



RECOVERY

Our thoughts on recovery and what helps us to recover from mental health problems.

April 2006

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What is HUG?

HUG stands for the Highland Users Group, which is a network of people who use, or have used, mental health services in the Highlands.

At present, HUG has approximately 360 members and 13 branches across the Highlands and has been in existence now for 10 years.

HUG wants people with mental health problems to live without discrimination and to be equal partners in their communities, they should be respected for their diversity and who they are.

We should:

- ◆ Be proud of who we are
- ◆ Be valued
- ◆ Not be feared
- ◆ Live lives free from harassment
- ◆ Live the lives we choose
- ◆ Be accepted by friends and loved ones
- ◆ Not be ashamed of what we have experienced

We hope to achieve this by:

- ◆ Speaking out about the services we need and the lives we want to lead.
- ◆ Educating the public, professionals and young people about our lives and experiences.

Between them, members of HUG have experience of nearly all the mental health services in the Highlands.

HUG's aims are as follows:

- ◆ To be the voice of people in Highland who have experienced mental health problems.
- ◆ To promote the interests of people in Highland who use or have used mental health services.
- ◆ To eliminate stigma and discrimination against people with mental health problems.
- ◆ To promote equality of opportunity for people with mental health problems irrespective of creed, sexuality, gender, race or disability.
- ◆ To improve understanding about the lives of people with a mental health problem.
- ◆ To participate in the planning development and management of services for users at a local, Highland and national level.
- ◆ To identify gaps in services and to campaign to have them filled.
- ◆ To find ways of improving the lives, services and treatments of people with mental health problems.
- ◆ To share information and news on mental health issues among mental health service user groups and interested parties.
- ◆ To increase knowledge about resources, treatments and rights for users.
- ◆ To promote cooperation between agencies concerned with mental health.

INTRODUCTION

Recovery is not a new idea, we have always hoped and looked forward to the days when we could leave mental illness behind and start life afresh. However for many of us the idea that we could ever get better or manage our symptoms has been a distant one. To some of us it also felt that the people that help us on our journey have low expectations about the lives that we might lead. However, around 30 years ago, with the developing rights based movements in America we found more and more people with mental health problems speaking out about the fact that despite having an illness we can lead positive and meaningful lives. They gave birth to the modern concept of recovery which has now spread across the world.

The word 'recovery' has gained this new meaning in Scotland over recent years, partly inspired by the work of Ron Coleman and also by the Scottish Recovery Network.

A year ago the HUG Round Table (which is our committee) was privileged to be given a presentation on the subject from the Scottish Recovery Network. The talk was inspiring and encouraged us to look at the idea within our own organisation.

A few months ago members of our Friday Forum (a collection of our more active, mainly Inverness based, members) participated in research by the Scottish Recovery Network to provide stories of their own personal vision of recovery. Some of these stories are now on the Scottish Recovery Networks website.

At the same time one of our members created a HUG pamphlet describing her own personal journey to recovery which has now been printed and distributed to our members and is also on the Scottish Recovery Network website.

In October and November 2005 we discussed the idea of recovery in 11 of our 13 branches, involving 67 people, mainly HUG members and other users but also a small number of professionals.

The style of the meetings followed our traditional pattern where we asked a series of informal questions, developed by a HUG worker in consultation with the Scottish Recovery Network, which prompted discussion. This was written up and turned into a report which was then approved by our Round Table before being distributed in its present form.

WHAT DO WE MEAN BY RECOVERY?

We had a varied response to this question - from a celebration of who we are by the majority of us to a downright denial that recovery exists when looking at our lives and our mental health problems.

Many of us hold very positive views about the idea of recovery. The idea of encouraging us and the professionals who help us to look at the idea of mental health in a positive and optimistic way felt very appealing.

Many of our ideas were based on how we felt about ourselves and using this awareness as a description of recovery. This included having an improved sense of wellbeing and being confident enough to look out for and help other people. We felt that when we were acknowledged and praised

for what we do in our lives this not only set us on the road to recovery but was a part of our recovery.

Being able to get out and to speak to others is a big step, especially if we are listened to. If we can be kind to someone or if we have carried out a piece of work successfully then this is also a part of our recovery.

Fundamental to recovery is our own confidence. When we suffer from mental ill health we can lose our confidence, but as we begin to slowly regain it this marks a move towards recovery. Having an insight into our own situation and feeling better about ourselves is also a big marker about feelings of the possibility of recovery.

Some of us see recovery as feeling that we have returned to ‘normality and normal society’ or at least as having that as our aim. It is also about living as well as we can expect to and being content with this.

To many of us it is a process. Recovery is a journey or road we all travel where we can never say we are fully recovered, but we can say we are engaged in recovery. To many of us this is a road that is life long or spans decades; just as we never stop learning so some of us feel that we never reach the end of the journey of recovery.

For many of us, we might feel that we have recovered if we get to a point where we are functioning and able to weather setbacks. Another way of looking at it is if we can feel that we can cope from day to day or live with the illness as best we can. Allied to this is to see recovery as a state where we can now manage and feel that we have a bit more control over our lives.

