsibility
- look after themselves, maintaining physical health and addressing mental health problems
- administer their own medication
- exercise self-awareness and act on this – including anticipating the onset of a crisis.

Of course some people, for example people in hospital and possibly detained under the Mental Health Act, have more limited opportunities to exercise choice and manage their life. But there are still important areas where they can make choices and take action – for example in developing social contact, looking after their health, and acquiring skills. Empowerment and self-management are the key to progress for everybody.

Achieving empowerment and self-management does not mean having to make choices and take action alone and without support. When a person takes the lead in making plans and taking action they still often need the help and support of other people. These supporters can be chosen according to their specialist skills and knowledge or because they are friends and family willing to help. The key challenge is to develop the **right relationship** with supporters, taking care to ensure that they do not take over responsibility. There are exceptions to this: in times of crisis or great need it may be appropriate that supporters intervene and take a degree of control. But this should be exceptional and care should be taken that this does not become routine. **Some examples of supporters are:**



...and some supporters, such as carers and Care Coordinators, may provide general support across all eight areas.

3 Whole Person Approach

Third, recovery requires a **"Whole Person Approach"** (sometimes called a **'holistic' approach**). This means addressing all key aspects of life which together contribute to well-being. By setting goals in all areas of life people can approach recovery more comprehensively. What the Whole Person Approach offers is a methodical way of doing this.

When looking at a person's care and treatment there has been a tendency in the past to focus only on areas such as medication. However, Hafal clients know from experience that making progress in all areas of the Whole Person Approach leads to far greater progress towards recovery. For example, some symptoms such as negative thoughts and passivity are not only addressed by looking at direct medical or psychological treatments – they can be relieved by focusing on areas such as housing, social life or education. That's because our state of mind and mental health is affected by the way we live.

We believe that a Whole Person Approach should take into account all of the areas identified in the diagram opposite.

The Mental Health (Wales) Measure (a Welsh law) puts a duty on service providers to ensure that people receiving secondary services in Wales have a Care and Treatment Plan that includes all of the eight areas listed opposite. We talk about the Measure in the following pages.

For further information on all areas of the Whole Person Approach go to:
www.hafal.org



The Mental Health (Wales) Measure

The good news for users of secondary mental health services in Wales is that after years of campaigning we now have a **legal right to a holistic Care and Treatment Plan under the Mental Health (Wales) Measure**. This gives service users the opportunity to set goals in all eight areas of life as identified in the Whole Person Approach opposite, to create a plan and, in the process, to take more control of their own recovery.

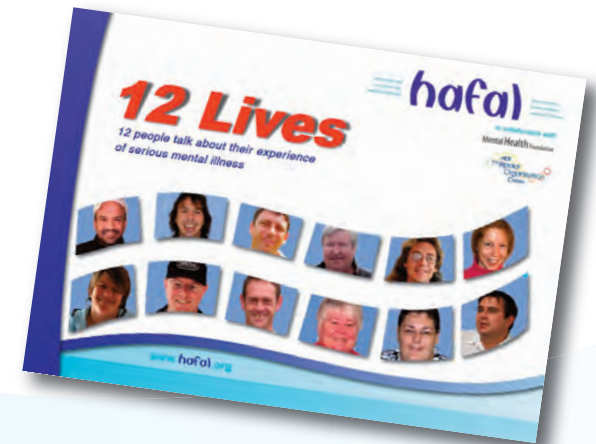
There is now a standard format for the Care and Treatment Plan in Wales.

For a detailed guide to the new Plan please download *Care and Treatment Planning: A step-by-step guide for secondary mental health service users* from www.hafal.org or contact us for a copy.

Recovery in practice

In the following pages we provide two case studies which show how recovery can work in practice. What these case studies show is that usually there are a set of different things which are important to an individual's recovery.

For more recovery case studies please download *12 Lives: 12 people talk about their experience of serious mental illness* from www.hafal.org or contact us for a copy.



Further sources of information on recovery:

- Hafal's *My Recovery* guide can be downloaded @ www.hafal.org
- The Mental Health (Wales) Measure, its accompanying Regulations and Codes of Practice, and *Together for Mental Health – A Cross-Government Strategy for Mental Health and Wellbeing in Wales*, can be downloaded @ wales.gov.uk
- Marjorie Lloyd, Senior Lecturer (Nursing) at Glyndwr University, has recently published a guide to care planning: *Practical Care Planning for Personalised Mental Health Care* (2012 McGraw Hill/Open University Press)
- For further resources visit www.mentalhealthwales.net

Case study 1



Lee's story

When Lee McCabe was diagnosed with paranoid schizophrenia his mum was told: "You'll never know the Lee you once knew." But with the support of mum Sandra and his Community Psychiatric Nurse, Lee made a full

recovery. His experiences inspired Jonathan Morgan's historic Legislative Competence Order which gave powers to the National Assembly to create Welsh law on mental health.