Recovery involves setting out what we believe to be the problem and then moving on:

“putting your life in perspective; you can get to the point where there are other things that are important to you. You don’t build your world around illness. Instead of going against the flow you’re going with the eddies and enjoying it – get out of the shallows and swim!”

It also involved accepting that what is past is past, that we need to live a day at a time instead of always looking to the future. However in order for acceptance to occur we also find it important that other people accept us too.

Relationships and friendships which we often lose when unwell are also important markers on the journey.

Recovery means many different things to different people – for some people having the confidence to get to a drop-in centre and mix with fellow users is a huge step on the road to recovery. For others it is growing beyond the expectations of other people. They can often want us to return to the person, career and the life we used to have, they don’t acknowledge that we have changed and now need to reassess our own personal priorities and what constitutes progress to us. We may feel better and on the right route when we look at our progress over the previous months. As we feel better about ourselves, and see ourselves growing back or into what we see as our true selves, we can feel that we have recovered.

For some of us recovery is a very personal journey:

“i wouldn’t want to recover if it meant going back to the way I was before. To me it’s been a time of growth even though it’s been hard”

It doesn't have to mean being well either:

“a state of physical and mental wellbeing in which I can lead a useful and productive life despite being on medication”

“it implies getting better – that is very wrong”

For many of us recovery includes finding an interest in life again as well as seeing both meaning and purpose to life and learning to enjoy it. It's about relaxing and moving away from stress and for many of us it represents the point where we can cope with life again without relying on the “mental illness world”.

However a few of us resented the word and the concept. We saw it as an imposition from ‘on high’. We felt that life was hard enough to manage without having to endure the idea that we should be encouraged to improve and develop our lives further. For those of us that felt this way we worried that we were being subjected to the latest in a series of fashions, that, instead of helping us, put pressure on us to achieve steps forward and a personal vision that are well beyond our capabilities. We wanted to say that however well we seemed to be doing our heads could still remain a mess with little prospect of this ever changing.

Some of us see mental illness as purely that - an illness. We are not interested in alternative ways of looking at mental health, and such concepts as the social model of disability are not attractive to us. For those of us who thought this way we felt that recovery could only be seen as getting better and being 100 % free from the symptoms that characterise our particular illness. Many of us who held this view made the point that there is no cure for many of the major mental illnesses and that therefore it was misguided to talk of recovery. We felt that a word had been adopted and given values that it didn't previously hold. We also felt that it distorted the reality of mental illness. Some of us said that if people were to say that they had recovered totally then they didn't have a mental illness in the first place. We felt that people were asking us to reach for perfection and resented this. Some of us also felt that the whole idea was wrong - we have very hard lives and to expect these to change for the better is silly and misguided.

A few of us felt that the word ‘recovery’ itself was misleading and that better words could be found to describe trying to live as good a life as possible despite illness.

“we can feel that we can only cope not recover”

“the scars in your heart will never go away”

“the idea could be too high in the clouds”

“it varies with illnesses, some of us get better, others never get better and have to accept their condition and will always suffer to an extent”

“you can feel a failure if you get ill and relapse”

“personality disorder has the awful connotations of never getting better”

CAN WE LIVE A SATISFYING LIFE DESPITE HAVING A MENTAL ILLNESS?

The majority of us felt that despite the pain of mental illness life can be satisfying. Many of us can reach a stage where we can cope with the illness and understand it and still live a reasonable life *"like normal people do"*. We felt that life can be very good on occasions and that we need to *"live in life and fight for it"*. We wanted to make the point that everyone can struggle and that sadness is not just confined to people with a mental illness:

"we are all sad sometimes and can feel miserable but that is just normal - we can never be totally blissfully happy"

"I'm living a life that is ok. I've got a mental illness – sometimes when you are a bit down you are not satisfied but on the whole i live my life as a person"

In order that we can live a satisfying life we are reliant on our opportunities and those around us:

"it depends on where you are living and the people around you: if you can get a job that meets your needs, how much care you get, how much support you get, and if help is there when you need it not just when it is convenient for those around you"

"first of all it depends on yourself - can you come to terms with what your position is and how it is hindered by illness? It can be hard to accept where you are. Secondly it depends on being somewhere where, whatever you are doing, you have the chance to do it and that depends on the attitudes of those around you"

However some of us say that life can only be acceptable, rather than satisfying, and others strongly believe that mental illness has ruined their lives and that every day is a battle.

WHAT HELPS WITH RECOVERY?

The things that help with this include:

Income –many of us have a meagre income; the amount of money that we have makes a big difference. For many of us this means having the right benefits, such as Disability Living Allowance which can transform a person's life.

Activity - having meaningful things to do can be a great help, as can voluntary work and work placements. Activity not only gives us occupation and distraction but if it is also valued by other people can make a big difference. To feel that we can 'give' can be very important.

"I do knitting and every so often have a car boot sale. This makes me feel very good."

"have stuff to do at night and in the evenings –these can be lonely times."

Attitude - the way we approach life also makes a difference. A sense of purpose makes a difference and becoming more responsible (which can be very scary) can have a large effect and helps us with

our confidence. It is good to try to get the most out of what we can do even though we can't do some other things.

Trust - being able to trust the people around us and to talk openly about our mental health and the problems it causes, can also be a great help.

Help from each other - the help we offer each other is very important.

Medication - this can make a huge difference and many people feel that not only does it promote and facilitate recovery, but that without it we wouldn't be alive to consider recovery.

Understanding - if we can understand what we are going through then this can help us with the idea of recovering. Equally if other people have some understanding about us and our lives then this can also make a great difference.

Services - the professionals and services that help us can be central to our recovery.

“having staff around that we can fall back on”

“knowing help is available in the evening and at night.”

Acceptance - if we can find acceptance for what we are going through and also find, through the acceptance of others, that we can accept ourselves then we can move towards recovery and a sense of wellbeing:

“having to admit to mental illness and to accept it and learn from your mistakes and learn from others- then you get a much bigger reward and it feels worthwhile after all”

“I did it myself, I went out and read every book that I could lay my hands on. I decided not to work and came to terms with it”

Reassessing priorities - once we have experienced illness we may have to look at our lives in new ways:

“I couldn't have imagined what life would be like when I got ill. The hardest part to grasp was what I could no longer reach. It took a long time to realise that I needed to live a different dream”

“if you are flexible and can see where the path will take you, you can have a good life”

Looking at the journey - if we can see this as something that has steps in it, it can be easier:

“you can get to a point where you can feel safe. It's almost going through the different stages of getting help so that you manage it rather than getting over it”

“learning to live with it rather than it running your life”

Seeing relapses as setbacks not disasters - when we have got to the point where we feel that we can cope well, a relapse can have a big effect but if we can put it into context this can help:

“you can feel well for ages and then relapse. You can never feel 100% recovered”

Working on it in the early stages - many of us felt that if we started looking at elements that promote recovery in the early days of illness then life would be easier:

“so much can change in the first few months, increased confidence, work, doing things despite having a mental health problem – it can even lead to a better life”

Equally early medical treatment of our illness itself gives us much better prospects than if we have to wait some time for our illness to be recognised or help provided.

Prevention - we felt that if resources were put into prevention then people would have better prospects.

Accept our limitations - it is important that we accept that mental illness can impose limitations on our lives but equally that we see that limitations are part of the experience of everyone that we all have to adapt to, whether we have an illness or not.

Allowing ourselves to grieve - for some of us the experience of mental illness can seem like a bereavement in that we can lose the person we felt we were and the expectations and dreams we had. Some of us need time to come to terms with this.

Have our voice listened to - we are often very well aware that we are getting ill and well versed in what symptoms we get when approaching crisis. However we can feel that we are not treated seriously or even listened to. If we were listened to we would have a better chance of recovery.

Planning - we need to know what to do when things go wrong. We need contingency plans and advance directives to help when we are not in a position to argue our case.

Self management - for some of us the skills given by self management can help us cope with illness and helps create better lives.

Believing in ourselves - this is very important even to the extent of reinventing ourselves in order to allow us to approach life differently. Accept that we can get out of the situation we are in and believe that change can happen.

Friendships and social networks – having close friendships and getting out and socialising with people creates change and can help as does the attitude that they have towards us.

“just saying hello to someone and being kind can make a big difference and help you feel a part of society”

“the more friends the better.”

“if you are isolated it can be very hard.”

“some of my pals – they all left me when I was diagnosed , now they have come back and are calling me a legend – so life feels good again.”

Go to places that help:

“going to the drop in centre helped me take the steps I needed and accept that change is a good thing – generally people are frightened of change”

Stop looking at yourself:

“focus on other people to stop the focus on you, this helps”

Self expression - being able to express ourselves is very important.

Creative expression - the use of artistic forms of expression can have a big impact on our recovery.

Feedback - if we get positive feedback on what we say and experience then we can feel much more confident.

Voluntary work - being able to do voluntary work makes a difference and would be even better if we could feel that our benefits would be protected whilst we did this work.

“work and non work –this is too black and white”

Family - the right support from our family can make a big difference.

Stability - some of us don't experience this but to have stability can be very helpful.

Housing - having a house to call your own is very important:

“homelessness decreases recovery it makes life too scary and confusing”

Equally the area in which we live is very important. Some of us live in areas which feel harsh and threatening. This can hinder our recovery.

Respite and holidays – getting away from your home situation is helpful, and having the chance to have a holiday provides the sort of break we all need in order to recharge and face life again.

Being able to give - too many of us feel that we don't have value; having opportunities to give to others changes this. Being appreciated for what we do is important.

Hobbies and interests - these liven up our lives and occupy us.

Physical activity - things such as horse riding, walking or prescriptions for physical activity can increase our wellbeing. It can feel really good to spend some timeout in the fresh air getting exercise and enjoying ourselves.

Having our experience acknowledged and heard - this is important to many of us.