Here Lee tells his story...

"I started to have what I now know were the first signs of schizophrenia in the summer of 1994 when I was 23; I began taking drink and drugs to block out some bad experiences. My family and friends began to notice changes in my character so a friend of my sister suggested I see my GP. I described my symptoms to him and he said I should go to the A & E department of the local hospital. I waited there for four hours until an ambulance was available to take me to a psychiatric unit. When I arrived at the psychiatric ward my sister's friend, who saw the GP with me, went home to tell my family what had happened. I was given a bed on the ward, I saw a psychiatrist and, ten minutes later, he diagnosed paranoid schizophrenia, an illness I knew nothing about.

"Being on the ward was very scary. After a couple of days I began ranting and raving. When my mother visited I started screaming at her, shouting: "What am I doing here?" My paranoid feelings and hallucinations

meant I started blaming my mother and taking my frustrations out on her. My mother had an awful time with the ward staff: they didn't give her any idea of what was wrong with me or any information on the medication I was taking. Shortly after I was admitted the ward manager told her: "You will never know the Lee you once knew." It was an awful time.

"I was in the ward for six weeks and then discharged. I was given a prescription but I had no support from the hospital when I went home. After a few weeks I began having panic and anxiety attacks, I felt paranoid, and I didn't know how to cope – and neither did my mother or my family. I tried to commit suicide by taking an overdose, the first of four suicide attempts I made when I was very ill. My mother phoned the ward and I was readmitted to hospital. After about six months I was discharged and for a while I was housebound: I thought people on the streets were spying on me, and that the IRA was after me. In the evening I'd be curled up on the floor; my muscles were so stiff I couldn't lift up my head. I didn't have the strength to pull my quilt up when I was in bed; I felt paralysed, terrified.

"Eventually, about eight or nine months after I was diagnosed, I was allocated a Community Psychiatric Nurse (CPN). The information and support I got from her was brilliant. **This was the first time someone had sat down and talked to me about my medication, what schizophrenia was, how to cope with my anxiety and panic attacks and what services were available.** My CPN carried out an assessment and made sure a care plan was delivered. I was really fortunate to see her because not everyone with a serious mental illness is lucky enough to have a care plan.

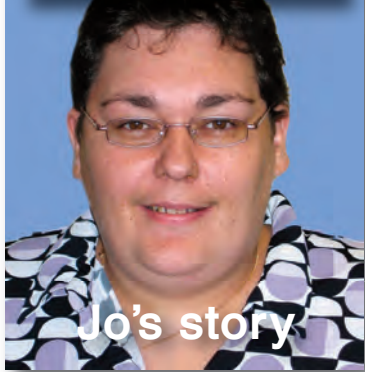
"A lot of credit must go to my mum, too. She was my

lifeline. I wouldn't be here now if it wasn't for her. Over time my mum helped me gain confidence to go outside. When it was dark and quiet in the evening she would watch me walk from the porch and to the end of the street and back. Eventually I was able to go into town to the National Schizophrenia Fellowship (NSF) in Pentrebach. The NSF (now Hafal) offered day services which gave my life structure and kept me busy. They helped me stop dwelling on my feelings and thoughts – the paranoia. After a while my confidence improved and, under the New Deal employment scheme available then, I spent a year working at a restaurant in Merthyr.

"In terms of medication, the first five years after I was diagnosed was a case of trial and error. Some side-effects were awful: the treatments caused dribbling, a dry mouth, a sedated feeling and weight gain – my weight rose to over 16 stone. When I finished working at the restaurant in 1999 I took a new medication which helped me a lot.

"From 2003 I started learning about computers with a tutor from the local college. I also started having certificates for catering courses. At the time Hafal service users were developing the charity's Recovery Programme and when I sat down to talk about mine I said my aims were to work full-time and come off medication. I've achieved both those goals: I became a Hafal staff member in 2006 and I've been off medication and fully recovered since February 2007. I now work with service users every day. They can see recovery is possible but you've got to put the work in and have the right support. **Looking back I wouldn't have been as ill as I was if an early intervention service for people with a serious mental illness was available.** My recovery would have been far quicker than the 12 years it took if there was one."

Case study 2



Jo's story

In 2008 Mental Health Consultant Jo Roberts set up a weblog which, along with the huge amount of feedback it received, influenced the Welsh Code of Practice for the Mental Health Act, giving it a strong patient focus. Jo, who was diagnosed with paranoid schizophrenia, says that when it comes to her recovery, "the sky's the limit."

Here Jo tells her story...