Concessions - leisure and recreational activities are very important but most of us can't afford them. Concessions that allow us to access these can help.

Learning the tools for recovery - not all of us know how to get on the road to recovery. Having the right tools could help.

Bus passes - many of us now have bus passes for free travel in highland and the rest of Scotland. These are a big help.

Motivation - without this the struggle to recover can be difficult. Equally gaining a sense of purpose and direction can help a great deal.

Encouragement:

“a kick in the arse to get us going”

although some of us would prefer gentler methods.

Education - if we can learn coping mechanisms, find out about different lifestyles and the risks attached to them as well as discovering healthy stress as opposed to negative stress, then this can all help.

Attitudes from professionals – we need to be treated with dignity and respect and not spoken down to or dismissed:

*“the first psychiatrist that I saw treated me as though it was a privilege to be a part of my life.....
the other one treated me as a non person or a kid”*

Having fun - jokes and humour are very important:

“being forced to do things together and to enjoy ourselves can be great and pushes us into the world”

Sexual relationships - many of us don't have friends and a large number of us do not have sexual relationships. This can be hard to bear and can be very isolating and discouraging.

Consistency - this is very important to us.

Confidence - having the confidence to do new things and take some risks can also help.

Achievements - if we do things that we know will help and if we keep a record of what we have succeeded at this can also help.

Moderation - if we indulge too much in drinking, smoking and drugs then we harm our chances.

Diet - having a healthy diet can be a way forward.

Meaning - if we can find things to do that give us meaning and which we believe in then we can feel much better.

The culture we live in - if we feel that we are respected for who we are and are not forced to be perfect then that can help, as can the friends and culture we are a part of.

Fear - if we can face our fears then that helps us along.

Starting a family - for some of us this can be the key to our recovery.

Work - some of us have found that getting back into work is a great step into recovery.

Self awareness:

“we can be so wrapped up in what happened that it is like we have blinkers on, but if we can see forward then life can get better for us”

“I knew the answers were inside myself. I did not need others to tell me what was good for me”

“I need to understand who I am but that means accepting the illness. The Bi Polar Fellowship (Scotland) can help us understand what the triggers are and what helps”

“when I got the diagnosis it seemed like I would never recover so I couldn’t accept this. I treated it as a spiritual journey which meant more to me than medication and illness”

Belief – if others believe in us and see that we have potential then this can also help.

Looking after our appearance - some people find that making an effort with our appearance can help us feel much better.

Reaching out - it can feel safe staying within the mental health world but some of us need to reach out into the wider community and do things in that environment too.

Practical help - some of us need help with practical tasks and activities such as cooking. Having this assistance can make a great difference.

Seeing life differently:

a form of re-awakening – it’s a reaction, people need revitalised, they need the long sleep to repair and recharge them, then wake up and see colour and life more vibrantly”

Avoid labels:

“ diagnosis can lead to non recovery; you conform to the label. It also influences people next to you which reinforces the way we behave”

WHAT CAN MENTAL HEALTH SERVICES DO TO HELP US RECOVER?

We felt that first of all they need more resources and investment from government to allow them to flourish and help us to try out some of these ideas. We also felt that we need to look wider than health services as many of the things that help us recover extend wider than conventional health services and can be found in many other agencies and communities. Some of us said that a key area of improvement might be to invest more in the voluntary sector and to look outside of health – a holiday or a change of scenery can make a huge difference.

We felt that health services needed to be more flexible and able to spend enough time with us to help us find new interests and possibilities. This includes health professionals helping us access mainstream services such as leisure and recreation activities as well as other services.

We need mental health services to join in with us in challenging stigma and we need to look at the attitudes of services themselves which can unwittingly reinforce stigma.

People need to stop seeing us as invalids and see mental illness as a hurdle that we need help in overcoming:

“don’t see us as just symptoms, let the doctors see the person behind the illness. We are not an illness confined to a doctors notes”

“we need doctors to realise that we are human - they don’t always do so”

“look at the reason behind the symptoms – don’t just put it down to a chemical imbalance. It can be caused by events happening in our lives. Pain can cause depression for instance”

We need our professionals to listen to us and realise that we need a variety of tools for recovery and that these vary from person to person. Some of us need medication, others need work, others need better housing and most of us need a combination of all sorts.

We need to realise that, for some of us, the bedrocks of medication and treatment are the route to recovery, and without these it doesn’t matter how much we talk and try to change our life the prospect of recovery will be distant.

Then again for some of us talking and putting our lives in perspective are just what we need but we need to do it at our rate. We need to get our minds in the right places but we don’t want to be put under pressure to recover. That is the opposite of what recovery should be about. We need to be sure that with the enthusiasm of the idea of recovery the professionals don’t push us, but allow us to take little steps at our own pace.

However we need to be sure of the attitudes of our professionals. We feel that some (especially doctors) can be too opinionated and controlling; we worry that this can damage us and make it harder to recover. These cultural clashes can make life hard:

“mental health professionals were previously very helpful although the new psychiatrist is not too good. Xxx got me to the mother and toddler group and out shopping - it took another three years to persuade me to the ‘drop in’ but now it makes a huge difference”

We need mental health services to give us enough information so that we can make decisions about our lives and we need them to help us discuss solutions together. We want a partnership rather than having treatment imposed.

We need services to look at our whole lives and to include our diet, our use of alcohol and drugs as well as our physical health. All of these things affect our mental health.

We also need the services to be consistent, both in the professionals we see and the advice they give us.

We need to know that services are there if we need them and also that we know about the variety of people that are there to help. We need to be sure that there are enough community services and that we can get help before problems escalate.

We need to look to the variety of services we can use. Both occupational therapists and community psychiatric nurses can bring out aspects of ourselves that we didn’t realise we had.

We feel that mental health services can do more than they do at the moment and although many of us benefit greatly from drop-in centres that are spread across the Highlands and feel welcome and supported there, there are some of us who feel that they just maintain us in our present state rather than helping us to grow.

However others have a different view:

“The Gardeners Cottage is a shining example of this. We are away from everything; in our own space. We do our own thing. In a sense we are one big family and belong to each together. It helps us to get up in the morning and gives us a reason to get up. It is a place where the early signs of relapse can be picked up – we all notice when one of our members is getting into difficulties. We can talk about our problems freely and are not afraid to admit when we are feeling low”

“the ‘Haven’ is perfectly named”

“Am Fasgadh accepts you and doesn’t judge you - this is very important”

“I don’t know what I would do without Stepping Stones - coming here helps me to speak again”

Some of us feel that if only we had realistic information about what to expect with our illness then we would be able to adapt to our new circumstances and possibly suffer less breakdowns. Not having a clear understanding of our lives and what this means to us can prevent us from moving on.

It would also be good if services could look at other ways of seeing the life that we experience. For some of them looking at the social model of disability and applying it to mental illness may cause a shift in the way that they view us. Some of us worry that some professionals have low expectations and although there is change there is too much emphasis on maintaining us in illness instead of helping us to move on.

Whilst many of us have great experiences from workers, ranging across the professions and including nurses and psychologists among others, we do need more from them and feel that sometimes they don’t have the time. Sometimes they don’t see our lives in the whole and occasionally don’t explain enough to us. If this could change then life could be better. We also felt that for professionals to help us with enthusiasm then they also need reward and acknowledgment for the help that they give us.

Equally life could improve if we could be sure that on discharge we were prepared and supported, as, many of us complain of leaving hospital for an empty cold house with little support and aftercare.

Relationships might improve and perceptions change as a result of the environment in which we meet those that help us – would it be possible to have appointments and visits by professionals in such places as drop-in centres? Or maybe drop-in centres could help us more if they had enough resources to employ extra staff, including those with qualifications in mental health.

It might be good if they could look at our lives before they try medication and look at how changes to our lifestyles and ways of thinking might help us to recover. If we had access to social networks and activities that we could engage in when we first became ill we may never have reached a point where we felt that we needed help to recover.

Sad as it may sound we need to be sure enough of our helpers to be able to trust them and be free from the worry that they look down on us or tell us what to do instead of discussing it. This can be achieved to some extent by knowing that we have time with them when we need it, by being sure we will be listened to, by being given space and by knowing something of their lives at the same time that we share our life stories.

Many of us wish that there was more access to cognitive behavioural therapy as well as other talking treatments.

In a rural area such as ours there is a worry that there are more services based in Inverness and there is a resentment that some of us have to travel considerable distances in order to get help. Having access to helplines can be helpful for some of us.

The advent of advance directives may also help a lot.

WHAT CAN FRIENDS AND FAMILY DO TO HELP?

Some of us find our family (and sometimes our friends too) more of a hindrance than a help in our recovery.

Sometimes they are overprotective and restrict and ‘molly coddle’ us, while at other times they hide the fact that we have mental health problems and keep it a secret. They can also fear mental illness or are ashamed of us and find it hard to talk about our experience. They can be so stigmatising about our illness that they try to stop us using the services that may help us. They can also be ignorant about what helps - being told to pull ourselves together doesn’t help and neither does impatience at the slowness of our recovery. Sometimes all they wish for is to get back the person that we used to be and do not realise that this is no longer possible. We can on occasion be abandoned by them or turned into ‘poor victims’. Sometimes we lose all links with friends and family:

“it is empty words - if we had friends and family, they think they know us so well. They say ‘I love you’ but they don’t mean it and don’t want to hear us. We need to be loved warts and all”

“people have expectations of recovery and set you a time limit of when they think you should have recovered - they see setback as a failure”

“when I got ill my friends dropped me like a hot potato”

The lack of understanding by friends and family can cause us to become very isolated and can make it easier for us to talk to fellow users where we find these barriers don’t often occur.