"I became ill when I was 18. I was a second year student nurse and I had just come back from a holiday with a gang of the girls. A fortnight after returning I began hearing voices, seeing things, and becoming paranoid. I didn't know what was wrong with me and I didn't tell anybody either. I began drinking a bottle of vodka a day to try and get rid of the voices and get some sleep.

"A fortnight later I couldn't take it any more so I took an overdose. My next memory is of waking up in a hospital ward with doctors and nurses around me. I felt very paranoid. I thought they were going to kill me or injure me in some way. I don't remember it but apparently I assaulted a nurse. The police were called; they could see I was ill but there was nowhere to place me. The best they could do was remand me to prison so I became a priority for a bed.

"I'd been in prison for two weeks, on the hospital wing, when a bed came up. They found me a bed at a

private hospital in Northampton which was a long way from my home. The ward I was sent to was a behavioural ward for teenagers which was run on a points system. I found this setting quite difficult. If you shouted, screamed or swore you'd lose points and be punished. I spent a year on this ward and I didn't see any of my family for that time which was very difficult. The only contact I had with them was through letters and a phone call once a week.

"From there I went to Caswell clinic in Bridgend. There were four beds there and I was often the only female on the ward. Time went on and unfortunately I assaulted a nurse. I've never forgiven myself for this assault. I know people say I was ill but there's not a day goes by when I don't think of what I did.

"After Caswell I spent a year at Ashworth Hospital in Liverpool. It was absolutely terrifying. I wouldn't drink a lot because if you went into the toilets you could see some of the girls trying to hang themselves. You'd have to shout: "Knife!" and the staff would come and cut them down. The only good thing that came out of that was being put on Clozaril. It was a new drug then and it seemed to work quite well.

"From Ashworth I went back to Caswell Clinic, to the rehab ward. It was a lot better, there was more structure to the day. I managed to get quite well on Clozaril and I was nearly back to my old self. It was while at Caswell I decided I wanted to live independently; however, the hospital wanted me to go to a hostel. I dug my heels in, stayed in a hospital a bit longer and went through a rehab programme which enabled me to live independently. I spent another two years at Caswell and I won a tribunal on conditional discharge. I was discharged to a flat which I'm living in now.

"A few years ago a new drug came out called Abilify. I discussed the possibility of taking it with my consultant and my care team. We decided I'd try it because by then I had gained a lot of weight and developed diabetes. Unfortunately, I tried the Abilify and became very ill again. I was taken into hospital voluntarily initially. Because I didn't want to stay the Home Office recalled me (I am subject to a Home Office section 37/41) so I spent another two years in Coity clinic which is a local hospital. That was very frustrating because I was unwell for about three months. The other eighteen months I spent there I was well but unable to be discharged.

"I'm still subject to a Home Office section 37/41 because of the assault on the nurse almost 20 years ago. Day to day the 37/41 doesn't affect me. If I could come off the section it would be the last piece of the jigsaw. I will appeal against it soon. I'm out of hospital now, I've got my job back, I've got a little car, and my flat is safe so everything has turned out right. I feel I'm living again. I've got a good quality of life but I still aspire to more. Where recovery begins and ends I don't know. How far can I go with recovery? The sky's the limit really. I've had my ups and downs in the last few years – I was in hospital with pneumonia for six weeks recently, and I went into a coma and on two occasions it was touch and go. But I came through and I don't give up! I'm happy with my life. I don't feel cheated.

"I'd just like to add that throughout the years my family have rallied around me. My auntie Moira in particular has always been there to support me. She's been a rock. Whenever she's phoned and I've said I'm not well she's come down to the flat and helped me out. She's been marvellous."

We are Hafal!

Hafal is a Member-led charity run by the people it supports: people with serious mental illness and their carers. We believe that people who have experienced mental illness at first hand know best about how to recover.

Providing a range of services and support across the 22 counties of Wales, Hafal is dedicated to empowering people with serious mental illness and their families to:

- achieve a better quality of life
- fulfil their ambitions for recovery
- fight discrimination
- enjoy equal access to health and social care, housing, income, education, and employment.

To find out more, or to get involved, visit www.hafal.org or contact us at:

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Tel: 01792 816600

Email: hafal@hafal.org

Facebook/Twitter: search for 'Hafal'



Hafal's National Learning Centre specialises in high-quality, cost-effective, accredited and bespoke training programmes for Hafal staff, volunteers and clients, and the public, private and voluntary sectors. We also offer placements for health and social care students and deliver training at universities and colleges in Wales.

Our team of experts are specialists in the fields of:

- mental health and recovery
- social care and housing
- charity management.

For full details of the services provided by Hafal's National Learning Centre go to:

www.hafal.org/hafal/learningcentre.php



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