However this is not always the case. Friends and family can also be very supportive, helpful and understanding. Some of us feel that friends and family are the people with the most knowledge of us and the clearest idea of what helps – after all they have spent years in our company and have seen us in many different situations:

“my granny was really good - we got out and about. She did stuff with me that I enjoyed too – doing things together”

We want them to support and accept us, to be there for us, to keep in contact with us and to refuse to feel ashamed on our account. If they are genuinely there for us then it can also be very good if they are involved in the care that we receive. We need them to avoid treating us with kid gloves and to be honest with us, which may mean that they act as a sounding board that helps us realise the effect and consequences of our illness on others. Sometimes we need them to forgive us.

In order that they can help us they need education about how to help and act with us - this includes helping them to understand our lives and the diagnosis that we have. We worry that families are given too little information and that the information they are given can be too much about medication with little about the other forms of help and service that we might access.

Family (and friends) can need considerably more than education, despite the good support they give, they can suffer as much as us and may need help and support with the problems our illness has caused them. This can include giving them breaks from us especially when we have young children or when we are approaching crisis – a safe house may help then.

We also need to make an extra effort on occasion, as we can be reluctant to tell them the whole story of what we are going through. We may also need to acknowledge the effect our behaviour has on them. Our own family can also promote recovery just by being family:

“my daughter changed my life; she needed me. I would never have gone out but my daughter needed me to go out with her”

WHAT CAN OUR COMMUNITY DO TO PROMOTE RECOVERY?

This area of inquiry was one that produced the most blank faces. We felt that it was often our community that did the most to prevent recovery through the stigma of ill informed or prejudiced attitudes and that asking what they could do to promote recovery was a strange question to ask as they are one of the main barriers that we face. There is at least one community where we know local residents started a petition to remove people with a mental illness from their neighbourhood. This made some of us angry.

We believed that many people believe the negative images that are commonly found in the press and cinema and that influences how they see us. (Possibly more an example of ignorance than prejudice). We felt that many communities have no wish to help and certainly don't bother much with the issue. We also found that many of us end up in similar areas of towns and cities which can be good but also bad.

They were poor at prioritising the need for mental health services and had inaccurate attitudes about our abilities and prospects.

Sometimes they had difficulty in responding to our needs because of a lack of resources and at other times the community we live in can be inappropriate – a profit orientated community may be less tolerant and less able to respond to the needs of people with mental health problems. Some of us worried about the attitude of some hospital based nurses – they see us at our most distressed and we worried that this distorted the image that they held about us when we were at home.

Some of us felt that it was not the community's responsibility to help us but was more a job for professionals, whilst others felt that the wider community has a responsibility to promote inclusion and acceptance and to combat stigma.

We felt that initiatives such as the 'Stigma' play and the 'See me' campaign were good examples of the ways in which community attitudes were changing and felt that programmes should be targeted

at schools, teachers and young people. We felt that challenging stigma and raising awareness was very important.

Some communities are very welcoming and there are wonderful people within our own neighbourhoods who stand out for what they offer us:

“neighbours were really kind to me when I was first unwell. They looked out for me; it felt really nice and I felt really looked out for. We were really before I got ill and they made it clear that I could ask for help at any time. It made me feel safe and looked after. It was very good”

The siting of drop-in centres in the community is a clear signal of the importance of inclusion. We felt that small communities or communities where we are well known can be particularly welcoming but that equally where there is stigma they can hinder us too. The lack of anonymity can also be hard to cope with. However many of us did feel that people suffered even more in cities.

There are initiatives within the community that we welcome such as ‘green gym’ but we struggle to find the information and opportunities that we could profitably take up and benefit from.

Some of us feel very isolated and alone – if we could share accommodation with like minded people our lives might be better.

We felt that if the community engaged with our lives more, life could be much better. This starts with raising awareness and reducing stigma but extends to many areas that we could all benefit from, such as looking at the connection between physical health and mental health, looking at the spiritual dimension and overall looking at our lives in a holistic way. This sort of approach needs the partnership of more than just users and professionals but includes teachers, schools, youth clubs, ministers, the media and many others.

The general public could also benefit from mental health first aid training, and also the professionals who may encounter us when distressed taught how to de-escalate tense situations.

MEDICATION AND RECOVERY

The great majority of us felt that without medication our chances of recovery, or even life, would be severely limited:

“it can be like the oil we need in a car”

“I am violently against it but it does help – for a lot it is a necessary thing. You need something to help you out. It can keep you on the right track but long term I am strongly against it”

Many of us felt that we had to live with medication and its side effects; seeing it as the lesser of two evils.

Some of us resented the fact that we were dependant on medication. A few of us felt that medication masked the problem and even damaged us:

“not being on medication can make you more creative”

“it can be liberating [to be medication free] but with risks attached”

We did worry that there was an over reliance on medication as the prime form of treatment. We need other approaches that stop isolation and promote relationships or things that help us become active.

Some of us wanted access to complementary therapies but many of us found them to be too expensive and wished to have access to them on the NHS.

We also made the point that prescription charges are high - many of us felt prescription charges should be free.

Some of us felt that medication can stabilise us but when we reach that point it is important to look at the underlying causes that may precipitate illness - or at least at some stage to consider whether we can live without medication. We also talked about the need for talking treatments such as cognitive behavioural therapy as a way of moving to recovery.

DO OUR FELLOW USERS HELP WITH RECOVERY?

Most of us felt that the help of fellow users was a key step in our recovery: the shared experiences, lack of stigma, comradeship, similar culture, and ability to help and support each other had a great impact on our lives. The ability to meet people in similar situations and the encouragement that they can give should not be underestimated:

“we know someone else has been there, we don’t have to explain but can talk about it and can know that they will understand it”

“we look forward to meeting each other for a coffee and a natter”

“we look forward to coming here all week”

“professionals can’t understand, however many books they have read”

“we would be lost without this”

However a small number of us had other thoughts and felt that, despite the benefits we get from each other, that there could be disadvantages: sometimes being ‘locked’ in a mental health system can drag us down and keep us in a perpetual state of semi-unwellness. Sometimes it is almost seen as a mark of status to be unwell and sometimes when all our friends are in varying states of illness it can be hard to push ourselves into a state of recovery where illness and all that goes with it becomes a thing of the past.

WHAT HELPS US BELIEVE IN OURSELVES AGAIN?

Many of the things that help us believe in ourselves are relatively simple and include:

- Having people that trust and accept us.
- Doing something meaningful.
- Hearing success stories and being inspired.
- Reading articles and books about coping.
- Completing a task.
- Getting up in the morning.
- Acknowledging even small achievements.
- Not setting ourselves up for failure.
- Doing things that make us feel better.
- Realising we are not alone and offering each other help.
- Being given chances and opportunities.
- Promoting the feeling of 'I can' instead of 'I can't'.
- God and our faith.
- Medication and cognitive behavioural therapy.
- Feeling the situation is better.
- Having close relationships.
- Channelling our mind.
- Doing things that raise our self esteem.
- Being able to speak out about our experience can help us come to terms with it.
- Being listened to.
- Stopping being ashamed of our experience.
- Seeing an improvement.
- Feeling support and recognition around us.
- Going on outings.
- Recognising our own condition.
- Seeing our potential.
- Being praised.
- The people around us.
- Professionals and the faith they have in us.

“just walking down the street and saying hello and having a hello back – being acknowledged”

“small goals can make a difference; like celebrating when we can manage a bus journey for the first time in week”

“help us to see when we don't think we can see”

“music- I got involved in two bands and had never played before. It was something I always wanted to do- being in a band helped me learn about give and take”

“finding a place where you feel valued and accepted and not judged”

“ the feeling of take me or leave me warts and all”

“ you need to love yourself in order to love others”

Some of us don't believe that we can ever reach that stage and have lost faith in the possibility. We may have no feeling of optimism or self-worth and may, because of illness, lose the capacity to believe in ourselves - only regaining this as we regain some of our health.

WHAT PROMOTES OPTIMISM AND HOPE?

There are a variety of things that help with this, which include:

- Being able to enjoy the activities ‘normal’ people do.
- Having a laugh and being silly.
- Not being too complex.
- Having a goal.
- Having optimistic people around you.
- Physical activity.
- Accepting our limitations and not aiming too high.
- Not trying to prove how worthless we are.
- Support from friends, professionals and family.
- Doing positive things and doing something useful.
- Being able to talk in groups.
- Meeting other people who have been through the same things.
- A sense of achievement and positive thinking.
- Seeing others do well.
- Empathy from others.
- Feelings of self worth.
- Being appreciated and kind words.
- Don’t aim too high.
- Honesty.
- Taking small, baby steps.
- Learning from each other.
- When you start planning things.

“education to understand that we may relapse but this doesn’t have to matter”

“ you can find a gift in every bad thing ”

“hope for my daughter”

“baking a cake and feeling really good about it”

“a smile is nice”

“having a hug”

Not all of us appreciate the idea of hope. Some of us have a life that is so fragile that to dare to hope is too big a risk – if our hopes are then dashed then we could be deeply damaged:

“we can be scared to hope for anything”

“if we have been really well for ages our hopes can be shattered if we relapse”

“if we don’t hope it can be a recipe for self limitation.”

“hope can be too much to ask for but if its not enough and we don’t get it, it can lead to despair”

ARE PEOPLE AROUND US POSITIVE ABOUT RECOVERY?

We have been helped by those around us and also hindered by them. They can be both optimistic and pessimistic.

We did feel that with so many people experiencing illness we needed to encourage a change in perception about how people regard our longer term prospects.

Some of us also felt that we have to be careful who we mix with. We should seek out those who are optimistic and avoid those who may damage us, whether consciously or unconsciously.

The attitudes they have can be very important. Some people are too optimistic which is hard because we can't live up to their expectations and others are misinformed and still persist in the idea that if only we 'pulled ourselves together' then we could recover much quicker.

DO WE NEED TO BE FREE OF SYMPTOMS TO FEEL THAT WE HAVE RECOVERED?

Many of us feel that if we still experience symptoms of illness then we are on the route to our recovery but have not yet reached the end of that journey.

Some of us feel that full recovery is an impossibility, but others feel that we need to learn to live with our symptoms:

“you can have a broken leg and end up with a limp but still feel that you have recovered”

“sometimes we need to acknowledge that it is not all symptoms. It can be just human to have problems – we can see all problems as illness”

“it is hard to see the possibility of complete recovery”

“some people work despite being ill still”

“we may not be totally symptom free but we can still be happy”

“some people will never recover – its so sad”

WHAT ATTITUDES DO WE NEED TO PROMOTE RECOVERY?

Again some of us are very sceptical about recovery and therefore don't see it as possible. Some of us believe that the very illness itself prevents recovery:

“some illnesses remove the ability and can make you think that nothing will ever be good again”

“find the answers within ourselves, but often the illness won't let us do this”

We felt that getting the 'right' attitude could be a struggle but that if we did it would include :

- Being positive and optimistic.
- Being brave, having high self esteem and being hopeful.
- Trusting ourselves and others.
- Willing to accept help.
- Know we are not alone.
- We need to believe in the future.
- Believe in ourselves.
- We need knowledge training and support.
- Take the initiative.
- Stop feeling drab and doudy.
- Encourage laughter and humour.
- Laugh at ourselves.
- Encourage camaraderie and look at each other positively.
- Feel normal.
- Stop feeling special.
- Acknowledge that we are special.
- Stop feeling self pity.
- Believe recovery is possible.
- Able to give.
- Pragmatic hope.
- Prepared to change and take some risks.

“with a little help from our friends”

“time promotes recovery – recovery can take a great deal of time to occur”

“the point at which you can accept trust and help is the beginning of the road to recovery”

“laugh about it, it is better than crying”

WHAT HINDERS RECOVERY?

There are a variety of factors that hinder our recovery which includes our own attitude towards recovery and the way we lead our lives. Sometimes we don't believe in ourselves, which doesn't help and at other times we assume people are 'against us'. Sometimes we try to do too much and overdo things but at other times it is other people who act as a barrier: their actions can be malicious or just be the fact that they ignore us or have little faith in us or are ignorant about us. This can make recovery more difficult as can the cultural environment we live in. The stigma, discrimination and stereotypes that are held about us can be very damaging, as can the poor value that society places on us and the language used to describe people with mental health problems.

“do you expect nothing and therefore take a lot out of each tiny step or do you put your faith in recovery and feel disappointed when you don't recover?”

“don't make us recover. Take it slowly. If there is no pressure then we can build up gradually and get to a better place”

“being stuck in the past feels safe, but isn’t”

“sometimes we like to be down; we can lose the sense that this is worth fighting for or caring about”

Our state of health can be its own barrier to recovery as can a shortage of the services that we use. Sometimes it is the shortage of activity:

“in hospital there is nothing to do and a great deal of monotony”

or else it can be inappropriate treatment such as being discharged too early from hospital or poor attitudes from those that treat us.

Sometimes our fellow users, friends and family act as barriers as do lifestyle choices such as the abuse of drugs and drink.

The environment we live in can make recovery harder and loneliness, isolation and poor relationships can be key factors as can poverty, poor housing, poor transport systems and the life that we lead:

“the only people that are nice to me are those that are paid to be nice to me; its good but I need more”

“the benefits system and its bureaucracy. We can be very frightened of losing our benefits. Even when we are ill we can feel like a sponger or self stigmatise ourselves”

“benefits can be enough to keep us going but it can be hard to manage on them”

“see the causes – our home can be the cause of our illness”

Some of us keep our condition a secret and don’t talk about it. This can cause us to feel shame and guilt which doesn’t help.

CONCLUSION

In summary, the views of our members about recovery vary and this is sometimes dictated by where they are in their life or by the way in which they view mental ill health.

For some of us the experience of mental illness is so devastating and damaging that to suggest that we might be able to find ways of adapting or coping with our lives in slightly more positive ways can feel offensive and ill considered. We struggle to exist and every day can dawn with such greyness that the thought of retaining a vestige of hope about our lives is far too much to want to contemplate.

However as can be seen from the report the idea of recovery struck a chord with many of us, including some of our members who were initially very sceptical. We had many ideas about what helps us and what other people could do to promote recovery. We hope that they are helpful although we do appreciate that what helps one person may be unhelpful for another so our ideas are not definitive answers.

We do need the help of professionals experienced in mental health, but equally we need professionals and others to realise that our lives are not just about illness. We are a part of wider society and the intervention and engagement with many in mainstream society and services can play a huge role in where we feel we are in our lives. Recovery involves all aspects of the way we live – having a fulfilling relationship can be just as important to our mental health or more important than being able to receive some therapies on the NHS.

We would hope that people within the Highlands who may be in a position to help us find our own road to recovery (if that is something that we wish to try) will discuss this report and look to see if it would signal changes to the ways in which they help us in the future .

ACKNOWLEDGEMENTS

With thanks to all the members of HUG, and other mental health service users, who contributed to this report.

Please feel free to photocopy this report.

However if you use this report or quote from it or use it to inform your practice or planning please tell us about this first. This helps us know what is being done on our behalf and helps us inform our members of the effect their voice is having.

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